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Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Janet L. Abrahm, M.D., FACP — $496,179 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1997 $70,000 University of Pennsylvania School of Medicine — *Faculty Scholar, 1997 (funding amount estimated) A Disease Management Program for the Care of the Dying in the University of Pennsylvania Health System*

http://www2.soros.org/death/1997_fs.htm
This project will develop a Disease Management program that will be responsible for attending to the medical, psychosocial, and spiritual needs of the dying and the bereaved throughout the University of Pennsylvania Health System whether they be in a hospital, a nursing home, or their own homes.

National Institutes of Health - National Cancer Institute (NCI) *$426,179*

1998 $57,682 University of Pennsylvania School of Medicine — *Palliative Care Fellowship*

http://grants.nih.gov/grants/award/state/fy1998.pennsylv.txt

2003 $185,005 Harvard Medical School - Dana Farber Cancer Insititute In — *Palliative Care Fellowship*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6631062&p_grant_num=1R25CA099922-01A1&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=100&p_audit_numfound=1&p_keywords=palliative

Grant Number: 1R25CA099922-01A1
PI Name: ABRAHM, JANET L.
PI Email: janet_abrahm@dfci.harvard
PI Title:
Project Title: Palliative Care Fellowship

Abstract: DESCRIPTION (provided by applicant): As the IOM reports in 1997 and 2001 document, there is a paucity of trained experts, educators, and researchers in palliative and end-of-life care. Physicians therefore lack expertise in palliative medicine, do not acquire the needed communication and self-reflection skills, and do not know how to work as members of an interdisciplinary team. They are unable to ameliorate the suffering of patients during active antineoplastic therapy; relieve the psychological, spiritual, and physical distress of patients who stop responding to chemotherapy agents; assist patients and their families in defining and achieving their last goals; or provide bereavement support for the survivors. This proposal describes a continuation and expansion of the previously funded year-long fellowship program in palliative and end-of-life care. Using the resources of Harvard Medical School, the Dana-Farber Cancer Institute, the Brigham and Women's Hospital, the Children's Hospital of Boston, a long-term care facility, and a community hospice, we now hope to train physicians who wish to become role models, educators, and researchers in adult or pediatric palliative medicine and end-of-life care. Training will include an adult and a pediatric tract, each with closely mentored didactic and clinical training. Required didactic training includes an introductory palliative care lecture series, palliative care grand rounds, and monthly palliative care seminars and journal club. Fellows will also be trained as palliative care educators. Fellows will receive the bulk of their clinical training as members of interdisciplinary palliative care and psychosocial oncology consult teams, and as members of a hospice team. Fellows will follow patients across treatment settings (inpatient, outpatient, home, and hospice). Other adult training sites include Anesthesia Pain Clinic, a geriatric long-term care facility, advanced cardiac/pulmonary disease or ALS clinics, the ethics committee, and chaplaincy service. For qualified fellows, a research elective is available. The fellow's progress will be formally assessed with tools designed to measure attitudes and knowledge; the fellowship director will closely monitor fellow skill development by personal observation and by discussion with other preceptors.

Institution: DANA-FARBER CANCER INSTITUTE
44 BINNEY ST
BOSTON, MA 02115
Fiscal Year: 2003
Department:
Project Start: 25-AUG-2003
Project End: 31-MAR-2008
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

2004 $183,492 Harvard Medical School - Dana Farber Cancer Insititute In — *Palliative Care Fellowship*

http://silk.nih.gov/public/cbz2zoz.@www.fy2004.massachu.txt

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Tim Ahles, Ph.D. — $569,026 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$569,026*

2003 $569,026 Dartmouth College *Improving Palliative Care for Patients with Cancer*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6559975&p_grant_num=1R01CA101704-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=37&p_audit_numfound=67&p_keywords=palliative+care

Grant Number: 1R01CA101704-01
PI Name: AHLES, TIM A.
PI Email: tim.a.ahles@dartmouth.edu
PI Title: PROFESSOR
Project Title: Improving Palliative Care for Patients with Cancer

Abstract: DESCRIPTION: (Provided by applicant) The recent report of the Institute of Medicine concludes that there is a critical need for research designed to improve care at the end of life. Project ENABLE, a Robert Wood Johnson funded demonstration project designed to improve end-of-life care in cancer patients, showed that a palliative care model that focused on early intervention (at the time of diagnosis of advanced cancer), patient education, preference- based treatment and coordinated care is: 1) feasible to implement in a comprehensive cancer center; 2) accepted by oncologists who are focused on aggressive/clinical trials- oriented care; and 3) accepted and valued by patients and family members. This application is designed to refine the ENABLE intervention and increase its efficiency by integrating approaches developed by the Dartmouth Northern New England Cooperative Research Group that have focused on practice system changes that improve quality and efficiency of care. The primary goal of this application is to test the efficacy of an intervention for improving palliative care for cancer patients that includes: 1) the Dartmouth Clinical Improvement System which emphasizes rapid assessment of problems and feedback to patients (including tailored educational materials) and practitioners; 2) telephone- base nurse educators who will provide ongoing symptom and problem assessment, coordination of care between the cancer center health care team and other services, and education regarding problem-solving, communication with the healthcare team, advanced care planning and symptom management; and 3) Drop-In Group Medical Appointments (DIGMAs) for symptom management. Patients with advanced lung, gastrointestinal, and breast cancer seen at the Norris Cotton Cancer Center will be identified at diagnosis and randomized to receive the ENABLE II intervention or standard care. The primary hypotheses are: 1) Patients randomized to the ENABLE II intervention will report better symptom management, higher quality of life, a better match between preferences and the care received, and lower health care utilization as compared to patients in the standard care group and 2) Family members of patients receiving the ENABLE II intervention will report better quality of care, symptom management, and match between preferences and care received as measured by the After Death Interview.

Thesaurus Terms:
breast neoplasm, gastrointestinal neoplasm, health care quality, human therapy evaluation, lung neoplasm, neoplasm /cancer palliative treatment, terminal patient care
health education, patient care personnel relations, quality of life, self care, telemedicine
clinical research, health services research tag, patient oriented research

Institution: DARTMOUTH COLLEGE
11 Rope Ferry Rd. #6210
HANOVER, NH 03755
Fiscal Year: 2003
Department: PSYCHIATRY
Project Start: 23-JAN-2003
Project End: 31-DEC-2007
ICD: NATIONAL CANCER INSTITUTE
IRG: HQER

Judith C. Ahronheim, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1995 $50,000 Mount Sinai School of Medicine *1995 faculty scholar (with Meier, Morrison, and Morris) (Grant amount is estimated.)*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Steven M. Albert, Ph.D. M.Sc.

tracked thus far

National Institutes of Health - National Institute of Mental Health (NIMH)

2000 Columbia University *DEPRESSION AND END OF LIFE CARE IN ALS*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6559975&p_grant_num=1R01CA101704-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=37&p_audit_numfound=67&p_keywords=palliative+care

Grant Number: 1R01MH062200-01
PI Name: ALBERT, STEVEN M.
PI Email: sma10@columbia.edu
PI Title:
Project Title: DEPRESSION AND END OF LIFE CARE IN ALS

Abstract: Description: (Adapted from investigator's abstract) Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that results in death, usually from respiratory insufficiency or aspiration, within 3 to 5 years of diagnosis. The disease affects all voluntary motor function except eye movement and sphincter control. In the final 6-9 months of life, patients must choose (either explicitly or by default) palliation or tracheostomy and long-term mechanical ventilation (LTMV). In this 4 year project, we will follow 140 patients diagnosed with definite or probable ALS who face a high likelihood of death within 6-9 months, as defined by poor pulmonary function, dysphagia and weight loss, or hospice certification or eligibility. These patients will be followed with bimonthly in-home assessments, and with an additional assessment in the last weeks of life. We will also interview the primary family caregiver on the same schedule and once after the patient's death, as well as conduct a survey of medical providers' influence on end-of-life decisions. In this observational cohort study, we propose (1) to assess the prevalence and course of depressive disorders and symptoms in ALS patients in the final months of life and its relevance for decision-making at the end of life; (2) to identify predictors of tracheostomy/LTMV use; (3) to examine the degree to which patients and families take steps to control the timing of death by adopting a strict palliative care regime; and (4) to examine associations between patient and caregiver distress in the final months of life. Key questions include the following: Do levels of distress and depressive symptoms increase as patients approach death, and does this relationship differ according to choice of palliative care or LTMV? What maintains hope in these patients, who are, in a medical sense, hopelessly ill? Of patients who receive LTMV, in what proportion is LTMV consciously planning for, as opposed to an unplanned emergency procedure? Is patient mental health or caregiver burden associated with decisions to forego or undergo LTMV? To what degree does use of non-invasive, temporary nasal ventilation (Bi-Pap) prevent use of LTMV? These questions have not been investigated in a prospective study. We will be able to address them through repeated, detailed assessments of patients and caregivers. This information will be critical for understanding the experience of patients with terminal disease as they and their families face end-of-life care decisions.

Thesaurus Terms:
amyotrophic lateral sclerosis, decision making, depression, extended care, terminal patient care
caregiver, longitudinal human study, positive pressure breathing, respirator, tracheotomy
behavioral /social science research tag, clinical research, human subject

Institution: COLUMBIA UNIVERSITY HEALTH SCIENCES
PO Box 49
NEW YORK, NY 10032
Fiscal Year: 2000
Department: GERTRUDE H SERGIEVSKY CENTER
Project Start: 20-AUG-2000
Project End: 31-JUL-2004
ICD: NATIONAL INSTITUTE OF MENTAL HEALTH
IRG: ZRG1

Rebecca Sue Allen-Burge, Ph.D.

$351,651 tracked thus far

National Institutes of Health - National Institute on Aging (NIA) *$351,651*

2000 $93,662 University of Alabama - Tuscaloosa *CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE*

http://grants2.nih.gov/training/data/RCPORG2003.TXT
ALABAMA, TUSCALOOSA (ZIP 35487): UNIVERSITY OF ALABAMA IN TUSCALOOSA
Allen-Burge, Rebecca S 5K01AG000943-04 $93,662
Care Integration Team Intervention During Hospice Care

2000 $78,313 University of Alabama - Tuscaloosa *CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE*

http://grants.nih.gov/grants/award/state/fy2000.alabama.txt
TUSCALOOSA, UNIVERSITY OF ALABAMA IN TUSCALOOSA
1 K01AG000943-01A1 ALLEN-BURGE, REBECCA S
CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE
SCHOOLS OF SOCIAL WELFARE/WORK
APPLIED GERONTOLOGY 78,313

2000 $91,563 University of Alabama - Tuscaloosa *CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE*

CARE

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6126990&p_grant_num=1K01AG000943-01A1&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=158&p_keywords=palliative+care
Grant Number: 1K01AG000943-01A1
PI Name: ALLEN, REBECCA S.
PI Email: rsallen@bama.ua.edu
PI Title: ASSOCIATE PROFESSOR
Project Title: CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE

Abstract: DESCRIPTION (adapted from the application): As a new investigator in the fourth year of her independent research career, the candidate has addressed this MRSDA application to the psychosocial geriatrics research objective of the NIA. The training phase of this application (Years 1-2) will provide supervised experiences and establish interdisciplinary collaborations in the following areas: (1) palliative care; (2) therapeutic interventions with terminal caregivers; (3) the assessment of medical decision making capacity and the legal issues involved therein; and (4) multivariate statistics for nested research designs. The purpose of the project in Years 3-5 is to develop and evaluate a two-pronged, Care Integration Team (CIT) intervention to improve communication among professional and personal caregivers for individuals receiving in-home hospice care. A two group comparison design with an embedded intrasubject comparison component will be used to test the intervention's effectiveness. The CIT intervention attempts to improve communication among the members of CIT by: (1) training registered nurses in the administration of advance care planning (ACP) interviews and the use of enhanced job structure to facilitate treatment fidelity, and (2) training personal caregivers in the use of problem solving skills. Aim 1 assesses the efficacy of training RNs to conduct ACP interviews and use enhanced job structure to track the impact of their ACP interviews on care recipient/personal caregiver dyads. Aim 2 measures the impact of RN-ACP interviewing on personal caregivers knowledge of advance directives and of care recipients medical treatment wishes. Personal caregivers satisfaction with the RN-ACP interview will also be assessed. Aim 3 assesses the efficacy of the two-pronged intervention on reducing personal caregivers experience of psychological and care-related distress during in-home hospice care. Secondary aims include measuring the longitudinal impact of the intervention among Caucasian and African-American dyads on changes in personal caregiver psychosocial outcome and on care recipient quality of life. Behavioral indicators of care recipient pain and communication will be assessed through videotapes and computer-assisted direct observational procedures.

Thesaurus Terms:
geriatric nursing, health related legal, home health care, hospice, nursing education
caregiver, decision making, patient care planning, problem solving, psychological stressor, quality of life, satisfaction, statistics /biometry
behavioral /social science research tag, clinical research, human subject, questionnaire, videotape /videodisc

Institution: UNIVERSITY OF ALABAMA IN TUSCALOOSA
BOX 870104
TUSCALOOSA, AL 35487
Fiscal Year: 2000
Department: APPLIED GERONTOLOGY
Project Start: 15-APR-2000
Project End: 31-MAR-2005
ICD: NATIONAL INSTITUTE ON AGING
IRG: NIA

2000 $88,113 University of Alabama - Tuscaloosa *CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE*

http://silk.nih.gov/public/cbz2zoz.@www.fy01.rcp.htm
5 K01 AG000943-02
ALLEN-BURGE REBECCA S
CARE INTEGRATION TEAM INTERVENTION DURING HOSPICE CARE
$88,113

Theresa Altilio, ACSW — $60,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$60,000*

2000 $60,000 Beth Israel Medical Center - NYC *Collaboration between social work and the multidisciplinary staff of a major Palliative Care Center; communications and education.*

This project developed a fellowship for a post graduate social worker within the Department of Pain Medicine and Palliative Care under the leadership of Russell Portenoy MD with opportunity to learn from multidisciplinary experts across practice settings working with patients along the continuum of life threatening illness. In addition to focusing on core competencies, the fellowship provides opportunity and encouragement to lecture, publish, explore grant writing and evolve a listserv for social workers involved in Palliative and End of Life Care. The listserv, an internet discussion group, currently has 109 participants creating an opportunity for networking, education and support across practice settings. A primary focus of this project is advocacy for inclusion of multidimensional pain and symptom management as a competency for social workers and an essential element to improve care of patients and families along the continuum of illness and at end of life. To this end, the Department Web Site WWW.StopPain will create a Social Work Page which will allow for dissemination of comprehensive teaching modules with particular emphasis on pain and symptom management.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Elizabeth Mayfield Arnold, Ph.D., LCSW — $60,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$60,000*

2000 $60,000 Carolinas Center for Hospice and End of Life Care — *Survey of hospice and health care social workers*

This research is a collaborative project between the school of Social Work at UNC-CH and Hospice for the Carolinas. Dr. Arnold will conduct a survey of hospice and health care social workers to examine social workers' attitudes, knowledge, and values concerning assisted dying. Findings will be used to develop training to improve social work intervention with those at the end of life who have unmet needs and/or are considering hastening their death.

Robert M. Arnold, M.D. — $506,190 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$228,190*

1997 $228,190 University of Pittsburgh — *Faculty Scholar, 1997: Teaching Physician Change-Agents To Communicate With Terminally Ill Patients About Psychosocial and Ethical Aspect of Care*

http://www.pitt.edu/~crhc/arnold.html
currently PDIA scholar "working to develop a cadre of physicians who can teach how to better communicate regarding ethical, psychological and existential issues at the end of life. His research efforts have concentrated on teaching ethics to residents, doctor-patient communication regarding advance directives and talking with families about organ donation."
----
http://www.pitt.edu/~crhc/arnoldfund.htm
Core Faculty Members: Robert M. Arnold, MD (PI)
Project Title: Teaching Physician Change-Agents to Communicate with Patients
Dates Funded: 07/01/97 - 06/30/01
Funding Agency: Soros Foundation
Award Amount: $228,190
=========
A cohort of oncologists, geriatricians and doctors caring for HIV-positive patients will learn skills necessary to more effectively communicate about the ethical, psychosocial, and existential issues surrounding terminal care. These physician change agents will in turn train other health care providers at their institution in an effort to improve the care of dying patients in Western Pennsylvania.

Greenwall Foundation — *$278,000*

1996 $278,000 University of Pittsburgh — *SHHV-SBC Task Force on Standards for Bioethics Consultation*

Robert Arnold & Stuart Youngner were Co-Directors. Mark Aulisio was executive director.
========
http://www.pitt.edu/~crhc/arnoldfund.htm
Core Faculty Members: Robert M. Arnold, MD (PI)
Project Title: Examining the Impact of Financial Incentives (voluntary benefit) on Organ Donation
Dates Funded: 1999-2001
Funding Agency: Greenwall Foundation
Award Amount: $92,736

Anthony L. Back, M.D. — $451,425 tracked thus far

Robert Wood Johnson Foundation — *$149,447*

2001 $149,447 University of Washington — *Establishment of a national educational resource center on palliative care and HIV/AIDS*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_user_view_html_701
In collaboration with the U.S. Health Resources and Services Administration (HRSA), this special opportunity project will establish an educational resource center on palliative care and HIV/AIDS, taking advantage of the University of Washington's (UW) regional contacts and the national network of HRSA-supported AIDS Education and Training Centers (AETC). The activities include: collecting and reviewing existing educational materials; conducting a needs asessment; and adapting and implementing existing palliative care curricula and create new materials to fill the gaps for the training needs of UW and AETC health professionals. Additionally, this project will cultivate opportunities to use the cirriculum and training models in non-HIV palliative care clinical setting serviced by HRSA.

Open Society Institute / Project on Death in America (Soros Foundation) — *$70,000*

1998 $70,000 University of Washington — *PDIA Faculty Scholar ((amount of funding is estimated)*

National Institutes of Health - National Cancer Institute (NCI) — *$231,978*

2001 $231,978 University of Washington — *End of Life Communication Skills for Oncology Fellows*

1R25CA092055-01 R25

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

F. Amos Bailey, M.D.

$446,993 tracked thus far

Robert Wood Johnson Foundation *$446,993*

35476 $446,993 Cooper Green Hospital Foundation, Inc. *Promoting Excellence in End-of-Life Care - Balm of Gilead Palliative Care Program*

Birmingham, AL: (3 years).

George I. Balch, Ph.D.

$238,697 tracked thus far

Robert Wood Johnson Foundation *$238,697*

1999 38049 $238,697 Balch Associates *Assessing Progress and Opportunities for the Last Acts Initiative*

http://web.archive.org/web/20030307011527/http://www.rwjf.org/reports/grr/038049.htmhttp://web.archive.org/web/20030307011527/http://www.rwjf.org/reports/grr/038049.htm

Recommendations

The grantee recommended that Last Acts:

** Maintain and build its network over the long term in order to change end-of-life care.*
** Five years or more are needed to change the medical, social and policy cultures. Continue to strengthen its network by clarifying its multiple foci.*
** Many stakeholders found themselves inundated by Last Acts' information and resources while also valuing its comprehensiveness. While some preferred to narrow down the focus to one that fit their own agenda, others wanted simpler ways to navigate and package information to disseminate. Develop a clear identity to convey what the program stands for.*
** Last Acts needs to solidify agreement on its vision, mission, goals, objectives, strategy and tactics and make them readily known to stakeholders, partners and other audiences. Continue to strengthen its structure by creating a national program office, engaging task forces and resource committee conveners more fully, and defining and strengthening partnerships.*
** Become more visible, especially to the public.*
Many stakeholders considered visibility crucial to changing end-of-life care and planning. Last Acts needs to develop consumer-based communication strategies to help partners reach their publics and to decide what role Last Acts should play in public policy and advocacy.

COMMUNICATIONS

Balch Associates shared its findings with RWJF and Last Acts stakeholders in meetings and phone conversations and prepared a report entitled Last Acts Assessment for RWJF.

NEXT STEPS

RWJF made Last Acts a national program and set up a national program office in August 2000; its Web site is www.lastacts.org. The national program office is at Partnerships for Caring in Washington.

John C. Baldwin, M.D.

$1,000,000 tracked thus far

National Institutes of Health - National Center for Research Resources *$1,000,000*

2000 $1,000,000 Dartmouth College *renovation of research laboratories for Dartmouth Medical School's Department of Genetics*

http://www.dartmouth.edu/dms/news/2000/7sept2000.shtml
Dartmouth Medical School (DMS) has received a $1 million federal grant to help support cutting-edge research in genetics.

The award, effective September 15, was announced by Dean John C. Baldwin, M.D., who is principal investigator for the project. It will support renovation of research laboratories for the medical school's Department of Genetics, established by Baldwin two years ago to ascertain Dartmouth's leadership in this rapidly emerging field, so important to biological sciences in general and to understanding of the fundamental bases for wellness and disease.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

D. Michael Ballard — $7,250,903 tracked thus far

Robert Wood Johnson Foundation — *$7,250,903*

29929 $181,000 Barksdale Ballard & Company — *Multi-Media Curriculum on End-of-Life Issues for Grassroots Organizations (Before I Die)*

See also #29469
The Foundation-sponsored SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) on care for seriously ill and dying patients revealed that death is a subject rarely discussed by most Americans. This project produced a multi-media curriculum to be used by grassroots organizations to promote the exploration of attitudes toward end-of-life issues. The project's centerpiece, a one-hour television broadcast, Before I Die, aired on Public Broadcasting Service stations April 22, 1997 and was rebroadcast September 19, 1997. The program featured a panel of experts in medicine, journalism, ethics, and religion who debated three hypothetical scenarios: a young mother dying from advanced breast cancer; a 65-year-old man who, in peak health, signs an advanced directive; and a young man with AIDS who seeks control over his death. The project also developed a "Viewer's Guide for Before I Die" and other educational materials for individuals and groups to further explore issues around end-of-life. The project held a pre-broadcast videoconference for 40 local stations or organizations designed to generate interest in organizing discussion groups following the actual broadcast. A World Wide Web site (www.wnet.org/bid) was also developed on end-of-life issues, which provided facts and figures, profiles of individuals confronting end-of-life issues, and on-line support groups. More than 646,000 viewers saw the original broadcast. Reviews of the program were featured in publications including The New York Times and The Washington Post. More than 30 newspapers and guides listed it as a recommended program. The Web site continues to promote the Before I Die videos and educational materials. The project produced an educational, interactive tool for bringing end-of-life issues to consumers, and it complements the Foundation's Last Acts initiative, a national program that seeks to better manage end-of-life care.

2000 33035 $7,069,903 Barksdale Ballard & Company — *Last Acts (contract)*

3 years.

David Barnard, Ph.D. — $174,229 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) — *$174,229*

2001 $174,229 University of Pittsburgh - Medical Center — *Undergraduate Medical Education for End of Life Care*

1R25CA090595-01 R25

Milan Basta, M.D., Ph.D. — $94,939 tracked thus far

Robert Wood Johnson Foundation — *$94,939*

1999 36976 $94,939 — *A project to review medicaid nursing home reimbursement policy and the impact on palliative care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_user_view_html__282
This project will review each state's Medicaid program and document how end-of-life services are reimbursed in nursing homes. Specifically, this project will examine the impact of reimbursement policies on the provision of palliative care in nursing homes. The funding of this project will begin to fill a gap in the policy literature on Medicaid-financed long-term care and palliative care.

See also: grant report at http://www.rwjf.org/reports/grr/036576.htm

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Samira Kanaan Beckwith, M.S.W., C.H.E. — $26,627 tracked thus far

National Institutes of Health (General heading) *$26,627*

1997 $26,627 Hope Hospice (H.O.P.E. of Lee County) *Internet Connection for Hope Hospice*

Note: Earl D. Livering is recorded as PI by NIH, but Samira Beckwith was CEO of hospice at the time.

G08 LM06634-01 http://silk.nih.gov/silk/brownbooks/library/detail/fy97

Grant Number: 1G08LM006634-01
PI Name: LIVERING, EARL D.
PI Email:
PI Title:
Project Title: INTERNET CONNECTION FOR HOPE HOSPICE

Abstract: DESCRIPTION (taken from applicant's abstract): H.O.P.E. of Lee County, Inc. d/b/a Hope Hospice has four specific goals in achieving an Internet network connection with broad staff access. These goals include: 1) providing a venue for professional collaboration/consultation related to hospice care and palliative medicine for professional staff, 2) enhancing clinical care and services to Hope Hospice patients/families and community by establishing on-line support groups, 3) expanding resources available for staff and student training, as well as training opportunities through Hospice Resources and, 4) supporting administrative activities. To achieve the above, a Gateway 133 Pentium with network interface, Adtran CSU/DSU and Cabletron router will be used to establish a link to an internet service provider. A 128K fractional T-1 line to the Internet service provider will be installed to allow for multiple Internet users. A two session, six hour, Internet user training program will be designed and implemented for all users. Training content will promote and develop user ability to use the Internet for professional consultation/collaboration, research, professional education, communication with patients/families and administrative purposes. CRITIQUE: A straightforward, standard approach for connecting an existing 120-node LAN to the Internet. Would provide Internet access to over 200 individuals. Several specific applications are mentioned. Plan to use the connection for information dissemination to the general public as well as for research and communication purposes. Technical plan is appropriate to the size of the operation. Clear understanding of aims and requirements to achieve them are demonstrated. Applicant appears to have progressed steadily and to be at an appropriate point for initiating this level of Internet access. Technical background of personnel is good; knowledge of Internet applications may be somewhat weak. Clear understanding of need for training and good detail in training plan. An ambitious project for two people because training and support demands may be more extensive than anticipated especially when Internet use takes hold. The applicant might consider staging Internet access in phases. CHAIRMAN GUAGLIARDO, Mark F., Ph.D. PLUTCHAK, T. Scott, M.L.S Manager of Research Computing Director Children's Research Institute Lister Hill Library Children's National Medical Center University of Alabama Research Center VI at Birmingham 111 Michigan Avenue, N.W. 1700 University Boulevard Washington, DC 20010 Birmingham, AL 35294-0013 RODBARD, David, M.D. ABBOTT, Patricia A., M.S., R.N.-C Assistant Vice President Faculty Office of Information Resources School of Nursing Association of American Medical Department of EAHP I Colleges University of Maryland at Baltimore 2450 N. Street, N.W. 655 West Lombard Street Washington, DC 20037-1126 Baltimore, MD 21201 JOHNSON, Frances E., M.A.L.S. CAVANAUGH, Sally H., Ph.D. Program Officer and Acting Director of Research Scientific Review Administrator York Hospital Division of Extramural Programs 1001 S. George Street National Library of Medicine York, PA 17405-7198 Bethesda, MD 20894 Voice: 301-496-4621 Fax: 301-402-2952

Thesaurus Terms:

There are no thesaurus terms on file for this project.

Institution: HOPE HOSPICE AND PALLIATIVE CARE
9470 HEALTH PARK CIR
FORT MYERS, FL 33908
Fiscal Year: 1997
Department:
Project Start: 30-SEP-1997
Project End: 29-SEP-1998
ICD: NATIONAL LIBRARY OF MEDICINE
IRG: ZLM1

Geraldine "Polly" Bednash, PhD, RN, FAAN — $2,251,659 tracked thus far

Robert Wood Johnson Foundation *$2,251,659*

1997 $27,116 American Association of Colleges of Nursing (AACN) *ELNEC: Strategy meeting on nursing education to improve end-of-life care*

This project convened selected nurse educators who have made important contributions to the research and practice of care for the terminally ill. The project resulted in the establishment of end-of-life competencies that were incorporated into the American Association of Colleges of Nursing revised baccalaureate essentials.

2000 37617 $2,224,543 American Association of Colleges of Nursing (AACN) *ELNEC: Nursing faculty development in end-of-life care (for 42 months)*

ELNEC (http://www.rwjf.org/reports/grr/032829.htm)

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Charles Bentz, M.D. — $500,000 tracked thus far

Robert Wood Johnson Foundation — *$500,000*

2001 44151 $500,000 Providence Health Systems, Oregon Region — *Evaluation of a tobacco cessation program using a primary care electronic medical record*

http://www.rwjf.org/programs/grantDetail.jsp?id=044151
CONTACT INFORMATION
Charles Bentz M.D. (Project Director)
cbentz@providence.org
503-216-262

Joan Berzoff, M.S.W., Ed.D., BCD — $60,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$60,000*

$60,000 Smith College School of Social Work — *EOLC Certificate Program for Social Workers*

This project will develop a certificate program in end-of-life care for post-master's level social workers working with terminally ill patients and their families in hospitals, nursing homes, and hospices. The program will include development of an innovative continuing education curriculum and textbook, which will serve as an educational resource for social workers throughout the United States.

J. Andrew Billings, M.D. — $3,226,613 tracked thus far

Robert Wood Johnson Foundation — *$2,783,893*

1998 $900,000 Harvard Medical School - Center for Palliative Medicine at — *Center for Palliative Care Education at Harvard*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_user_view_html_90
This grant will support the Center for Palliative Care Education at Harvard Medical School, a national resource for faculty development in palliative care practice and education. The project will train faculty members from around the country. Faculty completing training at the center will be prepared to teach other faculty, practitioners, and trainees in medicine and nursing about comprehensive end-of-life care, develop innovative educational projects, and build palliative care programs at their own institutions.

1999 34352 $997,873 Harvard Medical School - Center for Palliative Medicine at — *Establishment of a palliative care education center*

Two New Programs Will Train Medical And Nursing Faculty In End-Of-Life Care

Stanford and Harvard Receive Grants for Innovative Programs

PRINCETON, N.J., April 5, 1999 -- Two ground-breaking programs to train doctors and nurses in providing better care for the dying are being launched by universities on opposite sides of the country. Stanford University and Harvard Medical School will start their programs to train medical and nursing faculty with funds from the Princeton, N.J.-based Robert Wood Johnson Foundation.

The four-year, $831,931 grant to Stanford University will be used to establish an end-of-life care curriculum for medical faculty. Stanford's Faculty Development Program, co-directed by Kelley M. Skeff, M.D., Ph.D,. and Georgette A. Stratos, Ph.D., trains medical faculty from across the United States in its special month-long programs. These individuals, in turn, become resources for other faculty and for residents back in their home institutions, using formal training courses and large workshops to spread the word.

?Our medical faculty profoundly influence students and residents, the nation?s future physicians and teachers,? Stratos said. ?The goal of the Stanford program is to assist faculty across the country to effectively teach the best possible care for patients with serious and life-limiting illness,? she said.

The Stanford project expects to train 18 faculty members directly. Each subsequently will train an additional 360 faculty members and residents during a three-year period.

?We like the ?train-the-trainer? model because it?s a quicker way to reach a great many doctors?much quicker than working with one medical school at a time,? said RWJF Senior Program Officer Rosemary Gibson.

On the East Coast, the newly established Center for Palliative Care Education at Harvard Medical School, headed by J. Andrew Billings, M.D., and Susan D. Block, M.D., will offer state-of-the-art training for both doctors and nurses.

Based in the Palliative Care Service of Massachusetts General Hospital, the program will include training in the skills needed to teach effectively about this field and to promote palliative care in the trainee?s home institution.

?We are encouraged by the recent growth of interest in end-of-life care and palliative care programs. But physicians still have too few opportunities to learn about this field and how to teach it successfully,? said Billings. ?We will develop faculty around the country who are knowledgeable about end-of-life care, and can also convey essential attitudes and communication skills that students require to become humane, capable physicians for patients and families facing life-threatening illness.? Additionally, the program will help these faculty members be effective agents of change in their home institutions.

The Harvard project expects to train 60 faculty members during the three-year term of this $997,873 grant.

?With their emphasis on increasing the knowledge and skills of health care professionals, these grants represent an important contribution to the Foundation?s three-part strategy to improve care for dying Americans,? said Gibson. The Foundation?s other two strategies are: improving the institutional environment?including quality of care and financing?and public engagement.

2002 42971 $511,020 Massachusetts General Hospital — *Palliative care education center*

2003 47997 $375,000 Massachusetts General Hospital — *Promoting Palliative Care Excellence in Intensive Care*

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

$50,000 — *Faculty Scholar 1995 (http://www2.soros.org/death/prMay29-96.htm) (Grant amount is estimated.)*

Mayday Fund *$160,800*

1998 $20,500 Massachusetts General Hospital — *MGH Cares About Pain*

http://www.painandhealth.org/mayday/previous-grants.html

1998 $59,325 Massachusetts General Hospital — *MGH Cares About Pain*

http://www.painandhealth.org/mayday/previous-grants.html
Massachusetts General Hospital
Boston, Massachusetts
"MGH Cares About Pain"
$20,500 for a grant project "MGH Cares About Pain."
$59,325, the first payment in a grant of up to $235,200 in support of "MGH Cares About Pain" - a program to improve the treatment of pain throughout the hospital and its clinics.
Contact: J. Andrew Billings, M.D.
E-mail: jbillings@hms.harvard.edu

1999 $80,975 Massachusetts General Hospital — *MGH Cares About Pain*

http://www.painandhealth.org/mayday/previous-grants.html
Massachusetts General Hospital
Boston, MA
USA
$80,975.00, the final payment in a grant in support of the MGH Cares About Pain project.
Contacts: J. Andrew Billings, MD and David Borsook, MD, Ph.D
Email: jbillings@partners.org and dborsook@partners.org

National Institutes of Health - National Cancer Institute (NCI) *$231,920*

2000 $146,123 Massachusetts General Hospital — *Palliative Care Fellowship*

5R25CA082174-02 R25 (2001)

2000 $85,797 Massachusetts General Hospital — *Palliative Care Fellowship*

1R25CA082174-01A1 R25 (2000)

Susan Blacker, M.S.W., LCSW-C — $60,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$60,000*

2000 $60,000 Johns Hopkins, Department of Oncology Social Work — *EOLC Continuing Education for Social Workers*

This program will develop and offer an innovative training course to meet the continuing education needs of social workers practicing in the arena of end of life care and will create a post-master's training opportunity to encourage specialization. It will also establish a statewide network of social workers who will be trained to serve as role models in educating peers about the psychosocial needs of individuals and families facing life-threatening illness.

James A. Block, M.D. — $154,998 tracked thus far

Robert Wood Johnson Foundation *$154,998*

2002 46433 $154,998 J. A. Block Health Associates — *CAPC - Consulting services for the Center to Advance Palliative Care (1 year)*

Susan Dale Block, M.D. — $205,194 tracked thus far

Robert Wood Johnson Foundation *$41,856*

1996 29360 $41,856 Harvard Pilgrim Health Care, Inc. — *National Consensus Conference on Medical Education for Care Near the End of Life*

Open Society Institute / Project on Death in America (Soros Foundation)

Director, Faculty Scholars Program

National Institutes of Health - National Cancer Institute (NCI) *$163,338*

1994 $62,354 Harvard Medical School - Center for Palliative Medicine at — *Palliative Care Role Model Program*

5R25CA066818-07 R25 (2001)

1994 $100,984 Harvard Medical School - Center for Palliative Care *Palliative Care Role Model Program*

5R25CA066818-06 R25

1994 Harvard Medical School

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2110303&p_grant_num=5R25CA066818-02&p_query=%28hospice%29&ticket=14333335&p_audit_session_id=65197762&p_audit_score=100&p_audit_numfound=1&p_keywords=hospice
Grant Number: 5R25CA066818-02
PI Name: BLOCK, SUSAN D.
PI Email: sblock@partners.org
PI Title: CHEIF, DIVISION OF PSYCHOSOCIAL ONCOLOGY
Project Title: HOSPICE IN GENERAL MEDICAL EDUCATION AND PRIMARY CARE

Abstract: DESCRIPTION: (Applicant's Description) The Division of Primary Care of Harvard Medical School, the Department of Ambulatory Care and Prevention of Harvard Community Health Plan and Harvard Medical School, the Massachusetts General Hospital, the Trinity Hospice of Greater Boston, and the Hospice of Cambridge propose an educational partnership for the purpose of educating medical students and primary care residents about hospice and palliative medicine. Throughout its implementation, this program will focus not just on knowledge and skill development, but will have an intensive emphasis on the development of attitudes that facilitate the goals and process of hospice and palliative care. This collaboration will provide medical students and residents with basic competencies in caring for dying persons, and will enhance the educational skills of hospice team members and other faculty supervisors. It will prepare primary care residents to serve as leaders in the development of hospice and palliative medicine as academic and clinical disciplines, and will educate palliative medicine consultants,hospice team leaders, and primary physicians to care effectively for terminally patients. In consultation with an Education Steering Committee for this project, the principal investigator will plan a core curriculum in palliative medicine for medical students and primary care residents, develop educational materials (including written and videotaped cases) for both curricula, implement a new course for medical students and new training experiences for selected primary care residents,organize clinical experiences with hospice patients for students throughout all four years of medical school and for residents during their graduate training, implement a faculty development program for staff from the two affiliated hospice programs and faculty supervisors, evaluate the effectiveness of these educational experiences, disseminate curricular materials, and publish and present evaluative information about these programs.

Thesaurus Terms:
hospice, medical education, neoplasm /cancer palliative treatment, primary care physician, terminal patient care curriculum, education evaluation /planning, patient care management

Institution: HARVARD UNIVERSITY (MEDICAL SCHOOL)
MEDICAL SCHOOL CAMPUS
BOSTON, MA 02115
Fiscal Year: 1995
Department: PSYCHIATRY
Project Start: 30-SEP-1994
Project End: 31-AUG-1997
ICD: NATIONAL CANCER INSTITUTE
IRG: SRC

Diane Blum — $63,675 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$63,675*

$63,675 Cancer Care, Inc. *Support Cancer Care*

Project: Cancer Care aims to improve end-of-life care for terminally ill cancer patients by enhancing the practical, spiritual, and communication knowledge and skills of their health care professionals through a national, multi-disciplinary teleconference series.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

L. Thompson (Tom) Bowles — $105,995 tracked thus far

Robert Wood Johnson Foundation *$105,995*

1998 33887 $105,995 National Board of Medical Examiners *NBME: Physician Licensing Program*

Philadelphia, PA: (45 months).
http://www.rwjf.org/news/releaseDetail.jsp?id=980550076729

$106,000 to the National Board of Medical Examiners (NBME) to develop end-of-life questions for the United States Medical Licensing Examination (USMLE). All fifty states require that doctors take this exam.

Tom Bowles, president of the National Board of Medical Examiners and director for the licensing exam project, said that "formal academic training should place greater emphasis on humanistic and ethical issues" affecting the terminally ill. "Physicians needgreater expertise and knowledge about issues like advancedirectives, organ donation, palliative measures, pain management, psychologicaland spiritual support, and hospice care."

Bowles said that strengthening this area of content in the medical licensure examination reflects appropriate priority in medical studies. The exam influences faculty decisions about what to teach and encourages students in their selection of areas to study. The NBME will convene a working group of clinicians and ethicists in end-of-lifecare for a two-day meeting later this year to review the examination. The experts will suggest how to increase the quantity and quality of end-of-life questions, then monitor the project for an additional three years

Katherine (Kathy) Brandt, M.S. — $7,317,770 tracked thus far

Robert Wood Johnson Foundation *$7,317,770*

2004 52223 $2,376,370 National Hospice and Palliative Care Organization (NHPC *Caring Connections - Technical Assistance and Direction*

http://rwjf.org/applications/program/grant.jsp?id=052223&npo=LAX&type=690&page=1
An initiative to promote and expand consumer engagement in end of life care.

2005 53554 $4,941,400 National Hospice and Palliative Care Organization (NHPC *Caring Connections*

http://rwjf.org/applications/program/grant.jsp?id=053554&npo=LAX&type=692&page=1

An initiative to promote and expand consumer engagement in end of life care

William S. Breitbart, M.D. — $3,911,199 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 Cornell University - Weill Medical College *Faculty Scholar (Network Project; Textbooks)*

Grant amount is approximate;
http://www.soros.org/initiatives/pdia/focus_areas/professional_education/grantees/breitbart_1995
William Breitbart, M.D.
1995

Memorial Sloan-Kettering Cancer Center

Development of a consortium to address the psychiatric aspects of palliative care at Memorial Sloan-Kettering Cancer Center and across North America through the expanding Network Project, production of two textbooks, planning and implementation of a national and international conference, and working with two national task forces.

New York, NY
========
http://www2.soros.org/death/prMay29-96.htm
Development of an education and research consortium to address psychiatric aspects of palliative care across North America.

National Institutes of Health - National Cancer Institute (NCI) *$718,225*

1994 $86,714 Memorial Sloan Kettering *Network Project*

http://www.mskcc.org/prg/mrg/bios/274.cfm
As principal investigator of the NCI-funded Network Project, Dr. Breitbart has been testing novel approaches in the training and education of physicians and nurses across the nation on issues of pain management and psychiatric dimensions of palliative care, in order to improve patient care.

1995 $87,315 Memorial Sloan Kettering *Network Project*

http://grants.nih.gov/grants/award/state/FY1995.new.york.txt

1997 $94,441 Memorial Sloan Kettering *Network Project*

1998 $90,207 Memorial Sloan Kettering *NETWORK PROJECT*

http://grants.nih.gov/grants/award/state/fy1998.new.york.txt

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9436338&dopt=Abstract
J Pain Symptom Manage. 1998 Jan;15(1):18-26. Related Articles, Links

The Network Project: a multidisciplinary cancer education and training program in pain management, rehabilitation, and psychosocial issues.

Breitbart W, Rosenfeld B, Passik SD.

Department of Psychiatry, Memorial Sloan-Kettering Cancer Center, New York, NY 10021, USA.

Despite recent advances in cancer pain management and education, the undertreatment of cancer pain remains a national health problem. In response to the need for interdisciplinary education and training, we have developed "The Network Project" at Memorial Sloan-Kettering Cancer Center. This program includes a 2-week observership in cancer pain management, psychosocial oncology, and cancer rehabilitation. The efficacy of the Network Project Observership Program was evaluated with the use of a knowledge and attitude inventory which contains questions pertaining to cancer pain, psychosocial oncology, and cancer rehabilitation, and follow-up questionnaires completed one year after participation in the program. The knowledge and attitude inventory was completed by each participant both before and after the observership period. Analysis of the 152 observers who participated in the first 3 years of the Network Project's Observership Program demonstrated a significant improvement in knowledge of cancer pain, psychosocial issues, and rehabilitation issues (P < 0.0001). In addition, observers reported a significant increase in their local educational and training activities in the year following participation in the Network Project (P < 0.01). The Network Project, funded by the National Cancer Institute, is an interdisciplinary, multimodal training program which has been demonstrated to be an effective means for improving and disseminating knowledge regarding the multidisciplinary management of pain and psychological distress in cancer patients.

PMID: 9436338 [PubMed - indexed for MEDLINE]

1999	$129,078	Memorial Sloan Kettering	*Network Project*
2000	$150,521	Memorial Sloan Kettering	*Network Project*
2001	$79,949	Memorial Sloan Kettering	*Network Project*

National Institutes of Health - National Institute of Mental Health (NIMH) *$3,052,974*

1994	$279,420	Memorial Sloan Kettering	*PAIN IN THE AMBULATORY AIDS PATIENT*
1995	$196,715	Memorial Sloan Kettering	*PSYCHOSTIMULANTS FOR FATIGUE IN THE HIV INFECTED PATIENT*

http://grants.nih.gov/grants/award/state/FY1995.new.york.txt

1997	$206,946	Memorial Sloan Kettering	*PSYCHOSTIMULANTS FOR FATIGUE IN THE HIV INFECTED PATIENT*
1998	$353,525	Memorial Sloan Kettering	*DESIRE FOR DEATH AMONG TERMINALLY ILL PATIENTS WITH AIDS*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2649531&p_grant_num=1R01MH057629-01A1&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=24&p_audit_numfound=164&p_keywords=palliative
Grant Number: 1R01MH057629-01A1
PI Name: BREITBART, WILLIAM
PI Email: breitbaw@mskcc.org
PI Title: PROFESSOR AND CHIEF
Project Title: DESIRE FOR DEATH AMONG TERMINALLY ILL PATIENTS WITH AIDS

Abstract: DESCRIPTION (Applicant's Abstract): Despite the hope created by the recent introduction of protease inhibitors, patients with AIDS are still dying in large numbers,and palliative care/quality of life issues in patients with advanced AIDS remains an important area of clinical investigation. Perhaps the most compelling and clinically relevant issue in palliative care today concerns desire for death and physician assisted suicide (PAS). Despite the recent Supreme Court decisions, the issue of whether or not to legalize PAS will continue to be actively debated in many state legislatures. It is anticipated that several states will legalize PAS, and guidelines are being developed for its use that involve psychiatric evaluation as an important component. There have been several recent studies of patients with cancer or AIDS, including one on interest in PAS among ambulatory patients with AIDS published by the investigator's research group, demonstrating that depression plays an important and perhaps central role in some patients' desire for death or interest in PAS. With only one exception, these studies have failed to directly assess/measure desire for death among terminally ill patients,and no research to date has attempted to answer the question of whether treatment for depression has a significant impact on patients' desire for death. This project's overall aim is to describe desire for death among patients with end-stage AIDS, determine the correlates of desire for death, and assess the impact of treatment for major depression on patients' desire for death. Specifically, the investigators will assess the prevalence, severity, consistency over time (8 weeks), and medical/psychosocial correlated of desire for death among terminally ill AIDS patients, as well as the relationship between desire for death and a clinical diagnosis of Major Depressive Episode. Desire for death will be monitored over an 8-week period in a group of patients who receive a standardized pharmacological treatment for depression. This study aims to provide the first direct evaluation of the desire for death among terminally ill patients with AIDS, and will provide data on the critical issue of whether or not treatment for depression influences patients' desire for death.

Institution: SLOAN-KETTERING INSTITUTE FOR CANCER RES

NEW YORK, NY 100216007
Fiscal Year: 1998
Department:
Project Start: 01-JUL-1998
Project End: 30-JUN-2002
ICD: NATIONAL INSTITUTE OF MENTAL HEALTH
IRG: MHAI

1999	$351,901	Memorial Sloan Kettering	*DESIRE FOR DEATH AMONG TERMINALLY ILL PATIENTS WITH AIDS*

http://grants.nih.gov/grants/award/state/fy1999.new.york.txt

2000	$389,906	Memorial Sloan Kettering	*DEPRESSION/DESIRE FOR DEATH IN TERMINAL CANCER PATIENTS*
2000	$358,353	Memorial Sloan Kettering	*DESIRE FOR DEATH AMONG TERMINALLY ILL PATIENTS WITH AIDS*
2001	$151,102	Memorial Sloan Kettering	*Meaning-Centered Psychotherapy in Advanced Cancer*
2001	$364,999	Memorial Sloan Kettering	*DESIRE FOR DEATH AMONG TERMINALLY ILL PATIENTS WITH AIDS*
2001	$400,107	Memorial Sloan Kettering	*DEPRESSION/DESIRE FOR DEATH IN TERMINAL CANCER PATIENTS*

David Browning, M.S.W., LICSW, BCD

tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation)

Social Work Leadership Development Award

Richard D. Brumley, M.D.

$150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 Kaiser Permanente — *[Estimated amount] TriCentral Palliative Care Toolkit (http://www.growthhouse.org/palliative/)*

Kaiser Permanente TriCentral Service Area
Transferring End-of-Life Knowledge in Clinical Culture
In 1997, the Kaiser Permanente TriCentral Service Area initiated an outpatient Palliative Care Program. Modeled after Kaiser's hospice program, the palliative care program offers pain management, comfort care, and curative therapies to patients who have an estimated prognosis of less than one year. In order to promote replication of this model at healthcare sites both within and outside of Kaiser Permanente, this project will develop a comprehensive tool kit and website to provide all the educational, program design, and technical-assistance materials needed to replicate the palliative care model.

Jeffrey H. Burack, M.D., M.P.P., B.Phil.

$140,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1998 $140,000 University of California - Berkeley — *Faculty Scholar: Exploring the Transition to Terminal Illness*

The medical profession most commonly emphasizes the search for diagnosis and curing. When cure is no longer considered possible, or trying to achieve it becomes excessively burdensome, the emphasis shifts to palliation exclusively. Far more is at stake in this transition, however, than a mere shift in therapeutic emphasis. Coming to view oneself, and coming to be viewed socially, as terminally ill would appear to mark a life change of dramatic psychological, spiritual, and existential consequence. This project will study this transition into terminal illness, and the transition from primarily curative into exclusively palliative modes of medical care, from patients' perspectives as well as those of their physicians and caregivers.

William J. Burke, M.D., Ph.D.

$29,943 tracked thus far

State of Missouri *$29,943*

$29,943 — *For a pilot study concerning Parkinson's disease.*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Ira Bumin — $238,272 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$238,272*

2001		$238,272	Bazelon Center for Mental Health Law -- Pain and Palliativ	*To design and implement a litigation campaign to establish rights to palliative care.*

http://www.bazelon.org/about/2001annualreport.pdf
Mrs. Z.B. died in agony, with only over-the-counter Tylenol to ease her pain. Although her care plan called for effective pain control and no "curative care," her doctor didn't respond to frantic calls from her family and hospital staff. Mrs. Z.B.'s plight is all too common.

Many physicians know too little about palliative care. In particular, complaints of pain by people of color and those diagnosed with a mental illness or a disability such as Alzheimer's disease are often ignored. And Medicare limits on hospice care and restrictions on the prescription of narcotics for pain relief discourage effective pain management.

The Bazelon Center's palliative care program worked to establish the right of people being treated for pain or terminal illnesses to receive adequate palliative care. Like our mental health advocacy, the program emphasizes respect for an individual's choices and works to end discriminatory practices.

We developed litigation strategies to lower barriers to effective palliative care and provided legal support to Mrs. Z.B.'s attorney and others challenging the denial of effective pain management. Our Pain Law and Palliative Care Law Reporter (www.painlaw.org), offers resources to increase understanding of the right to palliative care in the treatment community and among the public.

Ira Robert Byock, M.D. — $6,587,037 tracked thus far

Robert Wood Johnson Foundation *$6,007,037*

	33718	$522,437	Missoula Demonstration Project / Life's End Institute	*Targeted End-of-Life Projects Initiative*

Missoula, MT: (1 year).

1997	30794	$53,675	Missoula Demonstration Project / Life's End Institute	*Supplementary funds for Missoula demonstration project on the quality of life's end (for 1 year).; Missoula, MT*

Missoula Demonstration Project Inc.

1998	31749	$645,868	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence in End-of-Life Care*

(Chronic Health Conditions) Missoula, MT: Technical assistance and direction for Promoting Excellence in End-of-Life Care (1 year).

1999	37526	$847,888	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence in End-of-Life Care*

Technical assistance and direction for Promoting Excellence in End-of-Life Care (20 months).

1999	34228	$799,904	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence in End-of-Life Care*

Technical assistance and direction for Promoting Excellence in End-of-Life Care (1 year).

2001	41114	$509,425	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence - Grantee communications efforts*
2001		$1,091,720	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence in End-of-Life Care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html__688
The Promoting Excellence in End-of-Life Care national program, approved in July 1996, focuses on improving care of the dying by expanding the scope of diagnosis of patients who receive hospice and palliative care, making hospice and palliative care available to patients earlier in their stage of disease, and creating a special opportunities fund to support projects that further the aims of the program. The National Program Office would use these funds to: (1) provide technical assistance to grantees through site visits, teleconferences, networking, and an annual meeting; (2) explore sustainability options and strategies for grantees; (3) put greater emphasis on communications efforts to leverage the work done by grantees and workgroups to foster national change; (4) use remaining funds in the authorization to address palliative care needs in critical care settings; (5) identify opportunities in the field for remaining special opportunities funds that further the program's goals; (6) maintain the program's Web site; and (7) continue supporting grantees with their evaluation of their projects through the innovative Evaluation Technical Assistance Plan.

2001	42313	$35,000	Missoula Demonstration Project / Life's End Institute	*Missoula Demonstration Project, Inc.*
2002	46051	$253,860	University of Montana - Center for Ethics (dba Practical Et	*Promoting Excellence in End-of-Life Care grantee communications efforts*
2002	42535	$593,400	University of Montana College of Arts and Sciences	*Technical assistance and direction for Promoting Excellence in End-of-Life Care*
2002	46571	$328,860	University of Montana College of Arts and Sciences	*Promoting Excellence in End-of-Life Care peer-to-peer work groups*
2003	46985	$325,000	University of Montana College of Arts and Sciences	*Technical assistance and direction for Promoting Excellence in End-of-Life Care*

Technical assistance and direction for Promoting Excellence in End-of-Life Care

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

		$50,000	Missoula Demonstration Project / Life's End Institute	*Missoula Demonstration Project*

http://www2.soros.org/death/delivery_models.htm

Project: A long-term, community-based organization which came together to study and transform the culture and experience of dying. Research will be done to define the attitudes, expectations, and experiences related to death and dying in Missoula County, Montana. The results will provide the platform for future interventions and research in the next 15 years focused on bringing quality to life's end.
Probably granted circa 1997. See http://www.lifes-end.org/mediastories/missoula_experiment.phtml

Nathan Cummings Foundation, Inc. *$500,000*

1997	$400,000	Missoula Demonstration Project / Life's End Institute	*Demonstration project*

To demonstrate, in practice and through research, that quality of life can be preserved during the dying process and that superior care of patients and their families can be provided in a cost-effective manner.

2000	$100,000	Missoula Demonstration Project / Life's End Institute	*Missoula Demonstration Project*

Renewal support: To engage the community of Missoula in an effort to demonstrate that quality of life can be preserved for people who are dying and their caregivers.

Engelhard Foundation (Charles) *$30,000*

1999	$30,000	Missoula Demonstration Project / Life's End Institute	*Enhancing the Sacred at the End of Life and During Bereavement*

http://www.lifes-end.org/annual_report/recent/recent_highlights.phtml

Arthur Leonard Caplan, Ph.D. — $32,482 tracked thus far

Robert Wood Johnson Foundation *$32,482*

1999	$32,482	University of Pennsylvania School of Medicine	*Content analysis of news coverage on the Kevorkian case*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html__184
The project conducted a content analysis of news reporting on the Kevorkian assisted suicide story aired on "60 Minutes" on November 15, 1998, in which the death of Thomas York after an injection by Jack Kevorkian was vividly portrayed. Mr. York suffered from amiyl lateral sclerosis (ALS), a progressive and fatal neurological disease. This analysis served as the centerpiece for two media seminars to educate journalists about the wealth of end-of-life stories they might cover to place the Kevorkian case in its proper perspective. The analysis examined the following questions: (1) did stories focus exclusively on Kevorkian or did they examine substantive issues related to physician-assisted suicide; (2) did media ethics or bioethics get more attention; and (3) did stories examine related issues such as care for the dying, pain relief, hospice care, depression, disability, the nature of ALS, etc.?

David Jonathan Casarett, M.D., M.A. — $124,794 tracked thus far

National Institutes of Health (General heading) *$124,794*

2000 $124,794 University of Pennsylvania School of Medicine *PATIENT PREFERENCES ABOUT END OF LIFE RESEARCH*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6046063&p_grant_num=1K01AI001739-01&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=24&p_audit_numfound=172&p_keywords=palliative
Grant Number: 1K01AI001739-01
PI Name: CASARETT, DAVID J.
PI Email: casarett@mail.med.upenn.edu
PI Title:
Project Title: PATIENT PREFERENCES ABOUT END OF LIFE RESEARCH

Abstract: DESCRIPTION (Applicant's Abstract): Dr. David J. Casarett, a Fellow in Palliative Medicine at the University of Pennsylvania Medical Center is applying for a Mentored Research Scientist Development Award in Research Ethics in order to develop and enhance the skills to become an independent investigator and national resource in research ethics. The candidate's research interests focus on assessing patient preferences about end of life research. This application requests support for a career development program that will include didactic course work, mentoring, and a program of mentored research that will generate important data about the way that patients near the end of life perceive the risks and benefits of research that may involve them. Increasing attention has focused on end of life care and symptom management, but it has become apparent that few data exist to guide clinical treatment decisions. Research to provide data is needed. However, this research involves patients near the end of life who may be unable to protect their own interests because of severe symptoms, cognitive impairment, depression, or dependent relationships with investigator/providers. Therefore, while this research is necessary, it creates significant ethical challenges. In order to protect these vulnerable patients, scrutiny of the risks and benefits of end of life research is necessary. However, it is not known how patients near the end of life perceive the risks and potential benefits of this research. This application proposes a 5-year program of mentored research and scholarship that builds on preliminary work to assess patients' preferences regarding end of life research. Dr. Casarett proposes that understanding these preferences will assist investigators in two ways: 1) Investigators will be better able to meet the informational needs of prospective subjects; and 2) Investigators will be able to incorporate these preferences into the design of clinical research. The first project proposed is a semi-structured interview study, the principal aim of which is to define the risks and benefits that are important to patients near the end of life. The second project will assess patients' informational needs regarding these risks and benefits. The third and fourth projects will survey researchers and patients to define and compare preferences about specific risks and benefits in the setting of palliative pain trials. By year five of this plan, Dr. Casarett will have established a foundation of substantial research into patient preferences regarding end of life research, and will have acquired the skills to compete successfully for further funding in the form of a R01 award.
Institution: UNIVERSITY OF PENNSYLVANIA
3451 Walnut Street
PHILADELPHIA, PA 19104
Fiscal Year: 2000
Department: MEDICINE
Project Start: 30-SEP-2000
Project End: 01-MAR-2001
ICD: NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES
IRG: ZRG1

Virginia Casey, PhD, MPH — $128,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$128,000*

2000 $128,000 Beth Israel Hospital *Measuring the Quality of End of Life Care – Producing the Video Component of the Toolkit Instruments*

This grant will support the production of an educational video tape as part of the Toolkit project: Development of a Toolkit of Instruments to Measure the Quality of End of Life Care (TIME). The goal of the Toolkit project is to help long term institutions improve the quality of end of life care by incorporating the dying person's and family perspective into their care. The Picker Institute and the Center for Survey Research at the University of Massachusetts are collaborating on this effort.

Christine K. Cassel, M.D. — $456,844 tracked thus far

Robert Wood Johnson Foundation *$190,966*

1999 $128,020 Mount Sinai School of Medicine *Research to develop an inventory of hospital-based palliative care programs*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___492
This grant created an inventory of what was happening in hospital-based palliative care around the country. An expanded network model and key informants were used to discover as many as possible the existing, new, and emerging programs in palliative care. The study: (1) identified lists of leaders in the field of palliative care through the Project on Death in America Faculty Scholars Roster, the VA Faculty Leaders Project, the AHA and NHO, and the participants in the AMA EPEC Program; (2) characterized the clinician leaders: speciality and subspecialty, level of seniority, academic emphasis, and length of time in palliative care, etc.; and (3) developed a typology of programs in which to categorize the information received. This study provided a "snapshot" of what is happening in palliative care in the United States in 1999 and may lead to another study in two-three years to identify trends in the field.

2000 $62,946 Mount Sinai School of Medicine *National meeting of hospice and palliative care leadership to develop standards, fellowship programs, and certification processes*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___341
NOTE: With Diane Meier
This grant would provide support for a one-day meeting of 25 key leaders in hospice and palliative medicine to begin the process of establishing a consensus on strategies for setting standards, developing a series of fellowship programs, and identifying effective and valid means of certification. This grant would cover meeting costs, a write-up of the meeting and possible publication of the proceedings, and a facilitator who will do substantial preparation.

Open Society Institute / Project on Death in America (Soros Foundation) *$75,000*

$75,000 Mount Sinai School of Medicine *Shaping Government and Institutional Policy: Create a DRG (Disease-related group) for payment of terminal services*

http://www2.soros.org/death/governmental_policy.htm (sometime between 1994-97)
This program, designed as a task force project, is to create a Disease Related Group (DRG) for payment for terminal care services delivered to hospitalized patients and all palliative care. This new code will validate and legitimize the practice of palliative medicine by hospital professionals on behalf of their dying patients, since a reimbursed activity is much more likely to be viewed as an appropriate function for doctors and hospitals.

Commonwealth Fund *$190,878*

1996 $190,878 Mount Sinai School of Medicine *Quality Indicators for Care at the End of Life*

Quality of Care for Frail Elders Grant

Victor T. Chang, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

2000 $50,000 University of Medicine and Dentistry of New Jersey, New J *Faculty Scholar, 2000-2002: Study of Outcome Measurement in Terminal Cancer Patients (Grant amount is estimated.)*

(Grant amount is estimated.) The development of an evidence-based system of palliative care medicine is of great importance to the field. This palliative care system relies upon the availability of outcomes, which can be assessed and compared. This project will contribute to the development and testing of outcomes for symptom management in palliative care of patients with advanced cancer.

Martin G. Chemiak, M.D., MPH — $966,579 tracked thus far

$966,579

2002 $966,579 University of Connecticut *Development of a Laboratory for Improving Communication Between Air Traffic Controllers and Pilots*

http://www.advance.uconn.edu/2002/020909/020909gr.htm
Uconn lists this as "Federal Research" to Physiology Dept., and sponsor is simply "Occupational & Environmental Medicine."

http://www.advance.uconn.edu/2001/011210/01121001.htm
Federal Research Funds Earmarked for UConn

Millions of dollars in federal funding have been earmarked for UConn faculty, allowing a range of key research projects to continue operating and giving a green light to investigators interested in developing several new programs.

Nearly $15 million has been committed to UConn as part of the next federal budget, while more than $12.5 million in additional monies awaits action in the Senate or in conference committees. The funding is expected to make this session of Congress one of the most fruitful in memory, University officials said last week….

Included in the bills President Bush has signed are:

** $1.5 million for a new study at the Health Center to find ways to enhance communication between airline pilots and air traffic controllers;*
** $3 million to continue the Health Center's prison health research program; ...*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Eileen R. Chichin, Ph.D., R.N. — $197,300 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$197,300*

2001 $197,300 Hospice and Palliative Nurses Association (HPNA) *Palliative Care Certification for Nursing Assistants*

(through Partnership for Caring coordinating center. See http://www.partnershipforcaring.org/WhatsNew/press_content.html
This program will develop and promote a certification process for Nursing Assistants (NAs) that advances quality in providing palliative care. The major project outcomes will be a valid, reliable and legally defensible scope of practice, a set of core competencies, and a certification exam based on identification of the major tasks and assessment of the role of the NA in a palliative care setting. Since NAs are the largest population of caregivers in long-term and other palliative care settings, this project will extend on a national level to a vast and important group. With Judy Lentz and Jeanne Martinez

Harvey Max Chochinov, MD, PhD, FRCPC — $460,083 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1996 $70,000 University of Manitoba *Faculty Scholar, 1996-97 (estimated funding amount)*

Research, education, clinical work and advocacy focused on the psychiatric dimensions of palliative medicine.

National Institutes of Health - National Cancer Institute (NCI) *$390,083*

2004 $390,083 University of Manitoba *Dignity Intervention for Terminally ill Cancer Patients*

(his 2002 cv gives the $1,607,121US amount)
Conducted with Breitbart, W., Kristjanson, L., Hack, T., McClement, S., Hassard, T. & Harlos, M. (2004-2008)
http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6771642&p_grant_num=1R01CA102201-01A1&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=24&p_audit_numfound=118&p_keywords=palliative+care
Grant Number: 1R01CA102201-01A1
PI Name: CHOCHINOV, HARVEY M.
PI Email: chochin@cc.umanitoba.ca
PI Title:
Project Title: Dignity Intervention for Terminally illl Cancer Patients

Abstract: DESCRIPTION (provided by applicant): One of the greatest challenges facing palliative care today is how to address suffering of dying patients, particularly suffering that derives from psychosocial, spiritual or existential domains of the patients' experience. Patient distress associated with symptoms such as pain, nausea, dyspnea, and even to a degree depression and anxiety, have been the focus of some targeted research. Less is know about how to address sources of distress outside of these traditional domains. Over the past three years, our palliative care research group has developed, manualized and pilot tested and refined a novel individual, brief intervention called Dignity Psychotherapy. This intervention is based on an empirically derived theoretical model developed from our qualitative and quantitative work on dignity in the terminally ill. This therapeutic approach is unique, in that it is a brief practical bedside intervention, designed specifically to enhance a sense of purpose, meaning, and overall quality of life for patients nearing death. The proposed randomized clinical trial will test the efficacy of this innovative intervention for patients with advanced cancer. A multi-centered international randomized control trial will be launched in Winnipeg Canada (coordinating center), Perth Australia, and NYC, New York. Three hundred sixty patients will be randomized to one of three arms, comparing the efficacy of Dignity Psychotherapy, Client Centered Visits and standard care, in a cohort of dying patients. Patients will complete a number of baseline self-report measures, and will complete these same measures post intervention. One family member per patient will be invited to provide baseline self report data on their own psychosocial distress; standardized grief inventories and family satisfaction measures 6 to 9 months following the patients' death to obtain useful regarding this approach as a potential bereavement intervention. This study will provide essential data regarding the impact of this intervention for dying patients and their families. The Dignity Intervention holds great promise for improving suffering and distress for dying patients and their respective loved ones, thereby adding a much needed therapeutic option for those who provide care to this vulnerable population.

Thesaurus Terms:
bereavement, neoplasm /cancer palliative treatment, psychotherapy, quality of life, terminal patient care
clinical trial, experience
behavioral /social science research tag, clinical research, human subject, patient oriented research

Institution: UNIVERSITY OF MANITOBA
WINNIPEG, MB R3T 2N2
Fiscal Year: 2004
Department:
Project Start: 01-SEP-2004
Project End: 31-AUG-2008
ICD: NATIONAL CANCER INSTITUTE
IRG: ZRG

Grace H. Christ, D.S.W. — $151,351 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$151,351*

$131,369 Columbia University School of Social Work — *To provide funding for release time for the Project Director for the PDIA Social Work Leadership Development Awards.*

some time between 1998-2000

$19,982 Columbia University School of Social Work — *To develop a white paper on the role of social work in end of life care.*

some time between 1998-2000

Nicholas A. Christakis, M.D., Ph.D., M.P.H. — $8,166,334 tracked thus far

Robert Wood Johnson Foundation *$4,564,391*

2003 46986 $4,564,391 Harvard Medical School - Center for Palliative Medicine at — *Clinical Scholars Program: Scholars in Health Policy Research Program*

http://www.rwjf.org/programs/grantDetail.jsp?id=046986

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 University of Chicago — *Faculty Scholar*

Amount of grant is approximate. http://www2.soros.org/death/prMay29-96.htm
Study of physicians' prognoses about death and their relation to patient referral to hospice.

National Institutes of Health - National Institute on Aging (NIA) *$3,461,943*

1998 $295,487 University of Chicago — *Population Based Study of Hospice Use and Consequences*

http://grants.nih.gov/grants/award/state/fy1998.illinois.txt
http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2558856&p_grant_num=1R01AG015326-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=196&p_keywords=palliative+care
Grant Number: 1R01AG015326-01
PI Name: CHRISTAKIS, NICHOLAS A.
PI Email: christak@hcp.med.harvard.edu
PI Title: PROFESSOR
Project Title: POPULATION BASED STUDY OF HOSPICE USE AND CONSEQUENCES

Abstract: DESCRIPTION: Employing the perspective and methods of the demography of aging, the investigators analyze the use and consequences of hospice terminal care in seriously ill elderly patients and their spouses. The benefits of hospice terminal care are well documented. Too little is known, however, about the factors that affect whether and when elderly patients are enrolled in hospice programs. Moreover, important questions about the effects of hospice on the mortality and morbidity of elderly patients and their families remain unanswered. These are serious deficits in knowledge because sub-optimal use of hospice might decrease the quality and increase the cost of terminal care in the U.S. The proposed research involves the creation of a multi-purpose data set containing clinical, demographic, socioeconomic, and market information about a population-based cohort of approximately 772,000 seriously ill elderly patients at risk for hospice referral; using a new technique, similar information will also be developed about their spouses (where possible). Data will be extracted and linked, on an individual level, from Medicare claims data (Standard Analytic File, Provider of Services File, MEDPAR Files, National Claims History Files, and Vital Status Files), Census data, and the Area Resource File. There will be three primary analyses. The first is the first-ever denominator-based study of hospice use. Its aim is to evaluate patterns of hospice use in a population-based sample of terminally ill patients that is developed at the time of diagnosis rather than at the time of hospice entry; using Cox regression models, it will evaluate whether and when in the course of serious illness hospice is used as well as the patient, provider, and market factors associated with the timing of use. The second is a retrospective cohort study of the effect of hospice on mortality. Its aim is to test the hypothesis that hospice use -- and the switch from curative to palliative care that it ordinarily implies -- is not life-shortening, and possibly even life-prolonging. This analysis will be conducted using several complementary approaches, including Cox regression, matched case/comparison methods, and instrumental variable methods. The third is a study of the effect of hospice use by patients on the morbidity, mortality, and health care consumption of their bereaved spouses. Its aim is to demonstrate that hospice care for dying patients may improve the health status of their bereaved spouses (attenuating the so-called "widow/widower effect"). Our work expands the field of the demography of aging in several ways, by: examining factors that might alter the life course at its very end, developing new methods to identify spousal pairs in Medicare claims data, extending social support theory by applying it to end-of-life care, and examining the elderly's access to hospice (a unique form of medical care). The work has policy implications as well: demonstrating that hospice does not meaningfully shorten life, or that it confers benefits to survivors, or both, might increase patient and physician interest in hospice, especially in specific clinical and market situations that we will be able to identify.
Institution: UNIVERSITY OF CHICAGO
5801 S ELLIS AVE
CHICAGO, IL 60637
Fiscal Year: 1998
Department: MEDICINE
Project Start: 01-JUL-1998
Project End: 30-JUN-2002
ICD: NATIONAL INSTITUTE ON AGING

IRG: SSP

1999 $239,439 University of Chicago *Population Based Study of Hospice Use and Consequences*

http://grants.nih.gov/grants/award/state/fy1999.illinois.txt

2000 $188,724 University of Chicago *Population Based Study of Hospice Use and Consequences*

http://grants.nih.gov/grants/award/state/fy2000.illinois.txt
R01AG015326-03 CHRISTAKIS, NICHOLAS A. POPULATION BASED STUDY OF HOSPICE USE AND CONSEQUENCES
SCHOOLS OF MEDICINE MEDICINE 188,724

2000 $39,500 University of Chicago *Population Based Study of Hospice Use and Consequences*

http://grants.nih.gov/grants/award/state/fy2000.illinois.txt
R01AG015326-03 CHRISTAKIS, NICHOLAS A. POPULATION BASED STUDY OF HOSPICE USE AND CONSEQUENCES
SCHOOLS OF MEDICINE MEDICINE 188,724

2001 $146,647 University of Chicago *Population Based Study of Hospice Use and Consequences*

5R01AG015326-04

2001 $650,136 University of Chicago *Relationship of Morbidity and Mortality Between Spouses*

http://grants.nih.gov/grants/award/state/fy2001.illinois.txt

2004 $703,858 Harvard Medical School *Relationship of Morbidity and Mortality Between Spouses*

http://silk.nih.gov/public/cbz2zoz.@www.fy2004.massachu.csv

2004 $683,831 Harvard Medical School *Social Network Study of Health Effects in Aging*

http://silk.nih.gov/public/cbz2zoz.@www.fy2004.massachu.csv

2005 $514,321 Harvard Medical School *Relationship of Morbidity and Mortality Between Spouses*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6843101&p_grant_num=5R01AG017548-05&p_query=&ticket=14595421&p_audit_session_id=66774369&p_keywords=

Grant Number: 5R01AG017548-05
PI Name: CHRISTAKIS, NICHOLAS A.
PI Email: christak@hcp.med.harvard.edu
PI Title: PROFESSOR
Project Title: Relationship of Morbidity and Mortality Between Spouses

Abstract: DESCRIPTION (provided by applicant): Employing the perspective and methods of the demography of aging, we propose to examine the relationship between the morbidity and mortality of spouses. We ask questions about how the morbidity and mortality or one spouse, and the timing and nature of that morbidity and mortality, affects the morbidity, mortality, and timing and nature of morbidity and mortality in the other spouse. For example, is the hazard of death in one spouse (the "proband") increased by illness or death in the other spouse? If so, how does the proband's hazard of illness or death change over time after the onset of illness or death in spouse? How do these affects vary according to the type of severity or duration of the spouse's morbidity? Do particular illnesses in spouses place probands at particularly high risk of development illness or dying themselves? What role do socio-demographic factors play in all these effects? To address these questions most effectively, we will create a new panel data set with demographics socioeconomic, and health information about one million elderly married couples followed up to ten years. Using a variety of even history and fixed effects methods, we will conduct four main analyses. First, we will evaluate morbidity in one spouse influences mortality in the other. We hypothesize that individuals married to unhealthy spouses will have worst mortality than those married to healthy spouses, and that the longer the spouses is ill, the greater the effect. We also hypothesize the certain types of spousal morbidity (e.g. those that most compromise activities levels) will be worse for probands. Second, we will reevaluate the widower effect (i.e. the increased tendency of the bereaved to die), but we will; adjust for the health of both spouses prior to widowhood; examine it's temporal shape in detail; and assess its dependence on socioeconomic factors. Third, we will evaluate how morbidity in one spouse influences morbidity in the other. Are healthy spouses better able then unhealthy spouses to provide health benefits in marriage? Four, we will evaluate the impact of widowhood on the morbidity, and not just mortality, of bereaved spouses. Our work advances the demographics of aging by; closely examine how an individual's morbidity and mortality are affected by the presence or absence of spousal support; focusing on cause-of-death specific aspects of demographics phenomena; examine theoretically interesting sub-populations along gender, race, socioeconomic, and health status lines; and shedding light on the mechanisms of inter-spousal health effects. Our work also has policy implications in that it; supports more accurate projections of the health burdens in the elderly; facilitates targeting of support services to the growing numbers to the widowed elderly; and addresses important populations, such as minorities the poor, the oldest old, those with dementia, and caregivers.

Thesaurus Terms:
human morbidity, human mortality, interpersonal relations, spouse
Medicare /Medicaid, bereavement, caregiver, death, dementia, epidemiology, gender difference, human old age (65+), human very old age (85+), longitudinal human study, mathematical model, medical record, racial /ethnic difference, social support network, socioeconomics, widowhood
behavioral /social science research tag, human data, human subject

Institution: HARVARD UNIVERSITY (MEDICAL SCHOOL)
MEDICAL SCHOOL CAMPUS

BOSTON, MA 02115
Fiscal Year: 2005
Department: HEALTH CARE POLICY
Project Start: 30-SEP-2001
Project End: 31-DEC-2006
ICD: NATIONAL INSTITUTE ON AGING
IRG: ZRG1

Myra J. Christopher — $2,509,199 tracked thus far

Robert Wood Johnson Foundation *$2,409,199*

	33645	$740,988	Midwest Bioethics Center (aka Center for Practical Bioeth	*Community-State Partnerships to Improve End-of-Life Care – Technical assistance and direction for CSP (1 year).*

Kansas City, MO: Technical assistance and direction for Community-State Partnerships to Improve End-of-Life Care (1 year).

1999	34036	$742,013	Midwest Bioethics Center (aka Center for Practical Bioeth	*Community-State Partnerships to Improve End-Of-Life Care*

Technical assistance and direction for Community-State Partnerships to Improve End-of-Life Care (1 year).

2000		$41,500	Midwest Bioethics Center (aka Center for Practical Bioeth	*Compassion Sabbath*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___494
Project Director: JoEllen Wurth
Due to an overwhelming turnout for Compassion Sabbath's conference and leadership training course, which provided clergy in Kansas City tools to use in providing spiritual support to congregants who are facing death in some way, these funds will be used to conduct the final activity of this grant, Compassion Sabbath Weekend, a weekend of activities devoted to exploring death and dying within the faith communities of Kansas City.

2000	36610	$749,698	Midwest Bioethics Center (aka Center for Practical Bioeth	*Community-State Partnerships*

Technical assistance and direction for Community-State Partnerships to Improve End-of-Life Care (1 year). ID#36610

2000	39267	$135,000	Midwest Bioethics Center (aka Center for Practical Bioeth	*Community-State Partnerships*

Developing a turnkey communications tool kit for Community-State Partnerships to Improve End-of-Life Care (6 months). ID#39267

Open Society Institute / Project on Death in America (Soros Foundation) *$75,000*

1998		$75,000	Midwest Bioethics Center (aka Center for Practical Bioeth	*Pilot project in nursing homes*

http://www2.soros.org/death/general_grants_98-00.htm
For a pilot project to improve end of life care in nursing homes through educational initiatives for healthcare professionals in a nursing home setting.

Fan Fox and Leslie R. Samuels Foundation *$25,000*

2001		$25,000	Midwest Bioethics Center (aka Center for Practical Bioeth	*Compassionate Options: End-of-Life Care for Nursing Homes Conference, August 2001*

"Compassionate Options: End-of-Life Care for Nursing Homes Conference, August 2001"
The Midwest Bioethics Center, a nationally respected center on ethics in health care decision-making, held a meeting to convene key stakeholders, including nursing home (NH) regulators, involved with the provision of high quality end-of-life care for residents of NHs. The majority of people admitted to NHs will spend the last days of their lives as residents of the facility. NHs should therefore be expert on state-of-the-art end-of-life care; but lack of staff training, inadequate reimbursement and perceived regulatory barriers hinder the quality of end-of-life care. It is this last problem that is one of the most difficult to overcome. One of the major goals of the conference was to address the reasons for the fear of regulation as it applies to end-of-life care in NHs.

Michael T. Claessens, M.D. — $150,000 tracked thus far

Kornfeld / PDIA (Soros) collaborative *$150,000*

2003		$150,000	Marshfield Clinic	*Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Elizabeth J. Clark, Ph.D., ACSW

tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation)

2003 National Association of Social Workers *PDIA Social Work Leadership Program*

From Fall, 2003 PDIA newsletter:
ELIZABETH J. CLARK, PH.D., A.C.S.W., N.A.S.W.
National Association of Social Workers
Washington, DC
Building Social Work Practice and Policy Competencies in End-of-Life Care
The National Association of Social Workers (NASW) is the largest professional organization for social workers in the world, and brings important institutional resources to shape both the public policy and social work practice related to the care of the dying. NASW Executive Director Elizabeth Clark has the opportunity to guide program development and mobilization within the social work profession to help transform health care systems. Dr. Clark will advance the role and competency of social workers in end-of-life care through the development of practice standards, communication, and continuing education.

James Cleary, M.D.

$70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1998 $70,000 University of Wisconsin - Madison Medical School *[$ amount is estimated] Introducting Graduate, Postgraduate, and Continuing Medical Education in Palliative Medicine with Practice Changes in Inpatient, Clinic, and Remote Settings*

Amount of grant is estimated.
From PDIA Report 1998-2000: "The University of Wisconsin Medical School provides a focus for the provision of health care and medical education throughout the state. This project will establish a clinical program in palliative care for the UW Health System, piloting the program at the UW Comprehensive Cancer Center. Essential to this program is a strong relationship between the Cancer Center and the community hospice. Dr. Cleary is developing and implementing educational initiatives in palliative medicine for faculty, residents, and medical students both within the UW Health System and with UW Medical School partners in clinical education throughout Wisconsin."

Elizabeth Lipton Cobbs, M.D. — $185,383 tracked thus far

Robert Wood Johnson Foundation *$35,383*

1998 34912 $35,383 George Washington University *Review of the Current Status of Home Medical Care (Chronic care)*

http://www.rwjf.org/reports/grr/034912.htm

Contact
Jean E. Johnson, PhD
Elizabeth Cobbs, MD
(202) 994-3725
hspjej@gwumc.edu

RWJF GOAL AREA
Chronic Care — To improve care and support for people with chronic health conditions.
This grant from The Robert Wood Johnson Foundation (RWJF) funded a study of the current status of home medical care, an assessment of the need for home medical care, and the identification of models of and barriers to providing this care. Home medical care provides medical assessment, diagnosis, and treatment services and is performed by medical professionals such as physicians and nurse practitioners. As part of the study, the principal investigators conducted interviews with experts in the home medical care field, focus groups with nurses and physicians, and a review of the medical literature to assess the current need for home medical care. Findings of the study included: (1) most home medical care models use interdisciplinary teams of physicians, nurse practitioners, and social workers; (2) limited payment, lack of training, and physician "territorialism" are key barriers to the expansion of home medical care; (3) it is unclear whether recent changes in federal funding will affect the willingness of medical practices to expand into home medical care. The research team identified 15 models of home medical care currently in use, and they developed their own model program, which they estimated would cost $3,000 per patient per year. The researchers recommended that RWJF and others: (1) support the development of home medical care; (2) examine the most cost-effective mix of providers; (3) consider the possible impact of technology, and (4) study financing issues. The researchers plan to publicize their findings and conduct a test of their model program.

The principal investigators reported the following findings to RWJF:

** Most home medical care models use interdisciplinary teams.*
** These teams typically include physicians, nurse practitioners, and social workers. Some are part of the federal Program for All-inclusive Care for the Elderly (PACE), which includes home care in a full-service program designed to keep individuals out of nursing homes. Another model, Senior Friendship Center, based in Florida, uses retired physicians, nurses, dentists, and mental health counselors who practice on a limited license to make home visits. Limited payment, lack of training, and physician "territorialism" are key barriers to the expansion of home medical care.*
** While most providers surveyed agreed that home medical care is needed, low reimbursement rates may discourage practitioners from providing it, especially given the travel time required to reach patients. Providers also felt that physicians and other health professionals had limited preparation for providing home medical services. Some physicians might be reluctant to recommend home medical care for fear of losing a patient by referring him or her to a home care provider. It is unclear whether recent changes in federal funding will affect the willingness of medical practices to expand into home medical care.*
The federal Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration or HCFA), which administers the Medicare health program for seniors, increased its reimbursement rates for home medical services, but the impact of that change on the market remains unclear. The researchers say that the model program they developed could provide reasonable home medical services at a cost of $3,000 per patient per year.

Kornfeld / PDIA (Soros) collaborative *$150,000*

2004 $150,000 George Washington University *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12

Lewis M. Cohen, M.D. — $137,656 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$137,656*

$137,656 Baystate Medical Center (Tufts University) *The Renal Palliative Care Initiative*

Project: A bioethical, psychiatric, and clinical study of the decision by patients to terminate life-sustaining kidney dialysis treatment. Approximately 100 patients with end-stage kidney disease will be observed, interviewed, and evaluated to explore their decision making process and to examine the quality of death that ensues. Funding spans two years.
And from the PDIA grant write-up: Death and dying are seldom discussed in dialysis treatment centers, perhaps because of fears that doing so would run counter to the prevailing sensibility about dialysis as life-saving treatment. Yet, while dialysis sustains life by substituting for kidneys, the underlying disease responsible for causing renal failure usually continues to progress and the mortality rate is higher than that associated with HIV or many types of cancer. The Renal Palliative Care Initiative will involve eight dialysis clinics in the Connecticut Valley Region of New England. This program is designed to address denial of death by dialysis patients and nephrology staff and widen the community and institutional role in end-of-life care for this population.

John R. Combes, M.D. **$83,995** tracked thus far

US DHHS - Agency for Healthcare Research and Quality (AHRQ) *$83,995*

2002 $83,995 Institute for Healthy Communities - Harrisburg, PA *Improving Care for the Dying: Transforming Patients' Wishes*

Original grant description did not include bioterrorism; bioterrorism was added to the second description
======
http://www.ahrq.gov/qual/partqual.htm
Improving Care for the Dying: Transforming Patient's Wishes.
Principal Investigator: John R. Combes, M.D., Institute for Healthy Communities, Harrisburg, PA.
FY 2003: $83,995.
Grant No.: HS13685.
Description: To improve the care of dying patients, this project will promote hospitals with model programs of palliative care as models for other institutions to learn from. The program will grow from a regional to a national network of hospitals and professionals, and will develop an appropriate tool to measure quality outcomes.
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http://www.gold.ahrq.gov/GrantDetails.cfm?GrantNumber=U18%20HS13685
Grant Number: U18 HS13685
RFA/PA: HS02-010 -Partnerships for Quality- change in mechanism [bioterriorism added]
PI Name: COMBES, JOHN
*Project Title: Improving Care for the Dying: Transforming Patiens's Wi**

Abstract:

The Institute for Healthy Communities a 501 (c)(3) non-profit organization and strategic partner of The Hospital & Healthsystem Association of Pennsylvania (HAP), will work with hospitals and health systems that include in the clinical practice of caring for dying patients advanced palliative care procedures and facilities. The primary objective of this approach is to promote models of hospital-based palliative care as centers of learning for other hospitals that struggle to strengthen an existing service. The centers of learning will share challenges and successes encountered in the unit's development and how these findings were translated into clinical practices and integrated into a palliative care program. The practice models were identified based on their ability to illustrate the facilities' capacity to influence the whole organization and its delivery of health care, to measure and evaluate the impact of improvement efforts. In Phase I, three Pennsylvania-based hospitals will open their palliative care units to visitors for site visits, creating learning environments that welcome questions for clinical, operational, and business staff related to the development and maintenance of the unit. HAP realized that a large percentage of patients spend the end of their lives in hospitals more often than in any other setting and hospitals have a unique role in assisting patients throughout the dying process. Recognizing that palliative care services can be better utilized, the Senior Medical Advisor of HAP organized the training of clinicians from its member hospitals with the Education for Physicians on End-of-life Care (EPEC) curriculum and trained more than 150 caregivers, creating a network of 40 hospitals committed to improving palliative care in their organizations. The hospitals identified as learning centers are members of this palliative care network and leaders in the development of palliative care units. Phase II will expand these learning environments nationally to identify recipients of the American Hospital Association's (AHA) Circle of Life Award that honors innovative programs that have improved the care people receive near the end of their lives in hospital, hospice, nursing home, or home. This expansion over time will include national participants and target evidence-based change in care to a broad range of hospital settings delivering care to a large number of people over a wide geographic area. Another objective is to create a national network of professionals that prioritize quality palliative care and apply evidence-based research to practice. A tool will be developed to measure outcomes including length of stay, patient satisfaction and financial implications of hospital-based palliative care.

Fiscal Year: 2002
Department: INSTITUTE FOR HEALTHY COMMUNITIES
Project Start: 09/30/2002
Project End: 09/29/2006
IRG: ZHS1

==========
Grant Number: 1U18HS013685-01
PI Name: COMBES, JOHN R.
PI Email: jcombes@haponline.org
PI Title: SENIOR MEDICAL ADVISOR
*Project Title: Improving Care for the Dying: Transforming Patiens's Wi**

Abstract: The Institute for Healthy Communities (Institute), a 501(c)(3) non-profit organization and strategic partner of The Hospital & Healthsystem Association of Pennsylvania (HAP), will work with hospitals and health systems that include in the clinical practice of caring for dying patients advanced palliative care procedures and facilities. The primary objective of this approach is to promote models of hospital-based palliative care as centers of learning for other hospitals that struggle to strengthen an existing service. The centers of learning will share challenges and successes encountered in the unit's development and how these findings were translated into clinical practices and integrated into a palliative care program. The practice models were identified based on their ability to illustrate the facilities' capacity to influence the whole organization and its delivery of health care, to measure and evaluate the impact of improvement efforts. In Phase I, three Pennsylvania-based hospitals will open their palliative care units to visitors for site visits,

creating learning environments that welcome questions for clinical, operational, and business staff related to the development and maintenance of the unit. HAP realized that a large percentage of patients spend the end of their lives in hospitals more often than in any other setting and hospitals have a unique role in assisting patients throughout the dying process. Recognizing that palliative care services can be better utilized, the Senior Medical Advisor of HAP organized the training of clinicians from its member hospitals with the Education for Physicians on End-of-life Care (EPEC) curriculum and trained more than 150 caregivers, creating a network of 40 hospitals committed to improving palliative care in their organizations. The hospitals identified as learning centers are members of this palliative care network and leaders in the development of palliative care units. Phase II will expand these learning environments nationally to identify recipients of the American Hospital Association's (AHA) Circle of Life Award that honors innovative programs that have improved the care people receive near the end of their lives in hospital, hospice, nursing home, or home. This expansion over time will include national participants and target evidence-based change in care to a broad range of hospital settings delivering care to a large number of people over a wide geographic area. Another objective is to create a national network of professionals that prioritize quality palliative care and apply evidence-based research to practice. A tool will be developed to measure outcomes including length of stay, patient satisfaction and financial implications of hospital-based palliative care.

Thesaurus Terms:
health care quality, neoplasm /cancer palliative treatment, terminal patient care
cooperative study, health care model, health care service availability, health care service utilization, hospital, patient care management, quality of life, satisfaction
health services research tag

Institution: INSTITUTE FOR HEALTHY COMMUNITIES
4750 LINDLE RD
HARRISBURG, PA 171058600
Fiscal Year: 2002
Department:
Project Start: 30-SEP-2002
Project End: 29-SEP-2006
ICD: AGENCY FOR HEALTHCARE RESEARCH AND QUALITY
IRG: ZHS1

Stephen R. Connor, Ph.D. — $1,779,282 tracked thus far

Robert Wood Johnson Foundation — *$1,519,282*

1998 35597 $64,673 National Hospice and Palliative Care Organization (NHPC — *National Hospice Outcomes Planning Grant*

Arlington, VA; (4 months).
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_region_summ_list_html___183
This project is designed to determine the scope and design of a national hospice outcomes project that would assess the impact of various treatment strategies on quality of hospice care. A national integrated database to determine what works best, and when, for the management of hospice patients is being created. The specific objectives are to: (1) assemble an Evaluation Advisory Panel of hospice experts including researchers, payers, and government officials, and to assemble a working group of clinical and administrative specialists from five potential hospice study sites; (2) hold a series of meetings to explore, develop, and propose a study design to measure quality of care; (3) develop a proposal to conduct the full hospice outcomes study; and (4) determine potential hospice sites for the larger study.

1999 36684 $347,365 National Hospice and Palliative Care Organization (NHPC — *National Hospice Outcomes Planning Grant II*

Feasibility Project for National Hospice Outcomes Planning
http://www.rwjf.org/reports/grr/036684.htm
See also:
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_region_summ_list_html___482
The objective of this research project is to conduct a feasibility study of collecting retrospective patient, process, and outcome data for a Clinical Practice Improvement study addressing the outcomes of pain control, dypsnea control, and self-determined life closure in hospice patients. In addition, the study will determine the need for supplemental, prospective data collection and the ability to collect such data through new or existing instruments such as charting forms and patient interview guidelines.

1999 $357,275 National Hospice and Palliative Care Organization (NHPC — *[Duplicate?] National hospice outcomes feasibility project*

NOTE: DUPLICATE?
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___482
The objective of this research project is to conduct a feasibility study of collecting retrospective patient, process, and outcome data for a Clinical Practice Improvement study addressing the outcomes of pain control, dypsnea control, and self-determined life closure in hospice patients. In addition, the study will determine the need for supplemental, prospective data collection and the ability to collect such data through new or existing instruments such as charting forms and patient interview guidelines.

2001 40459 $749,969 National Hospice and Palliative Care Organization (NHPC — *National hospice quality improvement project [Phase III of the Hospice Outcomes Project]*

http://www.rwjf.org/reports/grr/036684.htm AND
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_region_summ_list_html___689
Hospice services are a major component of care at the end of life, and there are now more than 3,000 hospice providers who care for approximately 700,000 dying patients annually. Hospice has been suggested as a model for quality end-of-

life care but, to date, there have been few studies of the effectiveness of hospice care. Funds for this project will be used to conduct a clinical practice study to improve the quality of the dying experience for hospice patients. Building on a feasibility study also funded by the Foundation, the project will include 1,800 hospice patients at 15 hospice sites through the U.S. The research will determine the treatment modalities and management strategies that are associated with better control of pain, shortness of breath, and life closure.

Open Society Institute / Project on Death in America (Soros Foundation) *$160,000*

2001 $160,000 National Hospice and Palliative Care Organization (NHPC *NHPCO Capacity Building Program*

The National Hospice and Palliative Care Organization (NHPCO) is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States.NHPCO advocates for the terminally ill and their families. It also develops public and professional education programs to enhance understanding and availability of hospice and palliative care.This grant will provide general capacity support for NHPCO 's initiatives to improve end-of-life care in America.t will support a set of policy initiatives designed to provide earlier palliative care intervention and increased access to hospice care.

AARP Andrus Foundation *$100,000*

2002 $100,000 National Hospice and Palliative Care Organization (NHPC *National Quality Partnership Program*

http://content.healthaffairs.org/cgi/reprint/21/4/278?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=NHPCO&andorexactfulltext=and&searchid=1102819997455_1653&stored_search=&FIRSTINDEX=0&resourcetype=1&journalcode=healthaff
National Hospice and Palliative Care Organization (NHPCO), Alexandria, VA.

This research grant funds "a key portion" of the NHPCO's "National Quality Partnership Program —a system to assess the quality of endof- life care delivered in the United States," a grantee press release said. The NHPCO aims "to develop and implement a system" for mea- suring the performance of hospice programs. With such a system in place, patients and families would gain knowledge "about the quality and range of end-of-life services being delivered" and thus would have the information they need "to get the best care." In addition, "end-of-life care providers, insurers, and federal and state regulators" would gain "key insights" from results of these outcome measures "to further advance the practice of hospice and palliative care." Specifically, the Andrus grant is being used to develop a methodology to help hospice and palliative care programs "gauge the extent to which patients experience self determined life closure," which is one of the NHPCO's desired outcomes of end-of-life care. When patients have such closure, they have "full autonomy to make decisions about how the remainder of their lives are spent," the release explained. Stephen Connor of the NHPCO told HealthAffairs that the grant is also being used for development and further refinement of other self-determined life closure performance measures. $100,000 over one year. Funded by the AARP Andrus Foundation.

Alfred F. Connors, Jr., M.D. — $810,483 tracked thus far

Robert Wood Johnson Foundation *$810,483*

1988 13726 $810,483 MetroHealth Medical Center *SUPPORT: Care of Chronically Ill Hospitalized Adults, Phase I*

With Neal Dawson, MD. Connors was Principal Investigator. http://www.metrohealthresearch.org/pdf/Dawson_cv.pdf

Barbara Coombs Lee, PA, FNP, JD — $109,000 tracked thus far

Mayday Fund *$90,000*

2000 $30,000 Compassion in Dying Federation *Advocacy on behalf of individuals to promote pain care*

Compassion In Dying Federation
Portland, OR
USA
$30,000 for projects, including advocacy on behalf of individuals, to improve pain care.
Contact: Barbara Combs Lee, FNP, JD
Email: BCoomsLee@aol.com

2002 $60,000 Compassion in Dying Federation *Bergman Suit*

Compassion in Dying Federation
Portland, Oregon
$60,000 for 2002 to support legal and advocacy work to create awareness of the undertreatment of pain. Compassion in Dying successfully brought the Bergman suit in California.
Contact: Barbara Coombs Lee, JD
Web Site: http://www.compassionindying.org

Gerbode Foundation (Wallace Alexander) *$19,000*

1998 $10,000 Compassion in Dying Federation *Northern California*

from Gerbode's Form 990-PF, pg 24

2002 $6,500 Compassion in Dying Federation *AUTONOMY*

from Gerbode's Form 990-PF, pg 269
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also: http://fdncenter.org/grantmaker/gerbode/commaff02.pdf
Compassion in Dying Federation of America
Support of its work with AUTONOMY: People

with Disabilities for Control of Our Lives.

2002 $2,500 Compassion in Dying *Program support*

from Gerbode's Form 990, pg 269

Kit Cosgrove — $35,000 tracked thus far

Robert Wood Johnson Foundation *$35,000*

2001 43339 $35,000 Mountain Area Hospice Corporation *Faith in Action*

Kit Cosgrove (Project Director)
kcosgrove@carepartners.org
828-255-0231

Patrick J. Coyne, R.N., M.S.N., O.C.N. — $150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 Virginia Commonwealth University *Faculty Scholar [amount is approximate]*

For the medically underserved, barriers to good end-of-life care are compounded by the experiences of poverty, social isolation, or geographic isolation. The goals of this project are to define barriers to good end-of-life care for the underserved, to promote provider and public awareness of these barriers, and identify ways to overcome them.

LaVera M. Crawley, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

$50,000 *Faculty Scholar, 1999-2001 (with Barbara Koenig) (Grant amount is estimated.)*

Laura Cross, JD, RN — $448,479 tracked thus far

Robert Wood Johnson Foundation *$448,479*

36186 $74,796 Oklahoma Association for Healthcare Ethics Inc. (see Ok *C-SP1: Community-State Partnerships to Improve End-of-Life Care (Chronic Health Conditions)*

Oklahoma City, OK: (6 months). (1998 Annual Report. I am guessing that Cross was contact, since she and Laura Edmonson founded the OkAHE

1999 37636 $373,683 Oklahoma Association for Healthcare Ethics Inc. (see Ok *C-SP2: Community-State Partnerships - Oklahoma*

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (30 months).
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from press release:

The Oklahoma program will be carried out by the Oklahoma Alliance for Better Care of the Dying (OkABCD), a 25-member coalition formed in May 1998. OkABCD was founded by the Oklahoma Association for Healthcare Ethics, Inc., a statewide independent notforprofit organization, which invited businesses, individuals and healthrelated groups to participate.

OkABCD initiated the project last January by collecting data to document what Oklahomans have experienced during the endoflife process. Information was gathered from focus groups and town hall meetings in several cities around the state. Family members and caregivers of the deceased, medical professionals in all health care fields, hospice staff, clergy, funeral home professionals, social workers, legal counsel and financial experts were instrumental in providing the initial data.

Issues raised during these meetings include hospice care and its rate of usage, management of pain, and insurance policies for end of life care. Other endoflife issues mentioned were the shortage of health care professionals in rural areas of the state and the cultural preferences of Native Americans and other minority groups.

Laura L. Cross, J.D., R.N., is director of the OkABCD project. Cross is the founding president of Oklahoma Association for Healthcare Ethics (OAHE), and a partner with Day, Edwards, Federman, Propester and Christensen, P.C., in Oklahoma City. Mary Jac Rauh, PMH, is the OkABCD project manager. Rauh is director of Rural Health Projects/Northwest Area Health Education Center in Enid. Linda Edmonson, LCSW, is OAHE executive director.

"With this grant and the matching funds from the Oklahoma Hopsice Foundation, the volunteers of OkABCD will be able to implement services tht we believe will improve endoflife care provided to all Oklahomans," Cross said.

A public awareness campaign will encourage older adults and those likely to care for them to talk with their loved ones and physicians about their care preferences. Through OAHE and partnerships with consumer organizations, OkABCD will offer speakers on various endoflife issues, workshop trainers, policy development assistance and webbased education materials and resources. OkABCD will sponsor interdisciplinary workshops designed to meet the professional education needs physicians, nurses, nursing home administrators, social workers, physician assistants, pharmacists, emergency medical technicians, clergy and other concerned professionals.

Misunderstandings about hospice care in nursing homes, pain assessment and other regulatory topics will be addressed in dialog sessions to be held around the state with directors of nursing homes, state regulators and surveyors.

Carol N. D'Onofrio, Dr.PH — $195,245 tracked thus far

Centers for Disease Control and Prevention — *$195,245*

1992 $195,245 Northern California Cancer Centers — *Improving Health Surveys for Minority Populations*

http://www.cdc.gov/nchs/otheract/grants/minpop/black/black.htm
Carol D'Onofrio, Ph.D, Northern California Cancer Center (NCCC), "Improving Health Surveys for Multi-Ethnic Populations," $195,245 (FY 1992).

June L. Dahl, Ph.D. — $3,983,327 tracked thus far

Robert Wood Johnson Foundation — *$3,876,965*

1992 20623 $444,546 University of Wisconsin - Madison Medical School — *Support for a Cancer Pain Resource Center*

http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=020623s.htm&iaid=142
This project supported the formation of a National Cancer Pain Resource Center modeled on the Wisconsin Cancer Pain Initiative (WCPI) to address the problem of inadequate treatment of cancer pain. The Resource Center was funded to encourage the development of cancer pain initiatives in other states by assisting and guiding grass-root efforts. State Cancer Pain initiatives disseminate information about palliative care to health professionals, promote media communication about pain treatment issues, and provide guidance to cancer patients and their families. During the course of the grant, the Resource Center was instrumental in developing initiatives in 20 states (in addition to the 27 already in operation due to the pre-grant efforts of the WCPI). The Resource Center also conducted two surveys of the state initiatives, created a computer web site (www.wisc.edu/molpharm/wcpi), and organized annual meetings to allow for cross-fertilization of ideas and activities of state initiatives. At the 1995 meeting, a decision was made to form the American Alliance of Cancer Pain Initiatives to address the issue of undertreated cancer pain on the national level. Resource Center volunteers outlined the core values and goals of the Alliance, and also obtained a federal trademark for the name "Cancer Pain Initiative" in order to set quality standards.

1997 32037 $1,601,991 University of Wisconsin - Madison Medical School — *JCAHO–Supporting quality improvement and Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) standard setting for pain management in hospitals (for 3 years).; Madison, WI*

http://www.rwjf.org *This grant supports the Wisconsin State Cancer Pain Initiative staff to provide technical support to the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) to establish standards for the assessment and treatment of pain in the terminally ill. These standards will be incorporated in the JCAHO's accreditation process. Project staff will simultaneously jump-start a nationwide quality improvement process in pain management in hospitals and other institutions accredited by JCAHO. Project staff will also provide technical assistance to cancer pain initiatives in other states that will, in turn, work with providers in their respective states that wish to participate in this voluntary learning opportunity.*

2000 37589 $1,408,628 University of Wisconsin - Madison Medical School — *Pain & Policy Studies Group (Supporting State Cancer Pain Initiatives)*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___401
This project will support state cancer pain initiatives which are statewide organizations of more than 12,000 volunteer physicians, nurses, pharmacists, social workers, and others nationwide. Project staff of the American Alliance of Cancer Pain Initiatives (The Alliance) will: (1) provide technical assistance to state cancer pain initiatives to help them build and solidify effective volunteer organizations; (2) help the initiatives remove regulatory barriers to evidence-based pain management; (3) help clinical leaders in the initiatives advocate for and institutionalize better pain management in health care settings; and (4) network the nation's leaders in pain management.

2002 43940 $421,800 University of Wisconsin - Madison Medical School — *National initiative to promote improved cancer pain management through collaboration with the American Cancer Society*

Open Society Institute / Project on Death in America (Soros Foundation) — *$105,362*

2001 $105,362 University of Wisconsin - Madison Medical School — *Institutionalizing Pain Management through Practice Change Programs*

The American Alliance of Cancer Pain initiatives (AACPI) is dedicated to promoting cancer pain relief nationwide by supporting the efforts of state cancer pain initiatives.Cancer pain initiatives are voluntary,grassroots organizations composed of nurses,physicians, pharmacists,social workers,psychologists,and representatives of clergy,higher education,and government.nitiatives and their participants provide education and advocacy to healthcare providers,cancer patients,and their families.n this project,the AACP will provide technical support and contract awards to two state cancer pain initiatives.Each contracted initiative will implement a program to help 20-25 healthcare organizations,including long term care facilities,home health agencies,and/or small,community-based hospitals,improve pain management practices.The programs will train teams from committed organizations in pain assessment and management,self-assessment and planning, implementation of an individual organizational plan,and evaluation of both patient and organizational outcomes.

Mayday Fund — *$1,000*

2003 $1,000 Wisconsin Cancer Pain Initiative — *Recognition of June Dahl*

Wisconsin Pain Initiative

Madison, WI,
A grant of $1000 to the Wisconsin Pain Initiative in recognition of all the work that Dr. June L. Dahl does to help educate the broader public about pain and the myths that surround the use of pain medication.
Web Site: http://www.wisc.edu/molpharm/wcpi/

Norma del Rio, M.S.W. — $30,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$30,000*

2000 $30,000 San Francisco State University — *Social Work Leader, 2000 (Amount of grant is estimated)*

(With Margo Okazawa-Rey) This project combines a grass roots program in northern California for minority and disadvantaged terminally ill individuals with the San Francisco State Multicultural Institute. Project goals are to 1) develop cross-cultural/cross ethnic assessment guidelines for the terminally ill and bereaved; 2) design and implement a curriculum for graduate social work students that integrates end-of-life care and multiculturalism and 3) test the application of available measures of professional cultural competency developed for other areas to end-of-life care.

Thomas L. Delbanco, M.D. — $563,829 tracked thus far

Robert Wood Johnson Foundation *$563,829*

1994 24032 $99,235 Beth Israel Deaconess Medical Center — *Clinical Crossroads - Creation of the JAMA "Clinical Crossroads" Series of Clinical Practice Case Studies*

http://www.rwjf.com/reports/grr/026983s.htm
Case Studies on Clinical Practice: A New JAMA Series

1995 24308 $58,625 Beth Israel Deaconess Medical Center — *Clinical Crossroads - Creation of the JAMA "Clinical Crossroads" Series of Clinical Practice Case Studies*

http://www.rwjf.com/reports/grr/026983s.htm
Monthly Series of Clinical Practice Case Studies for JAMA

1995 26983 $405,969 Beth Israel Deaconess Medical Center — *Clinical Crossroads - Creation of the JAMA "Clinical Crossroads" Series of Clinical Practice Case Studies*

http://www.rwjf.com/reports/grr/026983s.htm
JAMA Monthly Series on Case Studies on Clinical Practice

Michael A. Dubin, J.D. — $375,000 tracked thus far

Robert Wood Johnson Foundation *$375,000*

2000 38474 $375,000 Carolinas Center for Hospice and End of Life Care — *C-SP1-2: Community-State Partnerships to Improve End-Of-Life Care*

Implementing a statewide coalition to improve end-of-life care.

This project supports the North Carolina End-of-Life Care Coalition to improve the care of the dying. The aims of the project are to: (1) promote public awareness and raise expectations for high quality palliative care; (2) improve end-of-life care in nursing homes, rest homes, and assisted living facilities by increasing hospice referrals and access to other palliative services; (3) train and support a network of health professionals who will function as change agents for improved end-of-life care; and (4) foster leadership on end-of-life care issues from within the state's minority populations.

Nancy Neveloff Dubler, LL.B. — $248,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$248,000*

1997 $248,000 Albert Einstein College of Medicine - Montefiore Medical — *Support for the Pediatric Palliative Care Initiative*

http://www.samuels.org/hc_archive_99-96.htm
The development of a program dealing with issues of death and dying of children in acute settings.

World Health Organization

1998 — *Travelling Fellowship*

Dubler's c.v., online

Susan Edgman-Levitan — $573,296 tracked thus far

Commonwealth Fund *$573,296*

1998 $249,960 Picker Institute — *Documenting Effective Practices by Managed Care Plans in Providing Patient-centered Care*

Building on findings from plan member surveys, this Picker Program Grant will examine health plans' performance on measures of patient-centered care and assess their organizational characteristics. Detailed case studies and formal analyses will describe effective practices, and findings will be actively disseminated through reports and conferences.

1999 $323,336 Picker Institute — *Developing a Patient-Centered Quality-of-Care Survey for Physicians and Hospital Staff and Creating a Continuous Quality Improvement Tool*

Building on its expertise in surveying patients about their health care experiences, the Picker Institute will develop a complementary survey of physicians and other hospital staff. This new source of information on quality of care will help

identify specific actions that could be taken to improve care in such areas as patient-doctor communication, coordination of services, shared decision-making, and the physical environment of the hospital. In addition, the project will develop methods of rapidly collecting and reporting patient-centered care information back to hospitals as part of continuous quality-improvement activities.

Kathleen (Kathy) Egan, MA, BSN, CHPN — $288,603 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$288,603*

1994 $96,201 Hospice of the Florida Suncoast: Hospice Institute of the *HOSPICE INSTITUTE CERTIFICATION PROGRAM*

1 R25CA066889-01

1995 $96,201 Hospice of the Florida Suncoast: Hospice Institute of the *HOSPICE INSTITUTE CERTIFICATION PROGRAM*

R25 CA66889-02 http://silk.nih.gov/silk/brownbooks/research/detail/fy95B

Grant Number: 5R25CA066889-02
PI Name: EGAN, KATHLEEN A.
PI Email: kathyegan@thehospice.com
PI Title:
Project Title: HOSPICE INSTITUTE CERTIFICATION PROGRAM

Abstract: DESCRIPTION: (Applicant's Description) While hospice and palliative care is quickly developing as a distinct clinical discipline with its own philosophy and informational base, this base falls far beyond the scope of basic training that health care professionals currently receive in their associate, bachelor, master and even doctoral level programs. In fact, in 1992, extensive research and a survey of American hospice programs revealed that there is no comprehensive curriculum, manual or book available specific to the practice of hospice. The objective of The Hospice Institute Certification Program is to develop an interdisciplinary training program in palliative and hospice care that can be duplicated throughout the country. The Certification Program will provide health care professionals - specifically nurses,psychosocial counselors and chaplains - with the knowledge and clinical skills they need to then implement this training program in their own hospice facilities. The Hospice Institute of the Florida Suncoast will accomplish this by providing the curriculum, workbooks, training manuals, teaching aides, preceptor/mentor skills and clinical competencies needed for the certified hospice care trainers to actively and comprehensively provide palliative and hospice care to terminally ill patients in their own communities.This project's first year will be spent developing curriculum with related teaching materials, and clinical competencies for all disciplines, while the second and third years will involve the actual "Train the Trainer"certification process. The development of an interdisciplinary hospice core curriculum will include those topics and issues which are universal for providing hospice care in all settings, followed by discipline-specific curriculum as well as clinical competencies for each discipline.Since education evaluation differs from scientific research evaluation, this project's evaluation process will be both summative and formative. Formative evaluation will include: Questionnaires and surveys completed by the participants, instructors and monitor during the implementation of the program; evaluation by objectives for each teaching session and interviews between participants and the Principal Investigator for individual feedback and evaluation. Summative evaluation will include: Overall questionnaires completed by the participants, instructors, class monitors and preceptors working with participants; a grouping of evaluations by objectives with a review of the results followed by completion of program competencies. Additionally, ongoing observational evaluation will be performed by the principal investigator and curriculum specialist to assure that the goals and objectives of the program are being met.

Institution: HOSPICE INSTITUTE OF FLORIDA SUNCOAST
THE FLORIDA SUNCOAST
LARGO, FL 337703716
Fiscal Year: 1995
Department:
Project Start: 30-SEP-1994
Project End: 01-SEP-1997
ICD: NATIONAL CANCER INSTITUTE
IRG: SRC

1996 $96,201 Hospice of the Florida Suncoast: Hospice Institute of the *HOSPICE INSTITUTE CERTIFICATION PROGRAM*

1 R25CA066889-03

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Linda L. Emanuel, M.D., Ph.D. — $3,560,813 tracked thus far

Robert Wood Johnson Foundation — *$3,502,698*

1999 36767 $400,000 American Medical Association — *EPEC*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___515
[though this says 1997, the grant on the page is clearly dated 1999-2000, and the annual report shows same.]
In 1997, the Foundation funded a project at the AMA for the Education for Physicians on End-of-Life Care (EPEC). It addressed the overall goal of educating all U.S. physicians to be competent in end-of-life care and used a central dissemination and a professional colleague-to-colleague teaching model to achieve its goals. It provided education through a potentially self-perpetuating cascade of national and regional conferences and workshops that trained physicians to go forward and train their own cadre of colleagues. The goal of this project is to secure and foster the gains already made for end-of-life care skills among the leaders and role models of medicine and to provide follow-through to build on the achievements of the EPEC Project. Specifically, the project will: (1) facilitate further implementation of the EPEC materials; (2) track the use of EPEC; (3) evaluate the educational outcomes of EPEC; and (4) update the EPEC mateirals to keep them current.

2000 39301 $991,639 Northwestern University — *EPEC – Program to train physicians in end-of-life care*

EPEC

2001 40507 $2,111,059 Northwestern University — *EPEC*

Training physicians in end-of-life care (for 2 years).

Open Society Institute / Project on Death in America (Soros Foundation) — *$58,115*

$43,775 Northwestern University — *Education for Physicians on End-of-life Care (EPEC) Conference Webcast*

The EPEC Project is a widely acclaimed program to educate physicians in the United States about core competencies in end-of-life care that are not provided to most physicians during their training. It is the only national program that takes responsibility for direct physician training in this area. This grant will provide
for the worldwide webcasting of a training conference videotape so that each of the EPEC curriculum's 16 modules can be made available on both the Internet and institutional intranets.

2001 $14,340 Northwestern University — *EPEC presentation in Europe (Polermo, Italy)*

http://www2.soros.org/death/ee_2001.shtml
This travel grant will support a presentation on the Education for Physicians on the End of Life Care (EPEC) curriculum at the 7th European Association of Palliative Care Congress in Palermo, Italy on April 1-5, 2001.

Cathy (Catherine) P. Emmett, RN, MSN, CHHP — tracked thus far

Robert Wood Johnson Foundation

52502 Senior Friendship Centers, Inc. — *Faith in Action*

RWJF does not show amount or date, but Grant ID number is recent (52502) and amount is probably about $35,000

http://www.rwjf.org/portfolios/resources/grant.jsp?id=052502&iaid=144
Project:

Faith in Action
Grantee:

Senior Friendship Centers Inc.
1888 Brother Geenen Way
Sarasota, FL 34236-7118
(941) 955-2122
Contact Information

Catherine P. Emmett (Project Director)
cemmett@seniorfriendship.com
Phone: (941) 556-3224

Sheila R. Enders, M.S.W. — $64,440 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$64,440*

2002 $64,440 University of California - Davis, School of Medicine

Creating a Handbook for Advance Care Planning and Decision Making at the End-of-Life in Populations with Low Literacy, Mild Learning Disabilities, or Mild Cognitive Deficits

The Design and Implementation of a Handbook for Advance Care Planning and Effective Decision-Making at the End-of-Life in Selected Populations with Low Literacy, Mild Learning Disabilities, or Mild Cognitive Deficits
This handbook will be field tested with female inmate patients at the Central California Women's Facility and male inmate patients at the California Medical Facility, Vacaville within the California state prison system. Corrections staff at both institutions will be educated about the special concerns of these special needs populations in the corrections setting. The project will create a complimentary educational video to promote understanding of key end-of-life issues and will make the handbook and video available for social workers, nurses, hospice, and skilled nursing facility personnel.
http://www.soros.org/initiatives/pdia/news/grants_20020702
Press release dated July, 2002

Eva A. Eng — $110,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$110,000*

2001 $110,000 Catholic Health Services of Long Island

Moving Palliative Care Upstream: Integrating Palliative Care Perspectives into the Ethos and Norms of Faith-Based Communities to Enhance Quality of Life

Parish leadership have been invited to embrace and become champions for palliative care, thereby using the inherent, formal and informal leaders in the parishes to create a high profile for palliative care and to heighten community awareness. The initiative represents the first formal collaborative effort between Catholic Health Services, Good Samaritan Hospice, the Diocese and the 18 Catholic parishes.

From PFC press release: Fan Fox & Leslie R. Samuels Foundation and Partnership For Caring Award Grants to Improve Palliative Care For The Chronically Ill Elderly

New York, NY-- Through its coordinating center at Partnership for Caring, The Fan Fox & Leslie R. Samuels Foundation has announced awards totaling $600,000 to three organizations as part of the second phase of its "Applying Strategies to Move Palliative Care Upstream" initiative. Three organizations are receiving grants: Highbridge Community Life Center in the Bronx; The Jewish Home and Hospital in Manhattan and the Bronx; and Metropolitan Jewish Health System in Brooklyn. The awards support innovative projects that extend the benefits of palliative care to patients earlier in the course of chronic diseases.

The purpose of the Foundation's palliative care initiative is to develop ways to extend the benefits of palliative care, (care for the patient and family focused on comfort, preservation of function and quality of life), to patients who are not yet near the end of life and may still benefit from curative treatments. This is especially important for people burdened with multiple diseases and their associated disabilities. Currently, palliative care tends to be considered only as part of hospice care and offered almost exclusively to patients who have exhausted curative treatments.

In 2000, the Foundation funded a first round of projects examining how palliative care may be used with curative interventions for the elderly who suffer from chronic diseases and either require or are already using long-term care services. This first phase supported projects that addressed issues such as training, access, administration, regulatory hurdles and knowledge in the field of palliative care.

This second round of funding aims at providing direct access to palliative care services for elderly patients in various settings, specifically a nursing home, a long-term care managed care plan, and a home visiting service in the community.

"The elderly, especially those suffering from chronic illness, should not be forced to choose between curative or life-prolonging care and care that makes them comfortable, functional and enjoy life more," comments Julio Urbina, Senior Program Officer at the Fan Fox and Leslie R. Samuels Foundation. "By integrating palliative care into ongoing disease management, health care providers will greatly improve their patients' quality of life."

Further information on the awards can be obtained from the Vice President for Special Programs, Mary Meyer, at 718.622.0089 or mmeyer@partnershipforcaring.org

Michelle Grant Ervin, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1998 $50,000 Howard University Health Sciences Center

Faculty Scholar, 1998-2000: End-of-Life Care Provider Education in an Ethnically and Spiritually Diverse Community (Grant amount is estimated.)

(With Jean Linzau)
Howard University Hospital, located in the heart of Washington, DC, has a rich history of serving the local, predominantly African American community. The team will survey providers and patients about their spiritual and cultural attitudes toward end-of-life care and use the findings to develop an appropriate end-of-life care curriculum for medical students.

Stuart Farber, M.D.

$50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1995 $50,000 University of Washington

Faculty Scholar, 1995-96: Development of a curriculum for a large Family Medicine residency network (Grant amount is estimated.)

Press Release: PDIA AWARDS $1.6 MILLION TO IMPROVE CARE OF THE DYING

New York, NY -- 29 May 1996

Betty Rolling Ferrell, PhD, RN, FAAN

$1,569,910 tracked thus far

Robert Wood Johnson Foundation *$825,714*

1997 32829 $793,014 City of Hope National Medical Center

ELNEC and the Textbook Project – Strengthening nursing education in pain management and end-of-life care (for 3 years). Chronic Care Initiatives in HMOs Strengthening nursing education in pain management and end-of-life care (for 3 years).; Duarte, CA

http://www.rwjf.org/reports/grr/032829.htm
This grant from the Robert Wood Johnson Foundation (RWJF) funded an effort led by the City of Hope (COH) National Medical Center to improve nursing education in pain and End-of-Life care. Research has demonstrated that nurses lack critical knowledge about pain management and End-of-Life issues. To improve the situation, project staff: (1) reviewed and critiqued 50 nursing textbooks; (2) surveyed members of key nursing organizations to find out how End-of-Life education can be improved; (3) met with nursing licensure leaders to suggest changes in national licensing exams; (4) created and distributed resources for state nursing boards, nursing schools, and textbook publishers, authors, and editors; and (5) sponsored a national conference for textbook authors and publishers and a second conference for representatives of state nursing boards to inform and educate attendees about these issues.

The textbook analysis revealed that just 2% of textbook content addresses End-of-Life issues. The survey of nursing organizations suggests that case studies, access to clinical sites, and Internet resources would be the best tools for improving education in this area.

Since the project's inception, national nursing board officials have revised the national licensure exam for registered nurses to include more End-of-Life content. A one-year follow-up survey of textbook authors and publishers indicates that many textbooks either have been or will be revised to include improved End-of-Life content.

2002 46803 $32,700 City of Hope National Medical Center

Development of a pediatric version of the End of Life Nursing Education Consortium project

Open Society Institute / Project on Death in America (Soros Foundation) *$76,650*

1998 $76,650 City of Hope National Medical Center

HOPE at the End of Life: A New Training Program for Home Care Nurses

HOPE (Home care Outreach for Palliative care Education), a training program in palliative care for home care professionals, grew out of the survey findings. It was developed, with support from PDIA, to provide training that does not interfere with the demanding work schedules of home care professionals. HOPE consists of five teaching modules for implementation in home care agencies over a period of six months on the following topics: general end-of-life issues, pain management, symptom management, communication issues, and the death event. To supplement the sessions, each agency is provided with a resource kit consisting of videotapes, books, articles, and cassette tape recordings of the teaching modules.
http://www2.soros.org/death/news3.htm
"The first module, which focuses attention on the importance of end-of-life care, was well received in the pilot project," said Betty Ferrell, Ph.D., FAAN, a research scientist at City of Hope National Medical Center and HOPE project director. Findings from this pilot project were most recently published in the Journal of Palliative Medicine.
. . . HOPE will be expanded to other Los Angeles agencies in the next three to four years, thanks to a R-25 training grant from the National Cancer Institute. "We will then hold a national trainers conference bringing together people from all over the country, who will in turn take the curriculum back to their agencies," Ferrell said.
========
Project: A pilot demonstration to improve the quality of care for patients and families in non-hospice home care agencies through design, implementation, and evaluation of a model education program. This educational project will develop and evaluate a model education program which can be disseminated widely through home care agencies to improve care for terminally ill patients and families. Over two years, a curriculum will be developed and testing in 5 home care agencies representing various models of home care delivery and providing care to culturally diverse populations.

Mayday Fund *$5,000*

2003 $5,000 Partnership for Caring

National Consensus Project

from the Mayday web site, "Grants made in 2003":
"Partnership for Caring
Brooklyn, NY
Betty Ferrell, PhD, RN, FAAN
A grant of $5000 in support of the National Consensus Project for Quality Palliative Care.

Web Site: http://www.nationalconsensusproject.org/"

National Institutes of Health - National Cancer Institute (NCI) *$662,546*

1998	$189,070	City of Hope National Medical Center	*HOPE–Home Care Outreach for Palliative Care Education*
		5R25CA078198-04 R25 (2001)	
1998	$167,373	City of Hope National Medical Center	*HOPE–HOME CARE OUTREACH FOR PALLIATIVE CARE EDUCATION*
		5R25CA078198-03 R25 (2000)	
2003	$306,103	City of Hope National Medical Center	*Oncology Nursing Education in End of Life Care*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6662365&p_grant_num=1R25CA101706-01&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=24&p_audit_numfound=177&p_keywords=palliative
Grant Number: 1R25CA101706-01
PI Name: FERRELL, BETTY R.
PI Email: bferrell@coh.edu
PI Title: RESEARCH SCIENTIST
Project Title: Oncology Nursing Education in End of Life Care

Abstract: DESCRIPTION (provided by applicant): The primary aim of this proposal is to improve end of life care for cancer patients through the national network of oncology nurses in chapters of the Oncology Nursing Society (ONS). Recent national initiatives and major consensus documents have provided strong evidence of the need for improved professional education to impact end of life care in cancer care. The National Cancer Policy Board and Institute of Medicine's report of improved end-of-life care published in 2001 has documented the considerable need for improved end-of-life care for more than 550,000 individuals who will die of cancer this year in the United States. This primary aim will be achieved through 4 workshops for teams selected nationwide through ONS chapters. Each conference will be attended by 60 oncology nurses for a total of 240 participants representing their 120 ONS chapters and the project will later reach the remaining chapters through dissemination efforts. The project combines the efforts of the City of Hope National Medical Center, the American Association of Colleges of Nursing, and the Oncology Nursing Society. Specific aims include: 1) Adapt the existing End of Life Nursing Education Consortium (ELNEC) curriculum and teaching materials to be cancer specific for use in this Oncology Nursing Education End of Life Care (ONE-EOLC) project. 2) Evaluate the impact of the curriculum on participants' knowledge and attitudes about end-of-life care. 3) Support the network of ONE-EOLC educators through the ONS chapters to share experiences in dissemination of the curriculum. 4) Evaluate the effectiveness of participants' implementation efforts within the ONS chapters. 5) Describe issues related to dissemination of EOL education through CE efforts of ONS chapters. This project focuses on palliative care in the cancer network of ONS chapters to provide nationwide education as an efficient means to build upon the extremely successful project in progress, ELNEC. Supported by the Robert Wood Johnson Foundation, ELNEC has targeted undergraduate nursing programs and continuing education providers. The 9 content areas of the curriculum are nursing care at EOL, pain management, symptom management, ethical issues, culture, communication, grief/loss and bereavement, achieving quality care at EOL, and preparation and care at the time of death. This proposal includes extensive evaluation planned to monitor individual and institutional dissemination.
Institution: CITY OF HOPE/BECKMAN RESEARCH INSTITUTE
OFFICE OF SPONSORED RESEARCH
DUARTE, CA 910103000
Fiscal Year: 2003
Department:
Project Start: 05-AUG-2003
Project End: 31-JUL-2008
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

Frank D. Ferris, M.D.

$86,400 tracked thus far

Robert Wood Johnson Foundation *$86,400*

2001	43121	$86,400	San Diego Hospice	*CAPC - Preparing a practical guide to the establishment of palliative care services (4 months).*

I am guessing this is for the online CAPCManual. I am also guessing that Frank Ferris is the director

Open Society Institute / Project on Death in America (Soros Foundation)

1998	San Diego Hospice	*Consensus Building as a Process to Effect Change in Care of the Dying*

Faculty Scholars Program. In 1993, the Canadian Palliative Care Association embarked on a consensus building process to develop national principles of practice and standards that would reduce variability between the many hospice and palliative care programs that have been developed in the last twenty-five years. This project will assess the effectiveness and level of consensus that has resulted from the use of these proposed standards and will seek to further refine these principles in order to create an ideal standard against which all programs can be measured. It is expected that a new document outlining the nationally accepted principles of practice will result from this process. Mt.Sinai Hospital
Temmy Latner Centre for Palliative Care; Toronto, Ontario, Canada
Awarded sometime between 1994 and 2000.

Marilyn J. Field, Ph.D.

$350,000 tracked thus far

Robert Wood Johnson Foundation *$125,000*

1996 29725 $75,000 Institute of Medicine — *Study of Care at the End of Life*

Chronic Care — To improve care and support for people with chronic health conditions. To complete the study, IOM assembled an expert committee that included practitioners, health services administrators, researchers, policy analysts, lawyers, ethicists, and patient advocates (see the Appendix for a roster of members). The committee met six times between January 1996 and March 1997 for a range of information-gathering activities.

In its report, entitled Approaching Death: Improving Care at the End of Life, the committee identified four broad deficiencies in the current care of people with life-threatening and incurable illness:

2001 $50,000 Institute of Medicine — *Study to improve end-of-life care for dying children and their families*

There are significant deficiencies in the knowledge base of how to provide good end-of-life care to children and their families. This deficiency limits the quality of care that is being provided to dying children. In a study released earlier this year, interviews with parents indicated that 89 percent of children receiving care for cancer at the Dana-Farber Cancer Institute in Boston suffered a great deal from at least one symptom in their last month of life. This project will examine the special challenges of providing good end-of-life care to this population and develop recommendations to strengthen the knowledge base. In addition, it will highlight and advocate for more consistent application of existing knowledge. At the completion of the study, a report will be developed in accordance with National Resource Council (NRC) report review procedures and published by the National Academy Press. A shorter freestanding summary will also be published. A rigorous dissemination is planned targeting those groups with the interest and ability to improve end-of-life care for children and families such as policy makers, clinicians, medical educators, and advocacy groups.

Open Society Institute / Project on Death in America (Soros Foundation) *$200,000*

$200,000 Institute of Medicine — *The shaping of governmental and institutional policy*

sometime between 1994 and 1997
http://www2.soros.org/death/governmental_policy.htm
Project: To examine: 1) the state of knowledge about clinical, behavioral, legal, economic, and other important aspects of care for patients with life-threatening medical problems; 2) evaluate methods for measuring outcomes and predicting survival and functional status, determining patient and family preferences, and assessing quality of care; 3) identify organizational, legal, and other factors that impede or promote high quality care for patients approaching death; and 4) recommend steps that policy makers, practitioners, and others could take to improve the organization, delivery, financing, assessment, and quality of care for those with terminal illness and to increase agreement on what constitutes appropriate care.

Commonwealth Fund *$25,000*

1997 $25,000 Institute of Medicine — *Workshop on Quality of Care at the End of Life*

http://www.cmwf.org/grants/grants_show.htm?doc_id=222634
Workshop on Quality of Care at the End of Life

Award Amount: $25,000
Approval Date: July 1, 1996
Start Date: July 1, 1997
End Date: July 1, 1998
National Academy of Sciences, Institute of Medicine
2101 Constitution Avenue, Room #F 03113
Washington, DC 20418

Principal Investigator:
Marilyn J. Field, Ph.D.

Joseph Jack Fins, M.D.

$754,245 tracked thus far

Robert Wood Johnson Foundation *$49,016*

1995 28153 $49,016 American Geriatrics Society, Inc. — *Conference on the Ethics of Managed Care*

With the support of The Robert Wood Johnson Foundation (RWJF), The Hastings Center and the American Geriatrics society (AGS) co-sponsored the 1996 Congress of Clinical Societies, the fourth in a series that started in 1987. The conference featured 17 speakers and more than 45 invited guests representing nearly two dozen clinical societies and numerous ethical organizations. Joseph J. Fins, MD, associate for medicine at The Hastings Center, a practicing internist, and director of medical ethics at New York Hospital, organized the conference.

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1997 $70,000 Cornell University - Weill Medical College — *Reconstructing the Care of the Dying through the Integration of Clinical Ethics and Palliative Care*

http://www2.soros.org/death/1997_fs.htm
Recognizing that the care of the dying can be improved through the enhanced integration of clinical ethics and palliative care, a model educational program and scholarly literature will be developed linking these two disciplines. This inter-

disciplinary program will be based in a hospice-like Alternative Care Unit (ACU) currently under development.

Fan Fox and Leslie R. Samuels Foundation *$635,229*

1999 $116,229 Cornell University - Weill Medical College *From Contract to Covenant, Part I*

a project that explores how patients and their proxies regard the proxy relationship; whether as a contractual or covenantal one. The ultimate goal is to help physicians better understand the implication of these differing views of agency so that they may help agents navigate the process of making difficult health care decisions for someone else.

Byock's Life's End Institute collaborated on this project. See http://www.lifes-end.org/annual_report/recent/recent_highlights.phtml
"We also have begun work in collaboration with the Joan and Sanford I. Weill Medical College of Cornell University in a project to study how aging and terminally ill patients and their health-care proxies view their roles and responsibilities. The study, "From Contract to Covenant in Advance Care Planning," is funded by the Fan Fox and Leslie R. Samuels Foundation and administered by Choice in Dying, a national patient advocacy organization credited with developing living wills. The project will provide critical information to improve advance care planning in the United States."

2000 $154,000 Cornell University - Weill Medical College *From Contract to Covenant, Part II*

This grant supports the second phase of a project that explores how patients and their proxies regard the proxy relationship: whether as a contractual or covenantal one. The ultimate goal is to help physicians better understand the implication of these differing views of agency so that they may help agents navigate the process of making difficult health care decisions for someone else.
Top

2001 $150,000 Cornell University - Weill Medical College *Integrating Palliative Care into Hospital Practice*

To the Division of Medical Ethics: This is the first phase of a two-part effort that seeks to develop a means whereby physicians can learn how to appropriately set goals of care for patients whose conditions no longer respond to nor warrant curative treatments. The GCAT, developed by Dr. Fins, was the outgrowth of an analysis of 200 consecutive deaths at New York Hospital. It is a process-oriented, goal-setting instrument that will help clinicians to recognize when death is near and plan more timely and comprehensive end-of-life care strategies with patients and their families.

2002 $200,000 Cornell University - Weill Medical College *"Fidelity, Wisdom and Love: Interactive Patient and Proxy Materials"*

http://www.samuels.org/hc2002.htm
During the first round of the Healthcare Agency Initiative, Dr. Fins' project, "From Contract to Covenant in Advance Care Planning," developed a mechanism to describe clearly the complex, personal aspects of the patient-proxy relationship. This project takes that work to the next stage by creating a practical, educational tool to help patients and their proxies better understand and prepare for their roles and mutual responsibilities, and to enhance the likelihood that patients' preferences will be understood and followed. The product of the grant will be an educational kit, including an introductory video describing the patient-proxy relationship, educational workbooks, a leader's guide and supporting materials, such as proxy forms and questionnaires geared toward a lay audience.

2002 $15,000 Cornell University - Weill Medical College *From Contract to Covenant – Communications*

http://www.samuels.org/hc2002.htm
"Support for Communication/Dissemination Initiative for 'Contract to Covenant' Project"

This grant would provide funds for the development of a 24-page supplement to the Hastings Center Report for the "From Contract to Covenant in Advance Care Planning" project funded by the Samuels Foundation (see 2000 grants). Upon successful completion of the peer review process, the funds for this grant would be used to print the supplement.

Alan R. Fleischman, M.D. — $591,792 tracked thus far

Robert Wood Johnson Foundation *$268,792*

1999 35981 $268,792 New York Academy of Medicine *Targeted EOL Programs*

(I am just guessing that Fleischman is contact) 18 months

Fan Fox and Leslie R. Samuels Foundation *$323,000*

2000 $323,000 New York Academy of Medicine *Continuation grant for the Urban Health Initiative (UHI)*

UHI fosters volunteerism and helps organize community service activities for medical school students at the region's ten medical schools. For the past seven years UHI has provided technical assistance and support to students to develop volunteer community service projects; promoted networking among the students and the schools, equipped students with the skills and knowledge helpful to serving minority and marginalized populations and worked to institutionalize community service and volunteerism into the fabric of regional medical schools.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Kathleen M. Foley, M.D. — $15,000,000 tracked thus far

Soros Foundation — *$15,000,000*

1995 $15,000,000 Open Society Institute / Project on Death in America (Sor — *Creation of Project on Death in America (over 3 years)*

see http://www2.soros.org/death/george_soros.htm
The mission of the Project is to promote a better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death. To do this, the Project will support initiatives in research, scholarship, the humanities and the arts, as well as innovations in the provision of care, public education, professional education, and public policy. I have committed $5 Million a year to the Projects work for the first three years. The board has decided to use the money in two ways: by developing its own programs and by holding itself open for grant applications.

The first major program is to establish a number of faculty scholarships. We hope to identify outstanding faculty and clinicians who are committed to the Projects goals and to support them in their work of developing new models for the care of the dying and new approaches to the education of health professionals about the care of dying patients and their families. The scholars, who will receive two- to three-year fellowships for projects that explore critical aspects of the care of the dying, will become the academic leaders on this issue, the role models, and mentors to future generations of health professionals. Each year the project will select ten faculty scholars. In three years we will have a leader and role model in place in one-fourth of the country's medical schools.

Walter Forman, M.D. — $599,856 tracked thus far

Robert Wood Johnson Foundation — *$449,856*

1998 35487 $449,856 University of New Mexico Health Sciences Center — *Promoting Excellence in End-of-Life Care - Palliative Care Center of Excellence for Rural New Mexico*

Summary Title: Promoting Excellence in End-Of-Life Care
Project Title: A Palliative Care Center of Excellence for Rural New Mexico
Project Director: Walter Forman Degree: M.D.
Phone No.(Work): 505-277-0903
Fax (Work): 505-277-9213
Email: wbforman@unm.edu
Grantee Institution: University of New Mexico, Albuqu
Address: 2211 Lomas Blvd S.E.
5th Floor ACC
Albuquerque New Mexico United States.
Start Date: 10/01/1998 End Date: 09/30/2001
Amount: $449,856 Web Site:
Description: This project will assist seven diverse, multicultural communities in rural New Mexico with building a hospice network to serve patients. In addition, the Palliative Care Information, Referral and Training Center will be established at the University of New Mexico offering technical assistance in end-of-life care, establishing a website to link programs across the state, and developing a statewide hospice network. Doctors and nurses from the seven communities will receive training and certification in palliative care. Students attending UNM's Health Sciences will complete month-long rotations during which they will study palliative care within the communities. The UNM Health Sciences Center will also prepare future health care professionals to provide palliative care. The center will develop a palliative care curriculum that addresses Native American, Hispanic, and Anglo rural culture as well as develop awareness of local customs. As part of the effort, the new center will collaborate with the Indian Health Service Albuquerque area and the Zuni Home Health Agency to develop a Medicare-certified hospice program for the Zuni Nation.

Kornfeld / PDIA (Soros) collaborative — *$150,000*

2003 $150,000 University of New Mexico Health Sciences Center — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

Lachlan Forrow, M.D. — $170,000 tracked thus far

Robert Wood Johnson Foundation — *$100,000*

1997 30333 $50,000 Albert Schweitzer Fellowship — *Volunteer Service Program in US Communities for Health Professions Students (Beth Israel Deaconess Medical Center, Boston)*

Goal: Access — To assure that all Americans have access to basic health care at reasonable cost.
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A local USSFP director presented a talk at the 1997 American Public Health Association annual meeting in Chicago. An article on the USSFP appeared in Academic Medicine in June 1998. Media coverage of local programs included articles in the Boston Sunday Globe, the Pittsburgh Post-Gazette, the American Bar Association Journal, MS magazine, and Good Housekeeping magazine as well as a feature aired in October 1997 on WBEZ radio in Chicago.
==========
These grants from The Robert Wood Johnson Foundation (RWJF) funded The Albert Schweitzer Fellowship (ASF), part of the US Schweitzer Fellows Programs (USSFP), which enable health professions students to undertake volunteer services in the United States helping needy families. The Albert Schweitzer Fellowship, Inc., was founded in 1940 to support Albert Schweitzer's work at his Lambaréné hospital in West Africa.

In 1992 ASF established the USSFP to enable students in the full range of health professions — including medicine, nursing, public health, and social work — to undertake volunteer service in local agencies in high-need poverty communities, rural as well as urban, in the United States. The USSFP seeks to (1) bring needed talent to local service agencies working in health, (2) expose students to the problems of distressed and needy families and to affirm the service ideal of the health professions, and (3) strengthen the ethical commitment of students' institutions to the needs of their regions.
The first grant (ID# 030333) helped the USSFP:

** To fund a national program coordinator,*
** half of whose time was devoted under this grant to the strengthening of management and coordination. To prepare a uniform set of program materials.*
** This effort included the finalization of an earlier draft of the USSFP Guide and Operating Principles for the Establishment of a Schweitzer Fellows Program, the redesign and renaming of the USSFP recruitment publication Reverence, and the beginning of publication of an annual Alumni Newsletter to help link current and past fellows. To implement a common evaluation protocol for program sites*
** , including quarterly reports circulated by e-mail between sites and USSFP headquarters. To establish a regular series of meetings and conference calls among site directors.*
This effort included a June 1997 weekend meeting of program leaders from all sites, along with visits by USSFP officers and board members to local program sites for participation in the selection and orientation of fellows and for presentations at USSFP symposia.

1999 35511 $50,000 Albert Schweitzer Fellowship — *Volunteer Service Program in US Communities for Health Professions Students (Beth Israel Deaconess Medical Center, Boston)*

(Forrow was a SUPPORT investigator)

Goal: Access — To assure that all Americans have access to basic health care at reasonable cost.
These grants from The Robert Wood Johnson Foundation (RWJF) funded The Albert Schweitzer Fellowship (ASF), part of the US Schweitzer Fellows Programs (USSFP), which enable health professions students to undertake volunteer services in the United States helping needy families. The Albert Schweitzer Fellowship, Inc., was founded in 1940 to support Albert Schweitzer's work at his Lambaréné hospital in West Africa.

In 1992 ASF established the USSFP to enable students in the full range of health professions — including medicine, nursing, public health, and social work — to undertake volunteer service in local agencies in high-need poverty communities, rural as well as urban, in the United States. The USSFP seeks to (1) bring needed talent to local service agencies working in health, (2) expose students to the problems of distressed and needy families and to affirm the service ideal of the health professions, and (3) strengthen the ethical commitment of students' institutions to the needs of their regions.
 # Secured financial support for local programs from several organizations.
 # The USSFP worked to secure medium-to-long-term funding, with emphasis on local fund-raising for local chapters. Efforts included a 1999 phone-a-thon in the Boston area and establishment of advisory boards at the Baltimore and Boston sites. Strengthened existing programs.
 # The USSFP hosted 10 Fellows Programs Symposia ? in Boston, New York, North Carolina, and Baltimore — and strengthened the fellows alumni network, which by spring 2000 numbered approximately 600. (See the Appendix for details.) Continued expansion of its evaluation of program sites
 # (begun during the first grant) via quarterly e-mail evaluations circulated among sites. Building on written service reports (required from each fellow) and on mentors' feedback, in 1999 the USSFP began to collect information on evaluation techniques used by other service and service-learning programs in its site localities. In addition, in April 1999, Prof. Howard Gardner of the Harvard Graduate School of Education completed an in-depth study of 17 selected USSFP alumni as part of a larger project on the origins of human creativity and the relationship between intelligence, creativity, and human service. Gardner concluded that "The Schweitzer fellows offer a valuable — perhaps, exceptional — model in their integration of work and personal life through service to others." Increased communications among its local site programs.
The effort included (1) weekend retreats by local and national staff and a few fellows; (2) monthly conference calls

among local programs; (3) distribution of its annual Alumni Newsletter, its recruitment publication Reverence, and its Guide and Operating Principles; (4) distribution of 3,000 copies of a 1999 informational brochure "The Albert Schweitzer Fellowship"; (5) the 1999 upgrading of its Web site www.schweitzerfellowship.org; and (6) the establishment, in the fall of 1999, of a standardized budget process to unite local chapters administratively.

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1999 $70,000 Beth Israel Deaconess Medical Center *Faculty Scholar, 1999-2000 (amount of grant is estimated)*

Amount of grant is estimated

Irwin Sonny Fox **$27,000** tracked thus far

Robert Wood Johnson Foundation *$27,000*

1999 37127 $27,000 Population Communications International, Inc *Prime Time Television: Session on Death and Dying at a Conference for the Prime Time Television Industry*

From RWJF's 1999 Annual Report, "Goals Update: Chronic Health Conditions":
http://www.rwjf.org/files/publications/annual/1999/chronic-1.html
"Barksdale Ballard & Company, Vienna, Virginia, and Population Communications International, Inc., New York City, were each funded to work with Hollywood and New York-based writers, producers, and directors on end-of-life issues. Using an episode of the television show "ER" as a springboard, Last Acts®, our end-of-life communications campaign, launched a promotional effort to stimulate public interest in discussing end-of-life issues. "
=========
From grants result:
Grant Results Brief

Session on Death and Dying at a Conference for the Prime Time Television Industry
(last updated December 2000)

This grant from The Robert Wood Johnson Foundation (RWJF) provided partial support for a summit of leaders in the television community to discuss new approaches to portraying health issues within the context of their programs; one of the health issues was death and dying. The summit was organized by Population Communications International (PCI), a nonprofit organization that encourages the development of radio and television programming fostering sexual and reproductive health, gender equality, and environmental protection. PCI attempts to influence the overt and implicit health messages contained in television programs by engaging the people in the television industry who determine story lines and develop characters. PCI has already employed this approach in a companion series of meetings called "The Soap Summits," which gathered writers, producers, and others associated with television soap operas. (A 1997 Soap Summit received partial support from RWJF under grant ID# 032840.)

"The Prime-Time Summit," which was held in Los Angeles June 4-5, 1999, was attended by approximately 125 people, including producers, writers, and network executives affiliated with prime-time programming. It was co-sponsored by three industry organizations: The Caucus of Producers, Writers, and Directors; The Producers Guild of America; and the Writers Guild of America, West. The keynote speaker was David Satcher, MD, PhD, US Surgeon General, who emphasized a need for public health and television industries to work together to promote responsible and safe television programs. The next day's program consisted of three presentations followed by four panel/breakout sessions focusing on the following topics: (1) teenage sexuality (with emphasis on the role of the young male), (2) violence against women, (3) emerging diseases, and (4) death and dying. For the session on death and dying (the focus of RWJF's support), RWJF staff assembled a panel of four people: Terrance Sweeney, a five-time Emmy Award-winning television producer; Michael Rabow, MD, assistant clinical professor of medicine at the University of California, San Francisco, School of Medicine; Robert Potter, MD, associate clinical professor of medicine at the University of Kansas School of Medicine; and Alicia Super, RN, president of Pain and Supportive Care Services, Portland, OR.

Panel members recounted professional and personal experiences helping people come to terms with death and dying. They also discussed how doctors and nurses receive minimal training in end-of-life care and how television tends to equate a patient's death with failure. The session also provided resources for television writers, including information on Last Acts, a national coalition of nearly 500 organizations funded by RWJF to engage public and professional audiences in efforts to improve end-of-life care; its Web site is www.lastacts.org.

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GRANT INFORMATION

BIBLIOGRAPHY

GRANT INFORMATION

PROJECT
Session on Death and Dying at a Conference for the Prime Time Television Industry

GRANTEE
Population Communications International (New York, NY)
$25,000 (June 1999 to August 1999) ID# 037127
Contact
I. Sonny Fox
(818) 557-0893
pciusa@earthlink.net

RWJF GOAL AREA
Chronic Care — To improve care and support for people with chronic health conditions.

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Projects and programs in End of Life

BIBLIOGRAPHY
(As provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Books and Reports

Project staff. Prime Time Summit. Conference proceedings. Burbank, CA: Population Communications International Inc., 1999. Approximately 100 copies distributed.

Sponsored Conferences

"Prime Time Summit," June 4-5, 1999, Los Angeles, CA. Attended by approximately 125 producers, writers, and network executives affiliated with prime-time programming. One keynote presentation and four panels.
Keynote Presentation

** David Satcher, US Surgeon General and Assistant Secretary of Health, "Keynote Address."*

Panels

** "Violence Against Women," Mark Rosenberg, Centers for Disease Control and Prevention (CDC) Center for Injury Prevention and Control; Brenda Aris, a battered woman.*
** "Teenage Sexuality (with a Focus on the Role of the Young Male)," Claire Brindis, National Adolescent Health Information Center; Ron Johnson, National Life and Education Center; Jerry Tello, National Latino Fatherhood and Family Institute; Richard Pacheco, Ozzie Cruz, and Deonte Anderson: Teen Fathers.*
** "Emerging Diseases," Stephen Ostroff, Centers for Disease Control and Prevention.*
** "Death and Dying," Terrance Sweeney; Michael Rabow, University of California (San Francisco, CA); Robert Potter, University of Kansas School of Medicine; Alicia Super, Pain and Supportive Care Services (Portland, OR).*

Print Coverage

"Better Brand of Soap," in Los Angeles Times, June 2, 1999.

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Projects and programs in End of Life

Report Prepared by: Robert Crum
Reviewed by: James Wood, Richard Camer
Program Officer: Victoria D. Weisfeld

Gerri Frager, R.N., M.D. — **$70,000** tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1995	$70,000	Dalhousie University (Nova Scotia, Canada)	*Faculty Scholar, 1995-96 (amount of funding is estimated)*

Development of a comprehensive pediatric supportive care program.

Anthony N. Galanos, M.D. — **$220,000** tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

2000	$70,000	Duke University - Medical Center	*Center for Aging: Determining specific barriers to a good death at a tertiary care, academic medical center. (Faculty Scholar; amount of funding is estimated)*

Communication and symptom management have always been major issues in dealing with end-of-life care work. Poor family satisfaction and lack of closure, as well as staff satisfaction, are important issues. This study proposes to define the epidemiology of death at a tertiary, academic medical center, and to elicit feedback from providers and families on the care and resultant level of satisfaction at the end-of-life. This information will be used to identify and overcome barriers to a "good death".

Kornfeld / PDIA (Soros) collaborative *$150,000*

2004	$150,000	Duke University - Medical Center	*Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12
NOTE: Galanos and Tulsky co-direct the fellowship

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Linda Ganzini, M.D. — $100,154 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

1998 $50,000 Oregon Health and Science University — *Faculty Scholar, 1998-2000: Legalization of Physician-Assisted Suicide in Oregon (Grant amount is estimated.)*

(Portland VA Research Foundation) As the first state in the United States to allow physicians to help terminally ill patients end their lives, Oregon is being closely watched. The project examined cancer patients' requests for lethal prescriptions, the characteristics of patients who make the requests, the physicians' processes for assessing patients, and the impact of the experience on the physician, family, and other health care professionals. Dr. Ganzini surveyed physicians about their experiences with explicit requests for assisted suicide in order to compare current attitudes to those from a 1995 survey.

Greenwall Foundation — *$37,040*

2001 $37,040 Portland Veterans Affairs Medical Center — *Oregon Hospice Care Providers' Views and Experiences with Assisted Suicide and Voluntary Refusal of Food and Fluids*

Produced the much-written-about study to encourage old people to starve themselves to death as an alternative to PAS.

Gerbode Foundation (Wallace Alexander) — *$13,114*

1999 $13,114 Portland Veterans Affairs Medical Center — *Survey of physicians re DWD Act*

GANZINI was probably the contact. See press release at http://www.ohsu.edu/news/archive/2001/050801endoflife.html
OHSU press release, May 4, 2001:
PORTLAND, Ore. -- In the May 9 issue of the Journal of the American Medical Association, researchers report that Oregon physicians have made a priority of improving their ability to care for dying patients since passage of the Oregon Death with Dignity Act.

"Because Oregon is the only state in which assisted suicide is legal, it offers a rare chance to try to understand how such laws might affect overall medical practice," said first author Linda Ganzini, M.D., director of geriatric psychiatry at the Portland Veterans Affairs Medical Center (VAMC) and an associate professor of psychiatry at Oregon Health & Science University (OHSU). Since legalization of assisted suicide in 1994, Ganzini said, some people have expressed concerns that palliative care options would diminish for patients in Oregon.

. . . In addition to Ganzini, the research team included Heidi Nelson, M.D., M.P.H., of the VAMC and OHSU; Melinda Lee, M.D., of Providence ElderPlace and OHSU; Terri Schmidt, M.D., and Dale Kraemer, Ph.D., of OHSU; and Molly Delorit of the VAMC. Their work was supported by the Greenwall Foundation, the Gerbode Foundation and the Department of Veterans Affairs
==========

http://fdncenter.org/grantmaker/gerbode/grcomm99.html
"Support of its survey of Oregon physicians regarding their experiences with patients desiring a lethal prescription under the Oregon Death With Dignity Act."

Thomas L. Garthwaite, M.D. — $982,595 tracked thus far

Robert Wood Johnson Foundation — *$982,595*

1998 34588 $982,595 United States Department of Veterans Affairs — *Veterans Affairs Faculty Fellows Program in End-of-Life Care (Chronic Health Conditions)*

http://www.rwjf.org/reports/grr/034588.htm
"Faculty Leaders Program"
Veterans Affairs Faculty Fellows Program in End-of-Life Care
GRANTEE
U.S. Department of Veterans Affairs (Washington, DC)
$943,180 (June 1998 to June 2000) ID# 034588
Contact: Thomas L. Garthwaite, M.D. (202) 273-8379 WEB SITE
http://www.va.gov/oaa/flp

Nina Smith Gilbert — $35,000 tracked thus far

Robert Wood Johnson Foundation — *$35,000*

2004 50136 $35,000 Hospice of the Florida Suncoast — *Faith in Action*

http://www.rwjf.org/programs/grantDetail.jsp?id=050136

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Myra Glajchen, D.S.W. — $500,000 tracked thus far

Mayday Fund *$500,000*

1999 $500,000 Beth Israel Medical Center - NYC *Pain Resource Center at Beth Israel*

http://www.painandhealth.org/mayday/previous-grants.html
Beth Israel Medical Center
New York, New York
"Pain Resource Center at Beth Israel"
$500,000 over five years to establish a resource center in the Department of Pain Medicine and Palliative Care. To assist with dissemination of information to the public and professions on the effective management and treatment of all kinds of pain.
Contact: Myra Glajchen, DSW
E-mail: mglajchen@bethisraelny.org

Arnold Goldetz, M.D. — $65,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$65,000*

$50,000 Vermont Ethics Network *Shaping of Governmental and Institutional Policy*

Using a grassroots approach, VEN will hold a series of community forums to discuss what Vermonters generally think is the proper distribution of health care resources between hospital care home care hospice and long-term care. The results of the forums will be discussed with health care providers in order to develop practical guidelines for achieving the public's goals. The goals and guidelines will then be presented to policy makers for further discussion and eventual implementation.

$15,000 Vermont Ethics Network *Journey's End: Vermont Voices on Death and Dying*

"Journey's End: Vermont Voices on Death and Dying"
To identify the needs of patients and families in Vermont through community forums and personal interviews and to communicate these needs to health care providers in the state through a publication and broad community discussion.

Carlos F. Gomez, M.D., Ph.D. — $140,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 University of Virginia *Faculty Scholar (amount of grant is estimated)*

http://www2.soros.org/death/prMay29-96.htm
Development of a model program in end-of-life care and the education of residents in palliative medicine.

Sarah J. Goodlin, M.D., FAAHPM — $190,538 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 Dartmouth College *Faculty Scholar*

Amount of grant is approximate. http://www2.soros.org/death/prMay29-96.htm
Development of a quality improvement process for end-of-life care and the development of a care pathway for regional palliative care.

National Institutes of Health - National Cancer Institute (NCI) *$50,538*

1994 $50,538 Dartmouth College *Palliative Care Education through Quality Improvement*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2110287&p_grant_num=5R25CA066806-02&p_query=%28palliative+care%29&ticket=14351398&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=37&p_keywords=palliative+care
Grant Number: 5R25CA066806-02
PI Name: GOODLIN, SARAH J.
PI Email: sjg-pcer@comcast.net
PI Title:
Project Title: PALLIATIVE CARE EDUCATION THROUGH QUALITY IMPROVEMENT

Abstract:
This abstract is not available.

Thesaurus Terms:

There are no thesaurus terms on file for this project.
Institution: DARTMOUTH COLLEGE
11 Rope Ferry Rd. #6210
HANOVER, NH 03755
Fiscal Year: 1995
Department: MEDICINE
Project Start: 30-SEP-1994
Project End: 31-AUG-1997
ICD: NATIONAL CANCER INSTITUTE
IRG: SRC

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Jack D. Gordon — $100,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$100,000*

$25,000 Hospice Foundation of America — *Living with Grief: After Sudden Loss*

To provide funding for the annual teleconference on grief and bereavement.

1996 $75,000 Hospice Foundation of America — *Living with Grief: After Sudden Loss*

Project: Sponsorship of a national teleconference on the topic of sudden and traumatic death entitled, "Living with Grief: After Sudden Loss." The teleconference aired on April 17, 1996 and was offered in association with Mothers Against Drunk Driving and the Association for Death Education and Counseling. Cokie Roberts of ABC News and National Public Radio was moderator.

David A. Gould, Ph.D. — $775,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$600,000*

$300,000 United Hospital Fund — *Hospital consortium for Palliative Care Initiative*

(over 2 years.) To organize a consortium of five New York City hospitals to design, implement, and evaluate a Palliative Care Initiative in order to fundamentally assess and change the way hospitals provide care to persons at the end of life.

1999 $300,000 United Hospital Fund — *Palliative Care Initiative*

(over 3 years) To create a community-oriented palliative care initiative over three years, 1999 to 2001, to significantly extend the funds's earlier work to stimulate the development of palliative care services in New York City hospitals. While continuing to work with hospitals to strengthen inpatient care, the Fund will focus its analytic and grantmaking resources on the development of at least two major palliative care networks, comprising partnerships among hospitals, hospices, home care agencies, nursing homes, and community based service and religious organizations.

Fan Fox and Leslie R. Samuels Foundation *$175,000*

1998 $175,000 United Hospital Fund — *Family Perspectives on End of Life Care: A Survey of Surviving Next of Kin (over 2 years).*

http://www.samuels.org/hc_archive_99-96.htm

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Marcia Grant, DNSc, R.N., FAAN — $300,619 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$300,619*

2001 $300,619 City of Hope National Medical Center *Disseminating End of Life Education to Cancer Centers*

1R25CA092159-01 R25
http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6364985&p_grant_num=1R25CA092159-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=225&p_keywords=palliative+care
Grant Number: 1R25CA092159-01
PI Name: GRANT, MARCIA L.
PI Email: mgrant@coh.org
PI Title: PROFESSOR
Project Title: DISSEMINATING END OF LIFE EDUCATION TO CANCER CENTERS

Abstract: DESCRIPTION (provided by applicant): The primary aim of this proposal is to improve end-off-life (EEL) care for patients in cancer centers. In 2000, about 552.200 Americans are expected to die of cancer (1 in every 4 deaths). While national initiatives are providing evidence of the support patients and families need to deal with symptoms, decisions and burdens of dying, dissemination through professional education is minimal. The primary aim will be achieved through 4 annual workshops for 2 representatives each from 75 cancer treatment centers (600 total participants). The project builds on the investigators' previous experience with similar national workshops on pain management, palliative care education for home care staff, and a nursing EOL curriculum being developed with the American Association of Colleges of Nursing and supported by the Robert Wood Johnson Foundation. Specific aims to be accomplished are to: (1) Adapt the existing EOL curriculum to focus on patients with cancer and address an interdisciplinary professional audience in cancer centers. (Nurses, social workers and physicians in tier 1, and clergy, pharmacists, psychologists, rehabilitation professionals and unlicensed personnel in tier 2). (2) Implement the curriculum in national workshops to competitively selected staff from NCI-designated cancer centers, and members of the Association of Community Cancer Centers. (Two people from each institute with at least one from tier 1), (3) Develop a Community Cancer Center. participants-network to share experiences in dissemination, (4) Evaluate the impact of the curriculum on participants' and cancer center staffs' knowledge and attitudes about EOL care and the implementation of individual goals for improved EOL care, (5) Evaluate EOL care at 3 levels - the participant, the interdisciplinary cancer team, and the institution level - for the ability to change and sustain improvements in EOL care, (6) Describe successes and issues related to dissemination in terms of the characteristics of individual participants, interdisciplinary teams, and institutions, and (7) Refine the curriculum for broad dissemination to cancer centers to improve EOL care for cancer patients nationwide.

Thesaurus Terms:
education evaluation /planning, neoplasm /cancer education, workshop
attitude, curriculum

Institution: CITY OF HOPE NATIONAL MEDICAL CENTER
DUARTE, CA 91010
Fiscal Year: 2001
Department:
Project Start: 01-JUL-2001
Project End: 31-MAR-2006
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

Beatrice W. Greenbaum — $100,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$100,000*

$100,000 New York Citizens' Committee on Health Care Decisions *The shaping of governmental and institutional policy: Train the Trainer program*

sometime between 1994 and 1997
http://www2.soros.org/death/governmental_policy.htm
Project: A model Train-the-Trainer program will be developed for health care educators, so that they can empower senior adults to advocate on their own behalf in the physician-patient relationship. American Health Decisions, the Older Women's League, and the lderhostel Network are among the national organizations who have expressed an interest in assisting with this project.

Karen Greene — $35,000 tracked thus far

Robert Wood Johnson Foundation *$35,000*

2003 48620 $35,000 American Association of Retired Persons (AARP) *Faith in Action (Legal Counsel for the Elderly)*

http://www.rwjf.org/programs/grantDetail.jsp?id=048620

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Joan Halifax — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

$50,000 Upaya — *To create the Institute for Contemplative Work With Dying People*

(Date unknown; grant listed at Soros website) Project: The creation of 'The Institute for Contemplative Work with Dying People," a center for spiritual inspiration, education, and continuing support for dying people, their families, and care givers as well as health care professionals, educators, and administrators.

Howard R. Hall, III, PhD, PsyD — $65,539 tracked thus far

Mayday Fund *$65,539*

1998 $65,539 University Hospitals Health System (Cleveland) — *Relaxation and other methods to manage headaches in children*

Children's Research Foundation of Cleveland:
Rainbow Babies and Children's Hospital
Cleveland, Ohio
$65,539 in support of developing training (seminars and a manual) to teach primary care physicians how to use relaxation and other methods to manage headaches in children, adolescents and adults.
Contact: Howard Hall, PhD., Psy.D.
E-mail: hrh@po.cwru.edu

Mary Beth Hamel, M.D., M.P.H. — $100,806 tracked thus far

Robert Wood Johnson Foundation *$100,806*

1995 $100,806 Beth Israel Deaconess Medical Center — *Program on the Care of Chronically Ill Hospitalized Adults (SUPPORT)*

1995 Annual Report. Says grant was to "Beth Israel Hospital Association, Boston, MA" for 1 year.

Laura C. Hanson, M.D. — $35,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$35,000*

1997 $35,000 University of North Carolina - Chapel Hill — *Faculty Scholar, 1997 (amount estimated); Improving Nursing Home Care for the Dying*

http://www2.soros.org/death/1997_fs.htm
Two academically affiliated skilled nursing facilities serving 180 residents, staffed by 168 nurses and nursing aides, and 10 physicians will be used to conduct a two-year study to describe the unique social characteristics and health care needs of dying nursing home residents and to develop and implement a nursing home resident-centered model of terminal care to these needs.

Mark J. Hanson, Ph.D., M.A.R. — $661,180 tracked thus far

Nathan Cummings Foundation, Inc. *$200,000*

2001 $50,000 Missoula Demonstration Project / Life's End Institute — *Support MDP ($ paid in 2001)*

reference: Cummings' Form 990-PF (I am guessing Mark Hanson was the contact)
To diversify and expand MDP's funding base.

2001 $100,000 Missoula Demonstration Project / Life's End Institute — *Support MDP ($ paid in 2001)*

reference: Cummings' Form 990-PF (I am guessing Mark Hanson was the contact)
"To research the experience of dying and the determinants of quality at life's end, and to demonstrate a community-based approach of excellent physical, psycho-social, and spiritual care to improve the quality of life for dying persons."

2002 $50,000 Missoula Demonstration Project / Life's End Institute — *Technical Assistance*

reference: Mark Hanson's cv

United States Department of Commerce - Technology Opportunities Program *$461,180*

2001 $461,180 Missoula Demonstration Project / Life's End Institute — *Choices Bank Program (Advance directives online database)*

http://ntiaotiant2.ntia.doc.gov/top/details.cfm?oeam=306001045

award number: 30-60-01045
start-end date: October 1, 2001 - March 31, 2005
total project cost: $923,520
federal share: $461,180
contact: Ms. Lillian Tuholske
address: 320 East Main Street
Missoula, MT 59802
phone: (406) 728-1613
e-mail: lilyt@lifes-end.org

Project Description

The Choices Bank project is a collaborative project among Missoula-area health care institutions to create an electronic repository for advance health care directives. The Bank will store advance directives, in the form of living wills and durable powers of attorney, on a secure website that will be accessible to authorized individuals. Portals to deposit advance directives from the public for the Choices Bank will be developed at 22 area health care institutions in Western Montana, which serve more than one-quarter of Montana's population. The Choices Bank will use off-the-shelf hardware and software to make the latest copy of a person's advance directive universally accessible to anyone with security clearance, from anywhere, at anytime. Health care providers are required by law to ask patients if they have advance directives, but are not required to assist patients in storing or retrieving the directives. The Choices Bank project will be a community-based effort to use technology to make advance directives accessible to family members and health care providers at the time they are needed.

Project Significance:

The Missoula Demonstration Project: The Quality of Life's End (MDP) is an organization dedicated to improving the quality of life for dying people and their families. A community task force organized by MDP identified access to advance directives as a significant barrier to honor health care choices at life's end. The task force has developed the concept of the Choices Bank to address this barrier. The project will significantly improve the current plight of seriously injured or ill people and their families. These families are thrust into stressful decision-making roles and conflict within families is prevalent when patients cannot communicate, and evidence of their wishes cannot be found. In a two-year study of the medical charts of deceased persons, MDP found that fewer than 50% of those who were reported to have advance directives actually had them in their charts. This is because people store their directives in locations such as law offices or banks, where they are inaccessible evenings, weekends, or holidays. The Choices Bank project, with its 22 portals located in familiar community health care facilities, will make it significantly easier for people to get their advance directives written and stored in a manner that will make them accessible when they are needed. Choices Bank will implement relatively inexpensive software and hardware; this will facilitate its replication by other communities who want to ensure that their citizens' wishes are honored at the time of their death.

Partners

The partners include the Missoula Demonstration Project, Missoula's two hospitals, Western Montana Clinic and its satellites, Missoula Aging Services, Partners in Home Care, Nightingale Nursing Services, and a faith community.

additional project resources:
Project Website

Project Narrative--PDF Version

Richard Heffner — $40,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$40,000*

$40,000 Educational Broadcasting Corporation *"The Open Mind"*

To fund 6 episodes of "The Open Mind", a weekly half-hour public television interview and discussion program to explore the issues of death and dying.

Frances C. Henderson, R.N., Ed.D. — $277,004 tracked thus far

Robert Wood Johnson Foundation *$277,004*

1997 30747 $277,004 Alcorn State University School of Nursing *Training for caregivers/companions for rural people in Mississippi (for 3 years). ; Lorman, MS*

Annual report shows $299,943 for grant 30747, but Grant Report shows $277,004.
http://www.rwjf.org/reports/grr/030747.htm

People in poor rural areas who have chronic illness or disabilities often have very limited or nonexistent access to professional home care services, and the other health and social services they need. Instead, they must rely on family members or friends to provide care and assistance. RWJF awarded this grant to ASU SON, located in southwest Mississippi, to train family members and other individuals who have primary responsibility for providing in-home care to homebound elderly, chronically ill, and physically disabled individuals. The resulting project, The Nursing Center In-Home Companion and Care Giver Project, was also to provide training to a cadre of individuals who could provide respite relief to primary in-home caregivers.

Martha Henderson, M.S.N., D.Min. — $35,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$35,000*

1997 $35,000 University of North Carolina - Chapel Hill *Faculty Scholar, 1997 (amount estimated); Improving Nursing Home Care for the Dying*

Two academically affiliated skilled nursing facilities serving 180 residents, staffed by 168 nurses and nursing aides, and 10 physicians will be used to conduct a two-year study to describe the unique social characteristics and health care needs of dying nursing home residents and to develop and implement a nursing home resident-centered model of terminal care to these needs.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Joanne M. Hilden, M.D. — $150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 Cleveland Clinic — *Faculty Scholar [amount is approximate]*

Pediatric end-of-life care research has shown that terminal symptoms are not adequately relieved as a child dies and that palliative care and/or hospice care providers are frequently not trained to serve pediatric patients. The Children's Oncology Group (COG) is the national clinical trials unit for children with cancer; 94% of children with cancer are treated in COG. This project will develop and evaluate a care model for terminally-ill children that facilitates and documents communication among the provider-parent-patient triad. The project will incorporate and evaluate interventions for both psychosocial and physical symptom control throughout illness until death.

Kristine Hillary, M.S.N., R.N.P. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

2004 $50,000 Kaiser Permanente — *Faculty Scholar, 2001: Transferring End-of-Life Knowledge in Clinical Culture (Grant amount is estimated.)*

Co-directed with Richard Brumley, MD. In 1997, the Kaiser Permanente TriCentral Service Area initiated an outpatient Palliative Care Program. Modeled after Kaiser's hospice program, the palliative care program offers pain management, comfort care, and curative therapies to patients who have an estimated prognosis of less than one year. In order to promote replication of this model at healthcare sites both within and outside of Kaiser Permanente, this project will develop a comprehensive tool kit and website to provide all the educational, program design, and technical-assistance materials needed to replicate the palliative care model.

Bruce P. Himelstein, M.D. — $150,000 tracked thus far

Kornfeld / PDIA (Soros) collaborative *$150,000*

2003 $150,000 Medical College of Wisconsin, Inc. — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

Jimmie C. Holland, M.D. — $640,021 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$640,021*

1984 $299,700 Memorial Sloan-Kettering — *Psychiatric and Pain Research Training in Cancer*

5T32CA009461-17 T32 (2000) SLOAN-KETTERING INSTITUTE FOR CANCER RES, NEW YORK, NY

1984 $340,321 Memorial Sloan-Kettering — *Psychiatric and Pain Research Training in Cancer*

5T32CA009461-18 T32 (2001) SLOAN-KETTERING INSTITUTE FOR CANCER RES, NEW YORK, NY

Halsted Holman, M.D.

$345,598 tracked thus far

Robert Wood Johnson Foundation *$345,598*

1998 31162 $345,598 Stanford University School of Medicine *Creation of a Chronic Disease Management System for Primary Care Practice*

http://www.rwjf.org/reports/grr/031162.htm
THE PROBLEM

The U.S. health care system evolved at a time when the predominant concern was treatment of acute conditions. Chronic disease, usually incurable, requires substantial management over time. Proper management requires knowledge of how the illness progresses. Because the patient is in the best position to observe that progression, he or she should play a role in choosing a course for managing the disease.

THE PROJECT

This project — originally called the Program for Management of Chronic Disease — aimed to develop and evaluate a disease management/patient self-care program for patients with three chronic health problems: chronic lung disease, chronic heart disease and diabetes. Researchers at the Stanford Medical Center, an academic hospital, planned to recruit 900 patients into a randomized controlled trial, half of whom would receive an intervention including intensive training in self-management techniques, monthly group consultations and support group meetings with providers, increased home care and a system allowing them to consult with medical personnel by phone in lieu of office visits. The researchers were forced to abandon this approach because they could not recruit enough participants.

After consultations with the RWJF program officer, the researchers designed a revised project — renamed "Health Partners" to remove any pejorative implications of the words "chronic disease" — that offered patients the opportunity to participate in one or both of the following options:

** Self-management education workshops: Groups of up to 20 patients met for two hours a week for six consecutive weeks and addressed such issues as the continuous use of medication, behavior change, pain control and learning to interpret changes in the disease.*
** Group visits with physicians: Seven groups of 8 to 15 patients met approximately monthly with their principle doctor. Group sessions explored issues raised by the patients, including treatment effects and side-effects, nutrition, loneliness, fear, anger, family dynamics, sexual function, physical handicaps, dependency, maintenance of a personal sense of worth and effect upon caregivers.*

The project enrolled 226 patients with one or more chronic diseases. The age range of the patients was 25 to 81, with a mean age of 59. The most common five diagnoses were heart or lung disease, diabetes, osteoarthritis and inflammatory rheumatic disease.

Susanne F. Homant, MBA

$450,000 tracked thus far

Robert Wood Johnson Foundation *$450,000*

2000 38452 $450,000 Michigan Hospice and Palliative Care Organization (MHPC *C-SP2: Community-State Partnerships -- Michigan*

(see also http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___324)

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years). The Michigan Partnership for the Advancement of End-of-Life Care,
funded by a $450,000 grant from the Robert Wood Johnson Foundation, will focus on improving education and training for health care providers, improving care for the terminally ill living in nursing facilities and developing a public information campaign. Gov. John Engler has revamped and recharged the Michigan Commission on End-of-Life Care, and has appointed Hospice of Michigan's President and CEO Dorothy Deremo and other hospice leaders to the new commission.

While these efforts will go a long way to help raise the standards of
care for dying people in our community, we as health care professionals often fail to take advantage of current opportunities to help our terminally ill patients. Hospice is woefully underutilized in our state.

Unfortunately, hospice care is often viewed as the last resort when
all hope is gone. Nothing could be further from the truth. Hospice provides comprehensive comfort care, including practical support, to terminally ill patients and their families during the patient's illness. Beyond expertise in pain and symptom management, hospice gives equal attention to emotional and spiritual issues of end-of-life care. Attention to these issues helps people make the transition from a viewpoint based on unrealistic expectations, to one that offers an opportunity to live out one's life in comfort and with dignity. This is what we all hope for when we think of ourselves and our own family members facing life's end.http://www.msms.org/peml/elc/featuredart.html

Susan S. Hopper, Ph.D. — $341,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$341,000*

2001 $341,000 United Hospital Fund — *An Evaluation of the Community Oriented Palliative Care Initiative*

This is a multi-faceted evaluation of the six palliative care (PC) networks in New York City, developed with start-up funding from the UHF, called the Community Oriented Palliative Care Initiative (COPCI). UHF provided seed money to six hospitals, through a competitive process, to establish a PC service delivery network composed of themselves plus long-term care providers within their catchment area. Each network was awarded $350,000 over two years to build PC networks. Begun in 2000, the networks represent a major breakthrough in the effort to move PC "upstream" with the goal of identifying patients (and their families) earlier in the course of what will ultimately be a fatal illness. The thought is that earlier identification of patients who would benefit from PC services should permit more sensitive planning of appropriate care.

The evaluation will seek to document and understand the process of creating, adapting, and sustaining a community-based PC network; such information is extremely useful for replication elsewhere. It will also undertake a comprehensive assessment of whether and how these networks' services made a meaningful difference to patients and their families.

Edward F. Howard, J.D. — $2,102,139 tracked thus far

Robert Wood Johnson Foundation *$1,780,739*

1996 29298 $188,804 Alliance for Health Reform — *Issue Briefings on Managed Care and Vulnerable Populations for Washington-Based Policymakers and the Media*

http://www.rwjf.org/reports/grr/029298s.htm
This grant from The Robert Wood Johnson Foundation supported a series of four forums on the topic of vulnerable populations and managed care, sponsored by the Alliance for Health Reform and presented between March 1997 and February 1998 in Washington, DC. The four seminars and related issue briefs were designed to give opinion leaders and policymakers in Washington timely information on the impact of managed care on four specific populations: children with special needs, dual eligibles (individuals enrolled in both Medicare and Medicaid), working-age adults with disabilities, and persons needing mental health services. Between 120 and 200 people attended each of these presentations. Presenters were policy experts, or were individuals involved in the direct delivery of services to these populations in locations across the country. More than 3,000 copies of each issue brief have been distributed to conference attendees as well as other interested parties through direct mailings and through the Alliance's web site, www.allhealth.org. The Alliance also included these issue briefs in the February 1998 version of its sourcebook for journalists, Cost, Access, Quality: Managed Care and the American Health System.
The four forums produced by this grant were:

** "Dual Eligibles in Both Medicare and Medicaid — Few in Number with Costly Complex Care Needs: How Can Managed Care Help?"*

** This presentation, held on March 10, 1997, drew 188 Congressional staff, journalists, and national organization leaders. The speakers were: Diane Rowland, Kaiser Family Foundation; Tom Hamilton, Wisconsin Department of Health and Family Services; Pam Parker, Minnesota Senior Health Options Program; Mark Meiners, University of Maryland Center on Aging; Jane Horvath, National Academy for State Health Policy; Kathleen Buto, Health Care Financing Administration; and Olivia Mastry, Center for Healthy Aging. Senator Bill Frist, vice-chairman of the Alliance, moderated the discussion. In conjunction with this presentation, the Alliance published an issue brief, "Managed Care & Vulnerable Americans: Medicare and Medicaid Dual Eligibles." "Delivering Care to Kids with Special Health Needs: Can States and Private Plans Improve Service, Save Money with Managed Care?"*

** This presentation, held on July 31, 1997, drew approximately 200 Congressional staff, journalists, and national organization leaders. The speakers were: Dr. Ruth Stein, Albert Einstein College of Medicine; Karen Squarrell, New Jersey Department of Human Services; Dr. Mary Tierney, Health Services for Children with Special Needs, Inc.; and Betsy Anderson, Family Voices. Senator Jay Rockefeller, chairman of the Alliance, moderated the panel and Senator Frist participated. In conjunction with this presentation, the Alliance published an issue brief, "Managed Care & Vulnerable Americans: Children with Special Health Care Needs." "Health Care for Working-Age Adults with Disabilities: Can States and Private Plans Improve Service, Save Money with Managed Care?"*

** This presentation, held on November 24, 1997, drew more than 120 Congressional staff, journalists, and national organization leaders. The speakers were: William Scanlon, General Accounting Office; Stephen Somers, Center for Health Care Strategies; Donald Parsons, Kaiser Permanente; and, Myrl Weinberg, National Health Council. Senator Rockefeller served as the moderator. In conjunction with this presentation, the Alliance published an issue brief, "Managed Care and Vulnerable Americans: Adults with Disabilities." "Managed Mental Health Care: Boon or Bane, It's a Fact."*

This presentation, held on February 4, 1998, drew some 180 Congressional staff, journalists, and national organization leaders. The speakers were Gail Robinson, Lewin Group; Clarke Ross, American Managed Behavioral Healthcare Association; Lu Crowder, Federal Express Corporation; and, Laura Lee Hall, National Alliance for the Mentally Ill. Edward Howard, executive vice president of the Alliance, moderated the discussion. In conjunction with this presentation, the Alliance published an issue brief, "Managed Care and Vulnerable Americans: Mental Health Care Coverage."

1998 34296 $44,920 Alliance for Health Reform — *Briefing on Confidentiality of Medical Information*

http://www.rwjf.org/reports/grr/034296s.htm
This grant from the Robert Wood Johnson Foundation (RWJF) funded the Alliance for Health Reform (Alliance) to hold two briefings on the topic of confidentiality of medical information, in April and December 1998. The briefings were designed to provide US congressional staff, members of the media, and other opinion leaders with a summary of

innovative uses of medical information to benefit patients, communities, and clinical research; with an analysis of actual and potential abuses of medical information; and with an overview of current proposals to balance the need for confidentiality and privacy with the need for access. A total of 519 people attended the two briefings. Panelists were academic researchers and business and association executives directly involved with medical records. The audiotapes of the briefings are available to all interested parties either directly or through the Alliance Web site, www.allhealth.org.
Sponsored Conferences

"Confidentiality of Medical Records: Striking a Balance," April 2, 1998, Washington, DC. Attended by 221 participants from congressional offices, news media, and health-related organizations.
Presentations

* *Janlori Goldman, Georgetown University Health Privacy Project*
* *Kenneth Wells, WellCorp, Houston, TX*
* *John Nielsen, Intermountain Health Care, Inc., Salt Lake City, UT*
* *Harry Guess, Merck Research Laboratories*
* *Jeffrey Crowley, National Association of People with AIDS*
* *Sen. Bill Frist, MD (R-TN), moderator*

"Health Care Confidentiality: You Can Hear the Clock Ticking," December 8, 1998, Washington, DC. Attended by 298 participants from congressional staffs, the media, and national organizations
Presentations

* *Janlori Goldman, Georgetown University Health Privacy Project*
* *Tim Westmoreland, Georgetown University Federal Legislative Clinic*
* *Karen Grant, Partners Health Plan, Boston, MA*
* *Harriet Pearson, IBM*
* *Heidi Wagner, Genentech, Inc.*
* *Sens. Jay Rockefeller (D-WV) and Bill Frist, MD (R-TN), moderators*

Print Coverage

"How Private Is Your Health?" in Investor's Business Daily, May 28, 1998.

"Alliance Holds Health Care Privacy Forum," in Washington Weekly Wire on Health Care News, December 11, 1998.

"Confidentiality: Debate Narrows But Sticking Points Are Major," in Medicine and Health, December 14, 1998.

2001 40202 $1,547,015 Alliance for Health Reform *Health Policy Briefings for 3 years*

2001 Annual Report:
The Alliance for Health Reform
Washington, DC
$1,547,015—Issue briefings on health policy for policymakers and journalists (for 3 years). ID#40202

Commonwealth Fund *$321,400*

1998 $145,000 Alliance for Health Reform *Health Policy Briefings, 1999*

http://www.cmwf.org/annreprt/1999/grants99.asp
Briefings and a retreat for congressional staff and journalists will provide timely information on current health policy issues, including access to care for the uninsured, quality of care in managed care, the future of Medicare, and the financing of academic health centers.

2002 $176,400 Alliance for Health Reform *2003 Health Policy Seminars and Congressional Staff Retreat*

http://www.cmwf.org/annreprt/2003/abt_grants05_comm.htm
In the coming year, the Alliance will conduct seven briefings and roundtables and host a retreat for senior congressional staff. Possible briefing and retreat topics include: Medicare reform, a Medicare prescription drug benefit, health care access for the uninsured, employer-based health coverage, tax credits for the purchase of insurance, health care inflation, and health care quality initiatives.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Halden Ashby Huskamp, Ph.D. — $74,454 tracked thus far

Robert Wood Johnson Foundation — *$74,454*

1999 36415 $74,454 Harvard Medical School — *Impact of Medicare Financing Methods on End-of-Life Care*

This grant from The Robert Wood Johnson Foundation (RWJF) funded Harvard Medical School's examination of how Medicare helps and/or hinders health care providers in giving quality end-of-life care. Researchers interviewed 54 clinicians and administrators at 35 end-of-life provider organizations (hospitals, hospice agencies, home health agencies, skilled-nursing facilities [SNFs], and medical groups) in five cities (Boston, MA; Cleveland, OH; Greenville, SC; Miami, FL; and Seattle, WA) and one rural area (the Fargo, ND/Moorhead, MN, area). Key findings were (1) the hospice per diem (payment per day) does not reflect current treatment practice; it is too low for high-cost patients and results in access problems for patients in some markets; (2) some interviewees are concerned about quality of patient care due to reimbursement limitations on hospitals and hospices mandated under the Balanced Budget Act of 1997; (3) SNFs are under reimbursed for certain secondary services (pharmaceuticals, infusion [intravenous] therapy, respiratory therapy, lab tests, imaging services, and patient transportation), creating an incentive at SNFs to avoid patients who need many of these services; and (4) the reimbursement rate for rural patients may be too low, considering rural travel costs (including staff travel time).

The study's recommendations included the following: (1) pay hospices extra — above and beyond the standard per diem — for extremely high-cost hospice stays; (2) review hospice rates, focusing on how well current hospice per diems account for changes in treatment practices since the Medicare hospice benefit was implemented in 1982; (3) monitor the implementation of the 1997 Medicare home health payment system's impact on severely ill and dying patients; and (4) explore differences in travel costs among staff serving hospice patients, and adjust per diems accordingly. Researchers briefed congressional staff and end-of-life care provider organizations on the study's findings and recommendations in July 2000. They also presented the findings at the 2000 American Academy of Hospice and Palliative Medicine Conference and the 2000 First International Geriatric Palliative Care Congress. A May/June 2001 article appearing in Health Affairs summarizes project findings and recommendations.

Shirley S. Hwang, R.N., AOCN, M.S. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

2000 $50,000 University of Medicine and Dentistry of New Jersey, New J — *Faculty Scholar, 2000-2002: Study of Outcome Measurement in Terminal Cancer Patients (Grant amount is estimated.)*

(Grant amount is estimated.) The development of an evidence-based system of palliative care medicine is of great importance to the field. This palliative care system relies upon the availability of outcomes, which can be assessed and compared. This project will contribute to the development and testing of outcomes for symptom management in palliative care of patients with advanced cancer.

Carol A. Irvine — $450,000 tracked thus far

Robert Wood Johnson Foundation — *$450,000*

1998 35627 $450,000 Albert Einstein Healthcare Network (Jefferson Health Syst — *Building Health Systems for People with Chronic Illnesses*

Philadelphia, PA: (3 years).

http://www.rwjf.org/reports/grr/036615.htm
Carol A. Irvine
Demonstration of an Integrated Care Program for Chronically Ill Residents in Personal Care Homes, Grant ID# 035627
Albert Einstein Healthcare Network
Jefferson Health System
Philadelphia, PA

Stephen M. Jamison, Ph.D. — $30,000 tracked thus far

Haas Fund — *$30,000*

1999 $30,000 Bay Area Network of Ethics Committees (BANEC) — *For development of new approaches to the issue of medical futility (Note: with Gerbode; Date estimated)*

http://www.sfms.org/communty.htm
The SFMS CSF is the recipient of a $30,000 grant from the Walter and Elise Haas Fund and the Wallace Alexander Gerbode Foundation for the development of new approaches to the issue of medical futility. Under the grant, the SFMS-based Bay Area Network of Ethics Committees (BANEC) will convene representatives from hospital ethics committees to draft guidelines for review by the broader community and eventual publication and professional education. The procedural model for this project is the BANEC-developed consensus guidelines on physician-hastened death, published in June in the Western Journal of Medicine and widely discussed in the aftermath of the United States Supreme Court's decision on this topic last summer.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Paul S. Jellinek, Ph.D. — $467,150 tracked thus far

Robert Wood Johnson Foundation *$467,150*

2003 48809 $467,150 Health Policy Associates, Inc. — *Faith in Action: Producing a book manuscript on the Faith in Action program*

http://www.rwjf.org/programs/grantDetail.jsp?id=048809

Sandra H. Johnson, J.D., LL.M. — $340,044 tracked thus far

Mayday Fund *$340,044*

1995 American Society of Law, Medicine, and Ethics — *Legal Constraints on Access to Effective Pain Relief [amt of grant is unknown at present]*

With Nancy Dubler and Robert Levine.
http://www.painandthelaw.org/aslme_content/26-4c/26.4d.html

1997 $74,400 American Society of Law, Medicine, and Ethics — *Legal Constraints on Access to Effective Pain Relief*

With Nancy Dubler and Robert Levine. See http://www.painandthelaw.org/aslme_content/26-4c/26.4d.html

Reference to amount of grant is at http://www.slu.edu/publications/qc/v4-2/univ_grants.shtml
Sandra Johnson (School of Law) has been awarded a second-year grant from the American Society of Law, Medicine & Ethics by the Mayday Fund for $74,400. The project involves legal constraints on access to effective pain relief.

2002 $119,120 American Society of Law, Medicine, and Ethics — *Project on Pain Medicine and Emergency Medicine*

http://www.painandhealth.org/mayday/previous-grants.html
The American Society for Law, Medicine and Ethics
Boston, MA,
Sandra Johnson, JD, LLM and Benjamin Moulton, JD, MPH
A grant of $146,524 representing the second and final payment in the total grant of $265,644 in support of the "Project on Pain Medicine and Emergency Medicine." Among the goals of the project are to support research on the legal and ethical aspects of pain management in the emergency department; to provide educational opportunities for physicians and nurses in emergency care; and to raise public awareness of the issues involved, especially on a policy level.
Web Site: http://www.painandthelaw.org/

2003 $146,524 American Society of Law, Medicine, and Ethics — *Pain Medicine and Emergency Medicine*

http://www.painandhealth.org/mayday/previous-grants.html

Kornfeld Foundation (a right-to-die organization)

http://www.slu.edu/centers/chce/johnson.html mentions she is a Kornfeld grant recipient.

Amber B. Jones, M.Ed — $290,038 tracked thus far

Robert Wood Johnson Foundation *$290,038*

42986 $154,496 Amber Jones Consulting — *CAPC - Consulting services for the Center to Advance Palliative Care (1 year)*

42330 $135,542 Amber Jones Consulting — *CAPC - Consulting services for the Center to Advance Palliative Care (1 year)*

David E. Joranson, M.S.S.W. — $2,357,720 tracked thus far

Robert Wood Johnson Foundation *$2,057,720*

1997 32703 $78,830 Federation of State Medical Boards — *Development of guidelines for the use of controlled substances in treating pain (for 5 months).; Euless, TX*

Grar *http://articles.findarticles.com/p/articles/mi_m0DPE/is_1_31/ai_101939755/print*

Despite advances in medical knowledge regarding pain management, pain continues to be significantly undertreated in the United States. There are many drug and nondrug treatments, but the use of controlled substances, particularly the opioid analgesics, is universally accepted for the treatment of pain from cancer. Although opioid analgesics are safe and effective in treating chronic pain, there is continued research and discussion about patient selection and long-term effects. A number of barriers in the health care and drug regulatory systems account for the gap between what is known about pain management and what is practiced. (1) Among the barriers are physicians' fears of being disciplined by state regulatory boards for inappropriate prescribing. (2)

State medical boards are in a unique position not only to address physicians' concerns about being investigated, but also to encourage pain management. Prior to 1989, a few state medical boards had policies relating to controlled substances or pain. Subsequently, state medical boards began adopting policies regarding the prescribing of opioids for the treatment of pain; many of these specifically addressed physicians' fear of regulatory scrutiny. Since 1989, forty-one state medical boards have adopted such policies, including regulations, guidelines, and policy statements (see Figure 1). "Regulations" are official rules issued by the medical board pursuant to legislative authority; regulations have the force of law and establish the boundaries of acceptable conduct for licensed physicians. "Guidelines" are official statements that define the parameters of medical practice as viewed by the board. "Policy statements" are position statements that address matters of concern to the board and may clarify the board's expectations. While guidelines and policy statements may not have binding legal force, they do communicate the board's attitude toward certain medical practices.

Improving state medical board policies: influence of a model
Journal of Law, Medicine & Ethics, Spring, 2003 by Aaron M. Gilson, David E. Joranson, Martha A. Maurer
Continued from page 5.

ACKNOWLEDGMENT

The research described in this article was supported by a grant from the Robert Wood Johnson Foundation.
David E. Joranson, MSSW, is Director of the Pain & Policy Studies Group in the Comprehensive Cancer Center at the University of Wisconsin-Madison. Mr. Joranson received his degree from the University of Wisconsin in Madison.

Martha A. Maurer is a policy analyst at the Pain & Policy Studies Group in the Comprehensive Cancer Center at the University of Wisconsin-Madison. Ms. Maurer received a B.S. from the University of Wisconsin in Madison.

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1997 31461 $693,407 University of Wisconsin - Madison Medical School — *Evaluation about ways state regulatory practices affect clinical pain management (for 2 years).; Madison, WI*

[This was from RWJF annual report. It was Med. Coll of Wisconsin; therefore probably not Joranson
This is the grant that got the NC Med/Nursing/Pharmacy boards to issue a Joint Statement -- Anne Dellinger participated]
Annual report must have been incorrect. This was Univ. of Wisc, and it was Joranson. See
http://www.rwjf.org/reports/grr/035950.htm
"[Grant #35950] from the RWJF provided support for a study of state law and regulatory policies that may promote or impede the use of morphine and other narcotics for pain relief. Researchers at the Pain & Policy Studies Group at Wisconsin conducted the study. This grant was awarded under RWJF's Targeted End-of-Life Projects Initiative, which supports projects to improve care at the end of life. Under . . . grant [# 031461], the same researchers worked with state medical, nursing, and pharmacy boards to help them make more informed decisions with regard to physician practice in the treatment of pain, and collected data on pain-related policy and practice.

1999 35950 $87,033 University of Wisconsin - Madison Medical School — *Pain & Policy Studies Group*

Researchers at the University of Wisconsin-Madison Medical School conducted a study of state law and regulatory policies that may promote or impede the use of morphine and other controlled substances for pain relief. A grant from The Robert Wood Johnson Foundation (RWJF) supported the study. Under the grant, researchers at the Pain & Policy Studies Group at Wisconsin identified law and policies in 16 states and the District of Columbia that could affect pain management. Among the key conclusions they present in a report entitled A Guide to Evaluation: Achieving Balance in State Pain Policy, Part I:

** "Balance" should be the central principle of policies related to pain relief.*
** Government policies to prevent misuse or recreational use of controlled substances should not interfere with the use of these agents for the relief of pain. Federal and international policies show a balanced approach toward controlled substances.*
** For example, federal law governing controlled substances specifically states that many of the drugs "are necessary to maintain public health." In some states examined, policies are in place to promote use of controlled substances in pain control.*

** For example, the North Carolina state medical board assures physicians that they need not fear "reprisals" for "appropriately prescribing â€¦ even large amounts of controlled substances indefinitely for chronic, non-malignant pain." Most states examined by the investigators have policies that are likely to interfere with pain management and patient care.*

For example, California medical board regulations suggest that controlled substances be used only as a last resort, "where efforts to remove the cause of pain or treat it with other modalities have failed."

Under a follow-up RWJF grant (ID# 036509), the researchers are expanding the focus to all states and provide technical assistance to RWJF grantees and other organizations working on pain management or End-of-Life initiatives.

1999 36509 $998,000 University of Wisconsin - Madison Medical School *Pain & Policy Studies Group (see also #35950)*

http://www.rwjf.org/reports/grr/035950.htm
In a follow-up grant (ID# 036509), the researchers are conducting a state-by-state assessment of laws and regulations governing the treatment of pain with controlled substances. They are also providing technical assistance to RWJF grantees and other organizations working on pain management and end-of-life initiatives.

2002 43412 $200,450 University of Wisconsin - Madison Medical School *National profile of pain relief and public policy*

[I am just guessing that Joranson was project director for this one]
To support monitoring and analysis of state and federal pain-related policies. See also #31461, #35950, #36509

Open Society Institute / Project on Death in America (Soros Foundation) *$300,000*

$225,000 University of Wisconsin - Madison Medical School *Evaluating Public Pain Policy*

http://www2.soros.org/death/report/pdia98-00report_9.pdf
The Pain & Policy Studies Group of the university's Comprehensive Cancer Center works to improve care by evaluating the extent to which the regulation, or perception of regulation, of drugs and professional practice affects pain management. It identifies and addresses the barriers to medical use of narcotic drugs, which are essential to chronic pain management and palliative care. This grant will increase the group's capacity to meet the needs of the growing number of individuals and organizations advocating for improved public policy relating to pain management.

2001 $75,000 University of Wisconsin - Madison Medical School *PDIA in Eastern Europe*

http://www2.soros.org/death/ee_2001.shtml
This grant will support a three-day regional workshop to address the current national health care policies and drug regulations in six countries in Eastern Europe (Bulgaria, Croatia, Hungary, Lithuania, Poland, Romania) and to recommend the changes necessary to guarantee the availability and reimbursement of palliative care services including medications needed to relieve pain and suffering for terminally ill patients. The meeting will take place in Budapest on February 25-27, 2002.

Lauris Christopher Kaldjian, M.D., M.Div. **$300,000** tracked thus far

Robert Wood Johnson Foundation *$300,000*

2002 45446 $300,000 University of Iowa *Impact of foundational beliefs on reporting medical errors: A cross-sectional and longitudinal study*

http: *http://www.lifenews.com/bio606.html*

"Study: Doctors Will Prescribe Pain Drugs Even if They Hasten Death"
by Maria Vitale Gallagher LifeNews.com Staff Writer December 10, 2004
http://www.lifenews.com/bio606.html

Iowa City, IA (LifeNews.com) -- Two new studies indicate doctors are willing to administer drugs to ease pain -- even if it means hastening the dying process.

The studies, conducted at the University of Iowa and at Yale, involve a process known as terminal sedation, in which sedatives are used to control a patient's symptoms even if they result in a loss of consciousness.

In fact, most of the doctors in the studies saw a clear difference between assisted suicide and terminal sedation. But other medical experts worry terminal sedation could be a "creative" approach to the controversy surrounding assisted suicide.

"End-of-life care involves many treatment decisions, some of which are focused on extreme pain and other symptoms that are very challenging to control," said Lauris Kaldjian, M.D., an assistant professor of internal medicine who conducted both studies.

"We studied the specific ethical issues of treatments that control symptoms versus interventions that intend to cause or hasten death," Kaldjian added.

The first study, which involved a survey of internal medicine doctors, appeared in the October issue of the Journal of Medical Ethics. The other study, focusing on doctors in training, appeared in the September/October issue of the American Journal of Hospice and Palliative Medicine.

Seventy-eight percent of the internal medicine physicians surveyed supported the use of terminal sedation, while 66 percent of the doctors in training, or residents, agreed with the practice.

However, a surprising one in three doctors and residents supported physician-assisted suicide, which is legal only in the state of Oregon.

The study of internal medicine doctors involved 677 members of the American College of Physicians in Connecticut. The study of residents involved 236 doctors in training in three internal medicine residency programs in Connecticut as well.

Participants in each study responded anonymously.

The studies showed that doctors were more likely to support terminal sedation but oppose assisted suicide if they had had significant experience with terminally ill patients or if they frequently attend religious services.

In fact, 68 percent of doctors who had cared for 50 or more terminally ill patients in the past year were against assisted suicide.

"It was clear from our statistical analysis that those who had cared for a greater number of terminally patients in the preceding year were more opposed to assisted suicide and also

more supportive of terminal sedation," Kaldjian said.

"There seemed to be both a greater willingness to be rigorous in end-of-life care but also less willingness to cross that line into actually intending death," the researcher added.

A significant 76 percent of those doctors who attended weekly religious services oppose assisted suicide.

"We found that the more frequently respondents attended religious services, there was a trend toward less support for assisted suicide but more support for terminal sedation," Kaldjian said. "To my knowledge, this is the first study to show such a stepwise trend."

Kaldjian added, "Medical ethics involve not just a patient's autonomy but also a physician's integrity. On matters of such importance as end-of-life care, physicians' integrity must be respected. Patients should not see themselves as mere consumers of health care but as partners in a decision-making process with physicians, who are not mere robots."

But some medical professionals say terminal sedation itself can be ethically problematic. They note that, in some cases, such sedation is accomplished, in part, by withholding food and water -- the nutrition and hydration necessary for survival.

In an article entitled, "Sedated to Death?" nurse Nancy Valko stated, "As a former hospice nurse and now as an ICU nurse caring for some patients who turn out to be dying, I support the appropriate use of pain and sedating medications as ethical comfort care. However, even in circumstances where such medications are necessary, I have never seen a case where a patient 'needed' to be made permanently unconscious."

Valko, a spokeswoman for Nurses for Life, a national pro-life nurses groups, added, "The euthanasia movement is nothing if not creative and persistent. Many people now mistakenly believe that tolerating just a little bit of deliberate death -- with safeguards, of course -- will give them control at the end of their own lives."

"But as the 'culture of death' keeps seducing even well-meaning patients, families and medical professionals into making death decisions based on fear of suffering or diminished quality of life rather than following the traditional principles of not causing or hastening death, ultimately we are all at risk of being 'compassionately' rationalized to death," Valko wrote.

Karen Orloff Kaplan, MPH, ScD — $19,291,127 tracked thus far

Robert Wood Johnson Foundation — *$17,260,202*

1998	34373	$231,920	Partnership for Caring	*Improving the performance of healthcare agents for dying people (grant to Choice in Dying)*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___187
Health care agents, also known as proxies or surrogates, can make the dying process easier for patients, their loved ones, and their health professionals. Fulfilling the role of decision maker for someone who is not able to express his or her own desires can be a complex and emotionally wrenching task. This project will: (1) identify and describe the full scope of issues involved in the selection of a health care surrogate, agreeing to be appointed as a surrogate, and fulfilling the responsibilities of a surrogate; (2) employ and evaluate interventions with people selecting a surrogate, agreeing to be a surrogate, and performing as surrogates; and (3) broadly disseminate information about the project. This project will capture available information about the needs and concerns of those involved in health care surrogacy from a variety of perspectives.

2000	38720	$577,830	Partnership for Caring	*Targeted End of Life Projects*

From Annual Report; no description

2000	39049	$156,432	Partnership for Caring	*Last Acts strategic planning (1 month).*

From Annual Repor: Last Acts strategic planning.

2000	40892	$300,000	Partnership for Caring	*Targeted End of Life Projects*

From Annual Report; no description

2000	39432	$1,009,455	Partnership for Caring	*Technical assistance and direction for the Last Acts program*
2001	42652	$638,035	Partnership for Caring	*Last Acts continuing education for nurses and creation of a story bank and interactive Web site*
2001		$76,000	Partnership for Caring	*Planning for Rallying Points*

NOTE: Kaplan/PfC are not listed on the Last Acts report: this might have been to someone else?
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___681
Three hundred community coalitions were formed as a result of outreach for the Bill Moyers series, "On Our Own Terms." This project provides support for the ongoing work of coalitions around the country to engage their communities in efforts to improve end-of-life care locally. Some of the activities subsumed under this project would be carried out in anticipation of a larger initiative in fall 2001 to support these coalitions; other activities will be valuable to coalitions whether or not the major grant is approved. Funds from this grant would create a Rallying Points Web site, that would contain: (1) a searchable directory of coalitions and people; (2) information on turn-key programs and useful resources; (3) the Community Tool Box Center to aid coalition development; and (4) a peer-to-peer networking capability. Additional funds for program development of the anticipated larger initiative are being accessed through the Team Consultant Fund.

2001	40340	$1,133,039	Partnership for Caring	*Technical assistance and direction for the Last Acts program*
2001	42603	$12,000,000	Partnership for Caring	*Rallying Points: Support for Community Coalitions in End-of-Life Care*

http://web.archive.org/web/20030315040820/http://www.rwjf.org/programs/grantDetail.jsp?id=042603

2002	43797	$1,137,491	Partnership for Caring	*Technical assistance and direction for the Last Acts program*

Open Society Institute / Project on Death in America (Soros Foundation) *$94,977*

1994	$35,000	Choice in Dying -- see "Partnership for Caring"	*Support for Choice in Dying (Date is estimated)*

Support is provided to the organization's on-going efforts in public and professional education and counseling for the preparation and use of advance directives. (sometime between 1994 and 2000)

2000	$59,977	Partnership for Caring	*No Pain, All Gain--See PfC's "VOICES" Fall, 2001: "There a re more than 350 coalitions in 46 states in key positions to help get out the N o Pain, All Gain! messages and to work with legislators in their communities."*

To support PIC's [sic] national consumer-based, education and legislative pain initiative "No Pain, All Gain" and to create and disseminate an educational kit for state legislators and their staff that include nonpartisan analyses of the pain crisis in this country, the results of research about pain management, a description of the type of constituent-based educational efforts legislators can implement to educate their constituents about good pain management and a phone number which they can use for technical assistance in implementing this educational outreach.

Nathan Cummings Foundation, Inc. *$260,000*

1996	$50,000	Choice in Dying -- see "Partnership for Caring"	*Whose life is it anyway*

WHOSE Death Is It, Anyway?, a film about end-of-life decisions, broadcast nationally over PBS, Choice in Dying, New York, NY

1997	$50,000	Choice in Dying -- see "Partnership for Caring"	*For Choice in Dying*

For a national colloquium to improve the ability of clergy to meet the end-of-life needs of their congregants.

1997	$10,000	Choice in Dying -- see "Partnership for Caring"	*For Choice in Dying*

For a communications strategy responding to the Supreme Court's decision on physician-assisted suicide.

2000	$150,000	Partnership for Caring	*Changing the Course of the Caregiving Crisis*

To build an informed consumer voice at the national and state levels in support of changes in public and private policies that are needed to achieve improved end-of-life care.

Fan Fox and Leslie R. Samuels Foundation *$1,201,000*

1999	$10,000	Choice in Dying -- see "Partnership for Caring"	*For Choice in Dying*

Using Wit to Sensitize Medical Professionals to People's Perceptions and Concerns About End-of-Life Care.

2000	$290,000	Partnership for Caring	*New Activities and Additional Effort for Choice in Dying's Coordinating Center for Healthcare Agency and Palliative Care Initiatives*

In 1998 the Foundation initiated a new method of selection and management of grants with an award to Choice in Dying (which has since changed its name to Partnership for Caring or PFC) to operate a Coordinating Center for a program initiative to strengthen the process of health care agency (HCA1). This request is for funding adds several new activities to those originally projected (including the development of a second program initiative in palliative care for those with severe chronic illness, an interventional symposium, begin a 2nd cycle of funding in the original topic area (HCA2), etc).

2001	$200,000	Partnership for Caring	*Strengthening Health Care Agency (HCA1) Leadership Summit Conference*

PfC, with sponsorship from the Foundation, held a Summit on Health Care Agency (the Summit) in Princeton, New Jersey on January 25-27, 2001. Seventy invited experts in end-of-life care and caregiving participated. The goal of the Summit was to develop a blueprint for strengthening the process of health care agency that contained recommendations for

research, demonstrations and other initiatives in both policy and practice arenas.

2001 $321,000 Partnership for Caring — *Grant Coordinating Center: Partnership for Caring*

PfC operates a Coordinating Center for two program initiatives for the Samuels Foundation: 1) to strengthen the process of health care agency; and 2) to enhance palliative care for those with severe chronic illness. This grant extends the funding for a second round of grant making in each program area.

2002 $380,000 Partnership for Caring — *Coordinating Center: Continued Management of the Healthcare Agency and Palliative Care Initiatives*

PfC operates a Coordinating Center for two program initiatives for the Samuels Foundation: 1) to strengthen the process of healthcare agency; and 2) to enhance palliative care for those with severe chronic illness. This grant extends the funding for a second round of grant making in each program area.

Greenwall Foundation *$474,948*

1994 $349,609 Choice in Dying -- see "Partnership for Caring" — *Integrating Education about Care of the Dying into Existing Medical School Programs (over 5 years)*

Project support—Integrating Education about Care of the Dying into Existing Medical School Programs (over five years)

1995 $50,000 Choice in Dying -- see "Partnership for Caring" — *Integrating Education about Care of the Dying into Existing Medical School*

http://www.greenwall.org/exlist91-01.htm
CHOICE IN DYING, INC
Supplementary project support—Evaluation Component of Integrating Education about Care of the Dying into Existing Medical School Programs (over four years)
(see also RWJF grant report http://www.rwjf.org/reports/grr/029360s.htm "Initiatives of interest elsewhere include the Greenwall Foundation's "Integrating Education about Care of the Dying into Existing Medical School Programs" and the Faculty Scholars program of the Open Society Institute's Project on Death in America. The Faculty Scholars initiative supports individuals working to elevate the importance of caring for persons at the end of life in their respective institutions."

1997 $75,339 Choice in Dying -- see "Partnership for Caring" — *Integrating Education about Care of the Dying into Existing Medical School Programs [Integrate palliative care training in medical schools (DATE is estimated; info from 1997 Form 990)]*

(date is estimated. Info is from their 1997 Form 990, page 17) This is a five-year project involving 12 medical schools.

Timothy J. Keay, M.D., M.A.-Th., CAQGM, FAAFP — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1996 $50,000 University of Maryland — *Faculty Scholar, 1996-97 (Grant amount is estimated.)*

Development of a model quality improvement plan with a learner-centered educational program for nursing home physicians that improves the quality of end-of-life nursing home care.

Linda King, M.D. — $150,000 tracked thus far

Kornfeld / PDIA (Soros) collaborative *$150,000*

2003 $150,000 University of Pittsburgh — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

Linda Kinsinger, M.D., M.P.H. — $172,500 tracked thus far

Commonwealth Fund *$172,500*

2000 $172,500 University of North Carolina - Chapel Hill — *Developing Physician Leadership to Reduce Health Disparities*

Over the next five years, the School of Public Health at the University of North Carolina at Chapel Hill (UNC) plans to develop an initiative within its master's program in public health to attract minority physicians and medical students to the health policy and public health fields. The school also intends to provide all of its students with the means to address racial and ethnic disparities in health. This two-year project will help the school build capacity to reach these goals. Activities will include recruitment of a new faculty member with expertise in minority health issues, design of curriculum, and development of collaborations with historically black colleges and universities to encourage faculty and students to participate in the program.

William A. Knaus, M.D. — $752,783 tracked thus far

Robert Wood Johnson Foundation — *$752,783*

1995	27234	$752,783	University of Virginia	*Program on the Care of Chronically Ill Hospitalized Adults (SUPPORT)*

1995 Annual Report: Technical assistance and direction for the Program on the Care of Critically Ill Hospitalized Adults (14 months).
Also: http://www.rwjf.org/reports/anthologies/1997chap8.htm

Barbara Ann Koenig, Ph.D. — $4,141,726 tracked thus far

Robert Wood Johnson Foundation — *$69,727*

1996	$26,365	Stanford University	*Culture, End-of-Life Care, and Bioethics: What Differences Make A Difference?*
1998	$43,362	Stanford University	*Speaking About Death: Culture, Language, and Communication in End-of-Life Care.*

"Last Acts Campaign," $43,362 (Principal Investigator)

Open Society Institute / Project on Death in America (Soros Foundation) — *$209,987*

1995	$149,987	Stanford University	*Dying in an African-American Community: An Ethnographic Study of Death Across the Life Cycle.*

(Guessing that Stanford was recipient organization.)

1999	$60,000	Stanford University	*Improving End-of-Life Care for the Underserved through Targeted Continuing Education for African American Physicians*

PDIA Faculty Scholars Program; date sometime between 1999-2001. Amount of grant is estimated. Co-investigator, with LaVera Crawley. Among African Americans, attitudes towards end-of-life care are influenced by a unique sociohistoric perspective.
This project builds on the team's ongoing ethnographic research on death and dying in an African American community in the San Francisco Bay Area. The information from that study revealed specific cases where effective end-of-life care was hindered by language and cultural barriers, racial bias, and mistrust. Such cases highlight the need to provide culturally competent care, and African American providers may be more favorably situated to bring that care to their African American patients. By developing a series of continuing education programs on end-of-life care aimed specifically at African American physicians, this project will increase the network of physicians capable of providing comprehensive end-of-life care to traditionally underserved communities.

National Institutes of Health - Department of Clinical Bioethics — *$1,325,446*

1992	$447,547	University of California - San Francisco	*Cultural Pluralism and Ethical Decision-Making.*

National Institutes of Health/NINR, R01 NR 029060, $447,547. (with Anne J. Davis, Ph.D.; Project Director and Co-Principal Investigator through 6/94, then Principal Investigator; Score 105, Percentile 0.9%)

2000	$127,899	Stanford University	*The Ethics of Identifying Race in the New Genetics.*

NIH/NRSA, 5F32 HG00221-02, $127,899. (Research Mentor)

2002	$750,000	Stanford University	*Genetics of Nicotine Addiction-Examining Ethics and Policy.*

(Guessing that Stanford was recipient organization.)

Greenwall Foundation — *$508,064*

1993	$33,064	Stanford University	*Cultural Diversity and Bioethics in North America: A Review and Critique of Current Issues.*

(Guessing that Stanford was recipient organization.)

1994	$200,000	Stanford University	*Stanford Center for Biomedical Ethics "Core Support"*
1999	$100,000	Stanford University	*Filmmaker-in-Residence Program.*
2001	$150,000	Stanford University	*Ethical Challenges in Neuroimaging*

(Guessing that Stanford was recipient organization.)
Co-investigator

2002	$25,000	Stanford University	*Observing Death, Examining Bioethics.*

(Guessing that Stanford was recipient organization.)

Kaiser Family Foundation — *$33,970*

1997	$33,970	Stanford University	*Social/Ethical Impact of Presymptomatic Testing for BRCA1/2.*

US DHHS - Agency for Healthcare Research and Quality (AHRQ) — *$234,527*

2000	$234,527	Stanford University	*Promoting Effective Communications and Decision Making for Diverse Populations.*

NIH/AHRQ, 2370SC (AHRQ 1PO1 HS10856), $234,527. (Stanford Site Principal Investigator, E. Washington, UCSF, Principal Investigator)

State of California *$100,005*

1995	$100,005	Stanford University	*Cultural Diversity and Ethical Decisions in AIDS Care for Women.*

(Guessing that Stanford was recipient organization.)

SmithKline Beecham Corporation *$950,000*

1995	$950,000	Stanford University	*Stanford Program in Genomics, Ethics and Society.*

(Co-Director with Thomas Raffin, M.D., Henry Greely J.D.)

Beckman Foundation *$70,000*

1995	$70,000	Stanford University	*Stanford Program in Genomics, Ethics and Society.*

(Co-Director with Thomas Raffin, M.D., Henry Greely J.D.)

Haas Fund *$500,000*

1997	$500,000	Stanford University	*for Stanford University Biomedical Ethics Center Research, $500,000. (Co-Principal Investigator)*

United States Department of Energy *$140,000*

1999	$140,000	Stanford University	*Dilemmas in Commercializing Human Genome and Biotechnology Products: Developing a Case-based Business Ethics Curriculum for Industry.*

(Guessing that Stanford was recipient organization.)
Office of Biological and Environmental Research, Department of Energy, $140,000. (Principal Investigator)

Harold G. Koenig, R.N, M.D., M.H.Sc. — $1,636,834 tracked thus far

National Institutes of Health - National Institute of Mental Health (NIMH) *$1,636,834*

1996	$138,148	Duke University - Medical School	*DEPRESSIVE DISORDER IN HOSPITALIZED MEDICALLY ILL ELDERS*
1997	$138,268	Duke University - Medical School	*DEPRESSIVE DISORDER IN HOSPITALIZED MEDICALLY ILL ELDERS*
1999	$356,794	Duke University - Medical School	*PREDICTING DEPRESSION OUTCOMES IN MEDICALLY ILL ELDERS*
2000	$318,093	Duke University - Medical School	*PREDICTING DEPRESSION OUTCOMES IN MEDICALLY ILL ELDERS*
2001	$325,725	Duke University - Medical School	*PREDICTING DEPRESSION OUTCOMES IN MEDICALLY ILL ELDERS*
2002	$270,036	Duke University - Medical School	*PREDICTING DEPRESSION OUTCOMES IN MEDICALLY ILL ELDERS*
2003	$89,770	Duke University - Medical School	*PREDICTING DEPRESSION OUTCOMES IN MEDICALLY ILL ELDERS*

David R. Kuhl, M.D. — $140,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1996	$140,000	University of British Columbia (Canada)	*Faculty Scholar, 1996-97 (funding amount is estimated)*

Development of programs to enhance patient care and physician awareness, based on the results of a study of the emotional, psychological and spiritual issues surrounding the suffering experienced by people with terminal illnesses.

Jerome E. Kurent, M.D., MPH — $283,474 tracked thus far

Robert Wood Johnson Foundation *$163,474*

1998	35475	$163,474	Medical University of South Carolina	*The Enterprise Community: Improving End Of Life Care for Urban African Americans [Annual Report: Self-Determination for Persons with Developmental Disabilities]*

see http://www.lastacts.org/media/carol1.htm for connection to Byock's project.
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___114
This collaborative project by the Medical University of South Carolina's Program of Bioethics and the Center for the Study of Aging, with Charleston's Enterprise Community is investigating attitudes, beliefs and needs regarding end-of-life care among the area's African-American residents. University researchers are studying how people in the African-American community approach death, why they decline hospice care, and what are their preferences for end-of-life care. Area residents will participate in focus groups and structured interviews to provide information for the study.

See also: http://www.mywhatever.com/cifwriter/library/41/pe185.html

Open Society Institute / Project on Death in America (Soros Foundation) *$120,000*

2000	$120,000	Medical University of South Carolina	*Faculty Scholar: The development of an Institute for*

Community and Professional Education in End-of-Life Care.

NOTE: Amount of award is estimated. Faculty Scholar, 2000
http://www2.soros.org/death/2000_fs.htm
There is an explicit need for education on end-of-life care within the culturally diverse state of South Carolina. This project seeks to develop and organize an easily accessible comprehensive educational resource in end-of-life care for members of the community and healthcare professionals. Key content areas will include pain management, utilization of advanced directives in DNR, spirituality in end-of-life care, and the role of the faith community in achieving a "good death."

Jean S. Kutner, M.D. — $1,401,395 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$154,000*

2005 $154,000 University of Colorado Health Sciences Center *Use of HIT to Improve Symptom Mgt in Advanced Cancer*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6950923&p_grant_num=1R21CA115311-01&p_query=&ticket=17643455&p_audit_session_id=82077423&p_keywords=

Grant Number: 1R21CA115311-01
PI Name: KUTNER, JEAN S.
PI Email: jean.kutner@uchsc.edu
PI Title: ASSOCIATE PROFESSOR & ACTING DIVISION HE
Project Title: Use of HIT to Improve Symptom Mgt in Advanced Cancer

Abstract: DESCRIPTION (provided by applicant): Seriously ill and dying patients often suffer from treatable symptoms, both physical and psychological. There are several possible explanations for the persistence of significant symptom distress in this setting and population: 1) Patient-level pharmacologic or non-pharmacologic interventions may ineffective or inadequately studied in the terminally ill population; 2) Care providers (either informal or professional) may not recognize symptom distress, leading to under treatment of distressing symptoms; 3) Those who are experiencing the symptom distress (patients) and those who have the ability to address the distress (health care providers) may not have effective means of communicating. The purpose of this proposed project is to study the feasibility and determine preliminary effect sizes of implementing a patient-centered technology-based system for improving symptom management in hospice/palliative care settings. The Specific Aims of the proposed project are to: 1) Develop, test and refine components of a patient-centered health information technology (HIT) intervention that incorporates sequential standardized symptom and quality of life assessments with real-time feedback into routine care; and 2) Conduct a feasibility study of the reach and effectiveness of the patient-centered symptom management HIT intervention with diverse organizations providing hospice/palliative care and diverse people with advanced cancer receiving care from these organizations. This feasibility study will test a bi-directional system where patients, informal caregivers and hospice/palliative care providers can enter data and receive reports that summarize symptom distress information and prompt care interventions. The study will be conducted in a community-based hospice/palliative care research network. If shown feasible as a two-way symptom management and alerting system, the patient-centered system may be adapted to assist with symptom management in other settings and other cancer stages. Findings from this project will inform preparation of an R01 proposal for a larger-scale randomized clinical trial to test the efficacy of the symptom management HIT intervention for decreasing symptom distress among persons with advanced cancer.

Thesaurus Terms:

There are no thesaurus terms on file for this project.

Institution: UNIVERSITY OF COLORADO DENVER/HSC AURORA
P.O. BOX 6508, GRANTS AND CONTRACTS
AURORA, CO 800450508
Fiscal Year: 2005
Department: MEDICINE
Project Start: 12-SEP-2005
Project End: 31-AUG-2007
ICD: NATIONAL CANCER INSTITUTE
IRG: ZCA1

National Institutes of Health - National Institute on Aging (NIA) *$1,247,395*

2003 $407,698 University of Colorado Health Sciences Center *Efficacy of Massage Therapy at the End of Life*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6678602&p_grant_num=1R01AT001006-01A2&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=37&p_audit_numfound=140&p_keywords=palliative

Grant Number: 1R01AT001006-01A2
PI Name: KUTNER, JEAN S.
PI Email: jean.kutner@uchsc.edu
PI Title: ASSOCIATE PROFESSOR & ACTING DIVISION HE
Project Title: Efficacy of Massage Therapy at the End of Life

Abstract: DESCRIPTION (provided by applicant): Relief of physical and emotional symptoms is a key component of end-

of-life care. However, there is a significant burden of unrelieved symptoms among terminally ill patients. Individuals with advanced cancer often suffer from multiple symptoms; the pharmacologic interventions used for alleviation of one symptom may exacerbate other symptoms. Studies of the efficacy of therapies that have potential to mediate these symptoms deserve our highest priority. For these reasons, the goal of this application is to evaluate the efficacy of massage therapy for alleviation of symptom distress and improvement of quality of life for patients with advanced cancer who are receiving hospice/palliative care. The specific aim of this study is to demonstrate the efficacy of massage therapy for treatment of pain, reduction of physical and emotional symptom distress, and improvement of quality of life among cancer patients at the end of life. This will be a multi-site randomized clinical trial comparing massage therapy plus usual hospice care with a control group receiving "non-moving touch" plus usual hospice care. The study will be conducted in a community-based hospice/palliative care research network. Data will be collected at baseline, immediately preceding and following each intervention (massage therapy) or control (non-moving touch) session, and weekly for the three weeks of each patient's participation in the study. Analyses will determine the independent influence of the intervention (a series of massage therapy sessions) on the identified outcomes (pain, physical and emotional symptom distress, quality of life).

Thesaurus Terms:
human therapy evaluation, massage therapy, neoplasm /cancer palliative treatment, quality of life
cancer pain, cancer rehabilitation /care, clinical trial
alternative medicine, behavioral /social science research tag, clinical research, human subject, patient oriented research

Institution: UNIVERSITY OF COLORADO DENVER/HSC AURORA
P.O. BOX 6508, GRANTS AND CONTRACTS
AURORA, CO 800450508
Fiscal Year: 2003
Department: MEDICINE
Project Start: 15-JUL-2003
Project End: 31-MAR-2006
ICD: NATIONAL CENTER FOR COMPLEMENTARY & ALTERNATIVE MEDICINE
IRG: ZRG1

2004	$453,175	University of Colorado Health Sciences Center	*Efficacy of Massage Therapy at the End of Life*

see Colorado at http://grants.nih.gov/grants/award/state/state04.htm

2005	$386,522	University of Colorado Health Sciences Center	*Efficacy of Massage Therapy at the End of Life*

see Colorado at http://grants.nih.gov/grants/award/state/state05.htm

Nuha A. Lackan tracked thus far

National Institutes of Health (General heading)

2003 University of Texas *Ethnic Variation in Hospice Use Among Cancer Patients*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6594260&p_grant_num=1R03HS013547-01&p_query=%28hospice%29&ticket=14333335&p_audit_session_id=65197762&p_audit_score=100&p_audit_numfound=12&p_keywords=hospice

PI Name: LACKAN, NUHA A.
PI Email: nalackan@utmb.edu
PI Title:
Project Title: Ethnic Variation in Hospice Use Among Cancer Patients

Abstract: DESCRIPTION (provided by the applicant): Within the last three decades, hospice care has emerged as an important form of end-of-life care in the United States. Hospice care provides an alternative to traditional, curative medicine by offering dying patients palliation from physical, emotional and spiritual suffering. In the last decade, hospice utilization in the United States has increased rapidly. In addition, the type of patient entering hospice care has changed. Until recently, the majority of patients using hospice care were older, middle class, and non-Hispanic Whites with a cancer diagnosis. Now, as the older adult population becomes more ethnically diverse and advances continue to be made in life-prolonging technologies, the profile of the typical hospice patient is also changing. There is a growing concern in the hospice community that members of racial and ethnic minority groups are underutilizing hospice care in comparison to Non-Hispanic Whites. It is important to: 1) determine if disparities in hospice utilization exist among different racial and ethnic groups; and 2) explain why these disparities exist. The purpose of this study is to examine variation in the use of hospice care by patient race and ethnicity. The specific aims of this proposal are to: 1) investigate differences in the use of hospice care by patient race and ethnicity; 2) examine racial and ethnic differences in hospice use by type of cancer diagnosis; 3) assess racial and ethnic differences in the use of hospice care by geographic location; and 4) examine variation in the use of hospice care over time by patient race and ethnicity. Data from the linked SEER (Surveillance, Epidemiology and End Results)-Medicare database will be used to study hospice care utilization in subjects diagnosed with breast, lung, colorectal or prostate cancer from 1986 to 1996 at age 65 and over who died from 1991 to 1999. The SEER population covers approximately 14% of the United States. Logistic regression analyses and chi-square analyses will be used to achieve the study goals. The findings will contribute to the existing knowledge of hospice care utilization among four racial and ethnic groups (Non-Hispanic Whites, African Americans, Hispanics and Asians and Pacific Islanders) in the United States.

Thesaurus Terms:
African American, Asian, Hispanic American, Pacific Islander, caucasian American, health care service utilization, health disparity, hospice, racial /ethnic difference
breast neoplasm, colorectal neoplasm, epidemiology, geographic difference, hospital length of stay, lung neoplasm, neoplasm /cancer diagnosis, prostate neoplasm
clinical research, health services research tag, human subject

Institution: UNIVERSITY OF TEXAS MEDICAL BR GALVESTON
301 UNIVERSITY BLVD
GALVESTON, TX 77555
Fiscal Year: 2003
Department: SEALY CENTER ON AGING
Project Start: 15-APR-2003
Project End: 14-APR-2004
ICD: AGENCY FOR HEALTHCARE RESEARCH AND QUALITY
IRG: HCRT

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Shawn LaFrance — $449,747 tracked thus far

Robert Wood Johnson Foundation — *$449,747*

1999 37881 $449,747 Foundation for Healthy Communities — *C-SP2: Community-State Partnerships – New Hampshire*

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years).
http://www.healthynh.com/fhc/about/newsreleases/11-17-1999.php
The New Hampshire program will be carried out by the New Hampshire Partnership for End-of-Life Care, a 15-member statewide coalition formed in 1998. It is one of 23 statewide partnerships to receive funding under a new program encouraging state and community groups to improve end-of-life care.
Shawn LaFrance, MPH, will direct the project. LaFrance is also vice president of the Foundation for Healthy Communities, a nonprofit organization founded by the New Hampshire Hospital Association. "Planning for endoflife care is often not done or incomplete," said LaFrance. "In town meetings, senior citizen focus groups and through medical record surveys, we have learned that only about half of the adults who die in New Hampshire are likely to have living wills, and only one person in six will have completed a durable power of attorney for health care. We are concerned about why these numbers are so low and are looking at practical ways to promote dialogue and raise awareness about endoflife concerns."
The partnership has outlined a program that builds on findings from the 1998 statewide study, "Death in New Hampshire: A Review of Medical Charts." It will use multiple strategies to bring together health professionals, community leaders and the public to improve endoflife care in New Hampshire.
The centerpiece of the initiative is the creation of training programs in 15 communities across the state to help patients and families complete living wills, durable powers of attorney and other documents that tell about the kind of care they want if they are unable to speak for themselves.
Workshops and quality improvement efforts will inform health care professionals, insurers and community leaders about "best practices" related to good advance care planning. A related effort will design incentive programs to encourage doctors, nurses and social workers to talk with patients about advance care planning.

Dee Leahman — $15,000 tracked thus far

Rallying Points — *$15,000*

2003 $15,000 Community Partnership for End of Life Care (Winston-Sal — *Community Coalitions Awards of Excellence*

To the Winston-Salem Rallying Points coalition; awarded at RP Convention in Boston.

David Lee, M.P.A. — $2,250,000 tracked thus far

Robert Wood Johnson Foundation — *$2,250,000*

2004 50322 $2,250,000 Last Acts Partnership — *Last Acts Partnership - Technical assistance and direction*

http://rwjf.org/applications/program/grant.jsp?id=050322&npo=LAX&type=690&page=1
Active Grants
Last Acts

Project:
Technical assistance and direction for Last Acts Partnership

Grant Detail:
$2,250,000, (awarded on Jan 22, 2004, starting Apr 1, 2004 ending Mar 31, 2007) ID# 050322

Grantee:
Last Acts Partnership, Inc.
P.O. Box 66008
Washington, DC 20035-6008

Contact Information:
David Lee M.P.A. (Project Director)
lastactspartnership@yahoo.com

Susan B. LeGrand, M.D. — $150,000 tracked thus far

Kornfeld / PDIA (Soros) collaborative — *$150,000*

2004 $150,000 Cleveland Clinic - Horvitz Center for Palliative Medicine — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Marcia Levetown, MD — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

1996 $50,000 University of Texas — *Faculty Scholar, 1996-97 (Grant amount is estimated.)*

Development of a multi-disciplinary curriculum that will focus on inter-disciplinary team- building, pain and symptom management, legal and ethical issues in end-of-life care, and the medical professional's own response to helping patients with terminal illnesses and their families.

Bruce T. Levi — $375,000 tracked thus far

Robert Wood Johnson Foundation — *$375,000*

1999 38457 $375,000 North Dakota Medical Research Foundation — *C-SP2: Community-State Partnerships – North Dakota*

http://web.archive.org/web/20020318231543/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___463
Summary Title: Community-State Partnerships to Improve End-of-Life Care
Project Title: Establishing a statewide collaborative to improve end-of-life care
Project Director: Bruce T. Levi Degree:
Phone No.(Work): 701-223-9475
Fax (Work): 701-223-9476
Email: blevi@ndmed.com
Grantee Institution: North Dakota Medical Research Foundation
Address: Box 1198

Bismarck North Dakota United States.
Start Date: 01/01/2000 End Date: 12/31/2001
Amount: $375,000 Web Site:
Description: The North Dakota project, know as Matters of Life and Death, will develop the capacity of individuals, families, communities, and the state to meet the needs of the dying. Their work is focused in four areas: (1) educating medical and nursing students and continuing the education of health, human service, financial, and legal practitioners, and the clergy; (2) comparing current end0of0life care services against an ideal service continuum to identify and address gaps and deficiencies; (3) establishing a permanent end-of-life resource center and Web site for the distribution of current materials and (4) developing a single, simple advance directive form.

Wendy Levinson, M.D. — $2,734,458 tracked thus far

Robert Wood Johnson Foundation — *$2,734,458*

1995 26524 $108,940 Legacy Good Samaritan Hospital and Medical Center — *Resource Coordinators for Chronic Care Patients in an Independent Physician Association (Completed)*

http://www.rwjf.org/reports/grr/026524.htm
Traditionally, patients over the age of 65 are identified as "high risk" only after multiple hospitalizations, emergency room visits, or accumulated medical bills over a period of time. Community Resource Connection (CRC) — a collaborative program of an insurer (Blue Cross/Blue Shield of Oregon), a hospital system (Legacy Health System), and physicians (eight independent primary care physician groups) — identifies older patients as high risk early in their care and follows up with needed interventions. Using resource coordinators who act as an extension of the primary care physician's office, CRC identifies present or potential patient need and links patients to appropriate services available in the community and covered by their insurance. . . .
Interviews conducted by Legacy indicate that the program has helped to build a strong collaboration among the insurer (Blue Cross), the hospital system (Legacy), and the practicing physician group. The physicians are committed to the program and to providing the health resources the resource coordinators recommend. Physicians' offices have been enthusiastic about the program. Overall, patients have been receptive to the work of the resource coordinators and are eager to get help with finding health care services, communicating with the physician's office, and navigating the health care system. A close bond has developed between resource coordinators and patients. Community Resource Connection expects to continue the intervention and believes that it can be easily replicated in other communities.

1996 29070 $525,732 Legacy Good Samaritan Hospital and Medical Center — *Resource Coordinators for Chronic Care Patients in an Independent Physician Association*

Development of a Managed Care System for At-Risk Elderly People

1998 34652 $899,953 University of Chicago — *Clinical Scholars Program*

Grant report shows Wendy Levinson as site director for all of the RWJF Clinical Scholar grants at Univ. Chicago, and lists John Lantos and Nicholas Christakis as co-directors. 1998 Annual Report shows amount of this grant.

1998 34445 $1,199,833 University of Chicago — *Clinical Scholars Program*

Grant report shows Wendy Levinson as site director for all of the RWJF Clinical Scholar grants at Univ. Chicago, and lists John Lantos and Nicholas Christakis as co-directors. 1998 Annual Report shows amount of this grant.

Linda Lewis — $35,000 tracked thus far

Robert Wood Johnson Foundation — *$35,000*

2002 45696 $35,000 Hospice and Palliative CareCenter (HPCC) — *Faith in Action End of Life Care Ministries*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

John F. Linder, LCSW — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

2000 $50,000 University of California - Davis, School of Medicine — *Social Work Leader, 2000 (Amount of grant is estimated)*

Through development of a state wide coalition of Schools of Social Work and Schools of Theology and related field training agencies, this project will develop a highly interactive graduate level "end-of-life care" course that will be offered to social work, course that will be offered to social work, divinity and religious studies students at California State University,course that will be offered to social work, divinity and religious studies students at California State University, Sacramento, and at the Graduate Theological Union (GTU)/UC Berkeley, in academic year 2001/02.

Jean A. Linzau, M.D. — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1998 $70,000 Howard University Health Sciences Center — *Faculty Scholar, 1998 (estimated funding); End-of-Life Care Provider Education in an Ethnically and Spiritually Diverse Community*

Michael Lipson, Ph.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1996 $50,000 Columbia College of Physicians and Surgeons — *Faculty Scholar, 1996-97: To develop a skills-based training for health professionals that addresses their personal reconciliation to death and loss. (Grant amount is estimated.)*

Bernard Lo, M.D. — $2,600,000 tracked thus far

Greenwall Foundation *$2,600,000*

2001 $846,500 University of California - San Francisco — *Greenwall Faculty Scholars Program in Bioethics Project support: The Greenwall Faculty Scholars Program in Bioethics (four-year grant: $846,500).*

2001 $1,753,500 University of California - San Francisco — *Greenwall Faculty Scholars Program in Bioethics Project support: The Greenwall Faculty Scholars Program in Bioethics (four-year grant: $846,500).*

Gwendolyn London, D.Min. — $1,375,000 tracked thus far

Robert Wood Johnson Foundation *$75,000*

1999 36322 $75,000 DC Hospital Association (DCHA) Program Services Compa — *C-SP1: Community-State Partnerships to Improve End-Of-Life Care*

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years).

Foundation for End of Life Care, Inc. (Vitas Healthcare) *$1,300,000*

2003 $1,300,000 Duke University - Institute on Care at the End of Life — *For Duke Institute (not sure this was money from Foundation for EOL Care, or from Westbrook himself.)*

[I think Gwen London was contact, but not sure]
http://www.divinity.duke.edu/Documents/vitasgiftnov03.htm
Hugh A. Westbrook, co-founder and CEO of VITAS Healthcare Corp. of Miami, and his wife, Carole Shields Westbrook, have given $3 million to Duke University's Divinity School to enhance the Duke Institute on Care at the End of Life, Duke President Nannerl O. Keohane announced Thursday.

Westbrook, a 1970 Divinity School graduate and pioneer in hospice care, had previously helped arrange $13.5 million in gifts to launch the institute in 2000. The institute works to improve research, education and practice in the care of those near death.

"Hugh and Carole envisioned, and now continue to support, interdisciplinary study at Duke Divinity School that will benefit humanity," Keohane said. "Such scholarship is at the center of what we do at Duke, and our community is grateful to Hugh and Carole for all they and VITAS have done to foster it."

Of the recent gift, $2 million will be supplemented by $1 million from Duke's Nicholas Faculty Leadership Initiative to endow a distinguished professorship to be filled by a new institute director. This will be the Esther Colliflower chair, named for the VITAS co-founder who also has played a critical role in hospice development.

The remaining $1 million will pay for a portion of a $22 million Divinity School addition, which is currently under construction and will include a suite of offices for the institute.

The institute is the first academic entity in the country to bring together a broad spectrum of disciplines, schools and professions to study how best to care, as a community, for those in the last stage of life. It involves physicians and nurses at Duke Medical Center, theologians and ethicists from the Divinity School, humanities scholars from Duke's arts and sciences departments, pastors and other caregivers from across the nation, and social work faculty from the nearby

University of North Carolina at Chapel Hill, among others.

Activities include academic research and teaching; practical training for health-care providers, pastors and other caregivers; and providing information and educational programs for the wider public.

"I'm struck by the fact that Duke Divinity School, with the support of [Duke Divinity School] Dean [L. Gregory] Jones and President Keohane, is so willing to take on the hard work of the institute and work with other schools at Duke and the UNC School of Social Work," Hugh Westbrook said. "It takes a lot of institutional courage and risk-taking to do that. Knowing they have that kind of commitment inspires us to want to go ahead and get all of the resources we can together to create the critical mass that is needed by the institute to achieve its mission."

Jones said the Westbrooks' donation would strengthen an already successful program. Among other efforts, the institute has organized major conferences on access to end-of-life care as well as care for terminally ill children and end-of-life care in the African-American and Jewish communities. Adding a distinguished chair for a new director and creating new, specially designed offices will greatly contribute to the program's effectiveness, Jones said

"These gifts will continue to develop our leadership in reconnecting faith communities and effective health care, and it will enhance our commitment to joining together research, teaching and outreach in the wider community," Jones said. "We are grateful for Hugh and Carole's extraordinary vision, passion and commitment to the Divinity School, and especially to improving the quality of care for persons at the end of life and their families."

In earning his master's degree at Duke Divinity School, Westbrook specialized in ethics and pastoral care. For the next 10 years, he served as a pastor in North Carolina and Florida and worked as a hospital chaplain caring for terminally ill patients and their families. In 1978, he and Colliflower founded VITAS, which provides hospice care to approximately 50,000 patients and bereavement services to more than 125,000 people annually across the nation.

Westbrook said the Duke institute should become a model for end-of-life care.

"When you look around the United States, there is not another institute of an interdisciplinary nature that goes beyond one narrow way of looking at care at the end of life," he said. "This interschool program housed in an academy like Duke University presents a great opportunity, and this is something that I hope will be imitated. It needs to be duplicated in other settings, because we need to do a much better job of training people like clergy and social workers and nurses to be advocates for people who are dying and their families.

"The institute also presents a great opportunity to work across disciplines and with other academic institutions to continue to work to expand access to hospice to the African-American community and other traditionally under served groups," Westbrook concluded

Matthew Loscalzo, M.S.W. **$125,000** tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$125,000*

$125,000 Johns Hopkins *Oncology*

People who die of cancer and other chronic diseases receive most of their care, during the period just prior to death, from family members who are often unprepared and unskilled in dealing with the complex and demanding tasks they face. This project will develop a program to better prepare family members for caregiving responsibilities. Family caregivers will receive problem- solving education, information for solving caregiving problems, and continuing support for their problem solving efforts from health professionals and peers.

Gail Lovinger — $848,295 tracked thus far

Robert Wood Johnson Foundation *$848,295*

1998 33600 $50,000 American Hospital Association - HRET Washington DC — *Circle of Life Awards planning - "Planning an Award Program to Recognize Excellence In End-Of-Life Care"*

http://www.rwjf.org/reports/grr/036337.htm
These grants, which were part of RWJF's Targeted-End-of-Life Projects Initiative, supported AHA's development and implementation of an annual awards program to recognize organizations providing exemplary end-of-life care. Under the planning grant (ID# 033600), AHA appointed a 16–member interdisciplinary advisory panel to design the program. (For a list of the members, see Appendix 1.) Its recommendations served as the framework for an awards program proposal submitted in December 1998 by AHA to RWJF for implementation funding. AHA's contribution included staff support and the convening of focus groups to evaluate possible names for the awards.
Award to Recognize Excellence in End-Of-Life Care Planning Grant Advisory Panel

Christine Cassel, MD (Chair)
Chair, Department of Geriatrics and Adult Development
Mt. Sinai Medical Center
New York, NY

Margaret Campbell, RN, MSN
Advanced Practice Nurse
Detroit Receiving Hospital
Detroit, MI

Carolyn Cassin
Chief Operating Officer, East
VistaCare
Southfield, MI

James E. Cimino, MD
Director, Palliative Care Institute
Calvary Hospital
Bronx, NY

Richard D. Della Penna, MD
Physician-in-Charge
Continuing Care Services, Home Health and Hospice
Kaiser Permanente
San Diego, CA

Susan Edgman-Levitan
President
The Picker Institute
Boston, MA

Linda Emanuel, MD, PhD
Vice President, Ethics Standards Division
American Medical Association
Chicago, IL
(DeWitt Baldwin, MD, alternate member)

Lachlan Forrow, MD
Beth Israel Deaconess Medical Center
Boston, MA

Steve Franey
Consultant
Sisters of Providence/FACCT
Portland, OR

Susan Goldwater
Executive Director
Hospice of the Valley
Phoenix, AZ

Joanne Lynn, MD
President
Center to Improve Care of the Dying
Washington, DC
(Anne Boling, alternate member)

Robert Newman, MD
President and Chief Executive Officer
Continuum Health Partners, Inc.
New York, NY

Kenneth M. Rutledge
President
Oregon Association of Hospital and Health Systems
Lake Oswego, OR

Millie Z. Solomon, EdD
Director
The Center for Applied Ethics and Professional Practice
Education Development Center, Inc.
Newton, MA
(Anna Romer, EdD, alternate member)

Marilyn Webb
Author, The Good Death
New York, NY

Betty Lou Woods, RN
Board Member
Tyler Memorial Hospital
Factoryville, PA

1999 36337 $798,295 American Hospital Association - HRET Washington DC *Circle of Life Awards ("Project to Identify and Disseminate Excellent End-of-Life Care Models")*

http://www.rwjf.org/reports/grr/036337.htm
In an effort to change professional and societal attitudes that too often equate death with a failure of science, the AHA conceived of an award to recognize excellence in care of the dying. AHA sought to design an award that would highlight model end-of-life programs for others to emulate and also stimulate discussion of how death is handled in the medical system. The AHA, which has principal offices in Chicago, IL and Washington, DC, is a national advocacy and education organization whose membership includes hospitals, health care systems, and other health care providers. HRET is an AHA affiliate that manages grants made to the organization.
. . . In 1999 RWJF awarded AHA a three-year, $798,295 grant (ID# 036337) to implement the proposed awards program. Supported activities included: (1) determining a name and graphic design for the awards; (2) identifying other organizations to cosponsor the awards; (3) developing application materials; (4) mailing out calls for nominations (more than 27,000 in each of the first two years of the awards); and (5) appointing an awards selection committee. (For the committee's initial membership, see Appendix 2.) Additionally, in each award year AHA staff conducted a preliminary review of the applications and submitted a narrowed list of candidates to the awards selection committee for further review and ranking. An applicant program was eliminated if it was less than a year old, was insufficiently oriented to patient care, or involved activities that were already widespread. Each of nine to ten finalists received a site visit from a team that in most cases consisted of an awards committee member and an AHA staff member.
. . . Results of ID# 036337 - The Implementation Grant

** AHA selected the name "Circle of Life Award: Celebrating Innovation in End-of-Life Care." A circle open at the top became the logo for the award.*
** The National Hospice and Palliative Care Organization (NHPCO), the American Association of Homes and Services for the Aging (AAHSA), and the American Medical Association (AMA) cosponsored the awards program.*
** The first Circle of Life awards were presented May 2, 2000 in Orlando, FL at the annual meeting of Health Forum, an AHA affiliate. The three organizations receiving $25,000 cash awards and crystal replications of the logo were: Franciscan Health System West, Tacoma, WA; Hospice of Florida the Suncoast, Tampa, FL; and Louisiana State Penitentiary Hospice, Angola, LA. Six additional programs received honorable mention. Approximately 120 programs submitted applications.*
** The second-year winners were announced July 31, 2001 at the Health Forum annual meeting in San Diego, CA. The three awardees were: Beth Israel Medical Center, New York, NY; St. Joseph's Manor, Trumbull, CT; and Palliative CareCenter & Hospice of the North Shore, Evanston, IL. Six programs received Citations of Honor — a new name for the runner-up awards, replacing honorable mention. Approximately 115 programs submitted applications. Unlike the first year, the applicants included some nursing homes. AHA credited an expanded AAHSA effort to make its members aware of the awards program.*
** The 2002 winners are to be announced during the Health Forum annual meeting scheduled for July 25–27 in San Diego, CA.*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Nancy Lundebjerg, M.P.H. — $4,419,076 tracked thus far

Mayday Fund — *$75,000*

2000 $75,000 American Geriatrics Society, Inc. — *Research Agenda on Pain in Older Adults*

The American Geriatrics Society
New York, NY
USA
$75,000 to support the project to develop a Research Agenda on Pain in Older Adults.
Contact: Nancy Lundebjerg
Email: nlundebjerg@americangeriatrics.org

Hartford Foundation (John A.) — *$4,344,076*

2004 $4,344,076 American Geriatrics Society, Inc. — *Increasing Geriatrics Expertise for Surgical & Related Medical Specialties—Phase IV*

Principal Investigators: Nancy Lundebjerg, MPH, and John Burton, MD
Grant amount: $4,344,076 over four years
With Foundation support, the American Geriatrics Society will use mutually reinforcing efforts to help the 10 surgically related fields of medicine to transform or "geriatricize" themselves through education, research, and leadership development. This will be accomplished through the co-funding of the council of specialty societies, small grants focusing on geriatric needs of each society, updates to the recently published research agenda, a national competition to enhance residency training for 16 specialist physicians, the Jahnigen career development awards, and funds to augment those from The Atlantic Philanthropies to explore geriatrics training for some 207,000 practicing physicians in these disciplines.

Dale Ellen Lupu, Ph.D. — $599,750 tracked thus far

Robert Wood Johnson Foundation — *$380,370*

2001 39835 $380,370 American Board of Hospice and Palliative Medicine (ABH — *Development of fellowship program standards and an improved certification process*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___644
This grant supports the American Board of Hospice and Palliative Medicine's (ABHPM) efforts to develop standard program requirements for fellowship training in hospice and palliative medicine, and improve the existing certification examination to distinguish the critical knowledge, attitude, and skills which define the practice of high quality palliative medicine.

Open Society Institute / Project on Death in America (Soros Foundation) — *$219,380*

2001 $219,380 American Board of Hospice and Palliative Medicine (ABH — *Develop a Consensus on the Recognition and Advancement of Palliative Medicine as a Subspecialty*

http://www2.soros.org/death/general_grants_01-03.shtml and
http://www.soros.org/initiatives/pdia/press/abhpm_20010301
This grant supports ABHPM's plan to establish palliative medicine as a recognized subspecialty of medicine by seeking approval from the American Board of Medical Specialty (ABMS) for a palliative medicine subspecialty within one or more existing specialties of medicine. ABHPM will also seek the formation of a residency review committee (RRC) within the Accreditation Council of Graduate Medical Education (ACGME) to implement accreditation guidelines for palliative medicine fellowship programs.

Anne Lyerly, M.D. — $19,750 tracked thus far

Greenwall Foundation — *$19,750*

2001 $19,750 Duke University - Medical School — *Greenwall Fellow*

reference: Greenwall Form 990-PF 2001

Joanne Lynn, M.D., MA, MS — $6,528,954 tracked thus far

Robert Wood Johnson Foundation — *$6,391,254*

1986 23715 $6,079,743 George Washington University — *Program on the Care of Chronically Ill Hospitalized Adults (SUPPORT): Original National Program Office*

http://www.rwjf.org/reports/anthologies/1997chap8.htm
This was actually multiple grants to GWU and Lynn: ID#s 010562, 011077, 012352, 013466, 015153, 016758, 018255, 020776, 021297, 021971, 023715

1997 31101 $171,511 Dartmouth-Hitchcock Medical Center — *SUPPORT - Program on the Care of Chronically Ill Hospitalized Adults Analysis of narrative data from the SUPPORT study (2 years).; Hanover, NH*

Dartmouth-Hitchcock Medical Center

1997 31243 $140,000 Americans for Better Care of the Dying (ABCD) — *Assistance with the Foundation's Last Acts Campaign and related activities (for 2 years).; Washington, DC*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___511
Staff at the Center to Improve Care of the Dying participate substantively in the Last Acts Task Force and Resource Committees, and are involved in many other follow-up grants, conferences, and activities. This solicited project would enable the Center to continue their public education efforts, developing the scholarly field of end-of-life care, performing limited special analyses within the SUPPORT study data for other researchers, helping legislators and the judiciary understand end-of-life issues, and participating in Last Acts, enabling others to move ahead their research or understanding, assisting with drafting model legislation that is made available to wide audiences and explaining implications of legislative options, continuing their efforts to get more stories about normal dying into the news and information media, and working with various Last Acts Task Force and Resource Committees.

Open Society Institute / Project on Death in America (Soros Foundation) *$10,000*

Americans for Better Care of the Dying (ABCD) — *Textbook Review (amount of grant unknown)*

http://www2.soros.org/death/news5.htm
With a grant from the Project on Death in America, Lynn, director of the Center to Improve Care of the Dying, and two of her colleagues at George Washington University reviewed four widely used general medical textbooks, Harrison's Principles of Internal Medicine, the Merck Manual, Scientific American Medicine, and the Manual of Medical Therapeutics (The Washington Manual), for information about the care of the dying. Their conclusion: "General medical textbooks provide little information that would help a physician to care for a dying patient."

Writing in the January 5, 1999 Annals of Internal Medicine, the three investigators reported on their textbook search through 12 common causes of death-AIDS, dementia, chronic lung disease, congestive heart failure, kidney failure, cirrhosis of the liver, diabetes, stroke, and four types of cancer."

1998 $10,000 Americans for Better Care of the Dying (ABCD) — *Briefing for "Legal Initiatives to Improve End of Life Care"*

http://www.google.com/url?sa=U&start=2&q=http://www2.soros.org/death/general_grants_98-00.htm&e=10342
To prepare a briefing book for PDIA's meeting on "Legal Initiatives to Improve End of Life Care"

Fan Fox and Leslie R. Samuels Foundation *$127,700*

2001 $75,000 RAND — *Identifying Eventually Fatal Chronic Illnesses on Medicare Claims*

Here is how the PDIA Retreat document described this project: "RAND Corporation – to provide patients with more timely and human hospice care by improving our ability to predict the course of fatal chronic illnesses using Medicare Claims data (2001)"
Here is the description from the Fan Fox/Samuels site: "This project aims to improve our ability to predict the course of chronic diseases in order to provide patients with more timely, appropriate and humane hospice care. This project uses Medicare claims data to develop a profile of Medicare beneficiaries' costs and use of care in the last year of life. This information would then be used to recommend changes in Medicare financing and coverage."

2001 $52,700 RAND — *Planning Project for a Regional Collaborative on End-of-Life Care in New York City (2001)*

This planning grant was used to adapt the RAND/Institute for Health Improvements, a national model for quality improvement (Breakthrough Series Collaboratives), to a regional level and to lay the groundwork for a collaborative in New York City. Breakthrough Series Collaboratives bring together key stakeholders and experts in a community to discuss and recommend solutions for specific healthcare issues. The focus of the Collaborative in New York City was palliative care for the chronically ill elderly. When the planning was completed, Rand and the United Hospital Fund implemented this project.

Betsy MacGregor, M.D. — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1997 $70,000 Beth Israel Medical Center - NYC — *Faculty Scholar, 1997 (amount estimated): Project on Dying and the Inner Life*

http://www2.soros.org/death/1997_fs.htm
To gain a deeper understanding of the caregiving and dying process, this project will involve an investigation of the personal inner life experiences of those involved with dying – people with terminal illness, their family caregivers, and health care professionals. Through the use of relaxation and self-reflection techniques, together with in-depth interview and qualitative research analysis, the potential role of the inner life will be evaluated as a resource for support for those involved with dying.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Diana J. Mason, RN, PhD, FAAN — $281,480 tracked thus far

Robert Wood Johnson Foundation *$281,480*

2001 $281,480 American Journal of Nursing *ELNEC: Publication of nursing journal articles on end-of-life care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_user_view_html_744

This contract supports a project to develop and enhance nurses' knowledge of and skill in providing end-of-life care. This project will build upon the End-of-Life Nursing Education Consortium (ELNEC) trainings by reaching a broader nursing audience--in particular practicing nurses. Specifically, this project will: (1) publish a series of 15 peer-reviewed articles on end-of-life care in the American Journal of Nursing (AJN), focusing on the application of ELNEC concepts; (2) offer continuing education hours for each article; (3) reach a broader nursing audience--about 342,000 nurses receive AJN; (4) publish original, peer-reviewed research on nursing care at the end of life; (5) provide interactive opportunities for nurses to discuss articles and share/seek advice on improving end-of-life care; (6) survey 1500 readers to assess article influence on end-of-life care; and disseminate research and case studies to media, including press releases, outreach to journalist, Web sites, other journals/newsletters, etc.

Susan J. McGarrity, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1996 $50,000 Milton S. Hershey Medical Center *Faculty Scholar, 1996-97 (Grant amount is estimated.)*

Establishment of a hospital-based palliative care program to serve Penn State/Hershey Medical Center and its affiliated hospitals.

New York, NY -- 29 May 1996

Elizabeth A. McGlynn, Ph.D. — $149,920 tracked thus far

Commonwealth Fund *$149,920*

1997 $149,920 RAND *Analysis of Managed Care Quality Indicators*

Analysis of Managed Care Quality Indicators

Susan C. McMillan, Ph.D., R.N. — $1,265,202 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$1,265,202*

1995 University of South Florida *Enhancing Cancer Education*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2112215&p_grant_num=1R25CA068295-01&p_query=(palliative+care)&ticket=14351398&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=43&p_keywords=palliative+care
Grant Number: 1R25CA068295-01
PI Name: MCMILLAN, SUSAN C.
PI Email: smcmilla@hsc.usf.edu
PI Title: PROFESSOR
Project Title: ENHANCING CANCER EDUCATION--MEDICAL AND NURSING STUDENTS

Abstract: DESCRIPTION: (Applicant's Description) The purpose of this proposed educational project is to improve the care of persons at risk for or diagnosed with cancer by improving the skills of primary care providers. This will be accomplished by providing an innovative educational curriculum that allows medical and graduate nursing students to participate in both combined and separate learning experiences. The learning experiences will be provided as part of the required curriculum and as elective coursework and will involve both classroom and clinical experiences. Prior to development of the proposal a three part needs assessment was conducted that provided the basis for the intervention. This needs assessment included an analysis of the current curricula related to oncology and administration of an objective oncology test in both colleges, as well as a national survey of learning objectives related to palliative care. The proposed project will have four main thrusts: 1) to increase cancer prevention and detection content in the Physical Diagnosis courses for first and second year medical students and in the two core assessment courses for graduate nursing students; 2) to provide faculty enhancement activities for faculty teaching in all of these courses, such activities to include workshops and individual consultation; 3) to support medical and graduate nursing students to take two joint summer elective courses designed to increase the skills of primary care practitioners in the areas of cancer prevention/detection and symptom management during cancer treatment; and 4) to teach third year medical students how to manage symptoms in terminally ill cancer patients and how to collaborate with other health professionals by providing didactic and clinical experiences at a local hospice with nurse-preceptors. Project evaluation will include both project activities and outcomes. Each individual aspect of the project will be evaluated and the success of the innovation will be measured by use of a previously piloted Oncology Knowledge Assessment Test.

Thesaurus Terms:
health care personnel education, medical education, neoplasm /cancer education, postgraduate nursing education cancer prevention, cancer risk, curriculum, education evaluation /planning, hospice, neoplasm /cancer diagnosis, neoplasm /cancer palliative treatment, sign /symptom, terminal patient care

Institution: UNIVERSITY OF SOUTH FLORIDA
4202 E FOWLER AVE
TAMPA, FL 33620
Fiscal Year: 1995
Department: NONE
Project Start: 15-SEP-1995
Project End: 30-JUN-2000
ICD: NATIONAL CANCER INSTITUTE
IRG: CRME

1996 $127,446 University of South Florida *ENHANCING CANCER EDUCATION--MEDICAL AND NURSING STUDENTS*

http://grants.nih.gov/grants/award/state/FY1996.florida.txt

1997 $133,287 University of South Florida *ENHANCING CANCER EDUCATION--MEDICAL AND NURSING STUDENTS*

http://grants.nih.gov/grants/award/state/FY1997.florida.txt

1999 $144,162 University of South Florida *ENHANCING CANCER EDUCATION--MEDICAL AND NURSING STUDENTS*

http://grants.nih.gov/grants/award/state/fy1999.florida.txt

1999 University of South Florida *A Caregiver Intervention to Improve Hospice Outcomes*

http://24.73.99.138:777/Grants&Projects/care_giver_intervention.htm

A CAREGIVER INTERVENTION TO IMPROVE HOSPICE OUTCOMES

Principal Investigator: Susan C. McMillan, PhD, RN, FAAN

Co-Investigators: Michael Weitzner, MD, Linda Moody, PhD, RN, FAAN, William Haley, PhD, Ronald Schonwetter, MD, Mary Tittle, PhD, RN, Brent Small, PhD, Ann Holzheimer, MS, RN.

Funding: $1.25 million

Source: NCI/NINR

Although hospice family caregivers receive support from the hospice team, research indicates that a greater level of support and education are needed to assist them with the enormous responsibility they bear for physical and emotional care. If the caregiver is not adequately prepared to assess patients and provide needed care, the patient's quality of life may suffer, and the caregiver may experience feelings of inadequacy, anxiety, and depression leading to decreased caregiver quality of life. The primary aim of this experimental study, based on the stress-process model, is to improve the quality of life of hospice caregivers by helping them to master the skills needed to better assess and manage specific problems experienced by cancer patients (pain, dyspnea, and constipation), thus enhancing caregiver coping and self-appraisal of stressfulness of patient symptoms and quality of life for both patients and caregivers. The sample of 480 patient/caregiver dyads will be drawn from a large hospice in the local area and screened using measures of functional status and mental status. After consenting, subjects will be randomly divided into three groups, a control group receiving standard care (Group I), a group receiving standard care plus support visits (Group II), and a group receiving standard care plus the intervention (Group III). The intervention will be based on the COPE method (Creativity, Optimism, Planning, Expert Information). Groups II and III will receive visits on the same schedule to control for the effects of research time and attention. On visit one, caregivers in Group III will be taught to use the COPE method of managing patient problems. Visit one will last approximately 60 minutes: visits two and three will reinforce and extend learning and last approximately 30 minutes each. Group III Caregivers will also receive a copy of the Home Care Guide for Advanced Cancer. Group III caregivers will be taught how to assess patient symptom intensity and give a preformatted diary in which to record symptom intensity scores twice daily. Data will be collected from patients about symptom intensity, symptom distress, and quality of life. Caregiver data will include coping, self-appraisal, and quality of life including mastery. Data will be collected from all three groups on admission to the study, immediately post intervention (day 16), and four weeks after admission to the study (day 30). One year after admission to hospice, all caregivers again will be contacted for data collection (patients are expected to be deceased). Quantitative data will be analyzed using repeated measures multivariate analysis of variance and structural equation modeling.

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http://ninr.nih.gov/ninr/research/dea/2001grants/endoflife/mcmillan.pdf

Grant Number: 5R01CA077307-03
PI Name: MC MILLAN, SUSAN C.
PI Email:
PI Title: PROFESSOR
Project Title:
A CAREGIVER INTERVENTION TO IMPROVE HOSPICE OUTCOMES
Abstract: Although hospice family caregivers receive support from the hospice team, research indicates that a greater level of support and education are needed to assist them with the enormous responsibility they bear for physical and emotional care. If the
caregiver is not adequately prepared to assess patients and provide needed care, the patient's quality of life may suffer, and the caregiver may experience feelings of inadequacy, anxiety, and depression leading to decreased caregiver quality of life. The
primary aim of this experimental study, based on the stress-process model, is to improve the quality of life of hospice caregivers by helping them to master the skills needed to better assess and manage specific problems experienced by cancer patients (pain,
dyspnea, constipation), thus enhancing caregiver coping and self-appraisal of stressfulness of patient symptoms and quality of life for both patients and caregivers. The sample of 480 patient/caregiver dyads will be drawn from a large hospice in the local area
and screened using measures of functional status and mental status. After consenting, subjects will be randomly divided into three groups, a control group receiving standard care (Group I), a group receiving standard care plus friendly visits (Group II), and a
group receiving standard care plus the intervention (Group III). The intervention will be based on the COPE method (Creativity, Optimism, Planning, Expert Information). Groups II and III will receive visits on the same schedule to control for the effects of researcher time and attention. On visit one, caregivers in Group III will be taught to use the COPE method of managing patient problems. Visit one will last approximately 90 minutes; visits
two and three will reinforce and extend learning and last approximately 30 minutes each. Group III caregivers will receive a copy of the Home Care Guide for Advanced Cancer and receive two supportive telephone calls from the RA-intervention nurse, one after visit one and one after visit two. Group III caregivers will be taught how to assess patient symptom intensity and given a preformatted diary in which to record symptom intensity scores twice daily. Data will be collected from patients about symptom intensity, symptom
distress, and quality of life. Caregiver data will include coping, self-appraisal, and quality of life including mastery. Data will be collected from all three groups on admission to the study, immediately post intervention (day 16), and four weeks after admission to the study (day 30). One year after admission to hospice, all caregivers again will be contacted for data collection (patients are expected to be deceased). Quantitative data will be analyzed using repeated measures multivariate analysis of variance and structural equation modeling.

Thesaurus Terms:
caregiver, hospice, patient care
coping, education, neoplasm /cancer, patient care management, patient care personnel
attitude, quality of life, self concept
clinical research, health services research tag, human subject, outcomes research
Institution: UNIVERSITY OF SOUTH FLORIDA
4202 E FOWLER AVE

TAMPA, FL 33620
Fiscal Year: 2001
Department: NONE
Project Start: 01-SEP-1999
Project End: 30-JUN-2003
ICD: NATIONAL CANCER INSTITUTE
IRG: NURS

2000 $329,098 University of South Florida *A Caregiver Intervention to Improve Hospice Outcomes*

http://grants.nih.gov/grants/award/state/fy2000.florida.txt

2001 $312,365 University of South Florida *A Caregiver Intervention to Improve Hospice Outcomes*

http://grants.nih.gov/grants/award/state/fy2001.florida.txt

2002 $218,844 University of South Florida *A Caregiver Intervention to Improve Hospice Outcomes*

From summary found at:http://snrs.org/society/DistinguishedResearcherAward2004.doc
". . . Subjects were randomly divided into three groups, one receiving standard hospice care, a second receiving standard care plus supportive visits, and a third receiving standard care plus the COPE intervention. The COPE method emphasizes creativity, optimism, planning, and expert information in managing symptoms. Although both patient and caregiver data were collected at each of three time points (admission, 2 weeks and 4 weeks), only caregiver data are reported here. . . .
"One goal was to decrease emotion-focused coping and increase problem-focused coping among the caregivers. Results indicated that although emotion-focused coping significantly decreased (p=.014) in all three groups, there were no significant difference among the groups, indicating that there was no effect from the intervention. Further, problem-focused coping decreased slightly in the standard care and support groups, and increased slightly in the COPE group, but these differences were not statistically significant. Although no effect was seen on caregiver quality of life, the stress that caregivers perceived from the patient's symptoms decreased over time in all three groups (p=.001), and a significant difference was found between the standard care and COPE groups with the COPE group showing a significantly (p=.01) greater decrease in perceived stressfulness. The sense of mastery of being a caregiver was significantly increased over time (p=.002) in all three groups with a significantly higher increase in the Support group compared to the standard care group (p=.05). Investigators concluded that the COPE intervention decreases the caregiver's stress from patient symptoms while the support intervention had a positive effect on caregiver feelings of mastery. The fact that emotion-focused coping decreased over time may be attributed to the excellent standard care given by the hospice, however quality of life was not significantly increased. Further research is needed."

Stephen J. McPhee, M.D. — $216,638 tracked thus far

Robert Wood Johnson Foundation *$216,638*

1998 33472 $216,638 University of California - San Francisco *Textbook Project*

San Francisco, CA: (5 years).
http://www.rwjf.org/news/releaseDetail.jsp?id=980550076729
$216,638 to the University of California-San Francisco to review end-of-life content in the fifty most-used medical textbooks in the United States and thenwork with the publishers, editors, and authors of these texts to improve the quantity and quality of information about dying.

Sylvia Ann McSkimming, Ph.D., R.N. — $195,000 tracked thus far

Robert Wood Johnson Foundation *$195,000*

2001 43055 $195,000 Supportive Care of the Dying *Building on organizational and community strengths in providing end-of-life care*

For Supportive Care of the Dying (See press release in the documents database.). Listed as a grant to PROVIDENCE HEALTH SYSTEMS, OREGON REGION
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___702
Supportive Care of the Dying: A Coalition for Compassionate Care (the Coalition), is comprised of eleven Catholic healthcare systems, the Catholic Health Association, and the healthcare services of the Archdiocese of Philadelphia, representing healthcare ministries in 48 states. Each of the 13 members of the Coalition will designate a facility to develop a palliative care program that is unique to their institution. Foundation funds for this special opportunity grant would support a data coordinator in each setting.

Keith G. Meador, M.D., ThM., MPH — $13,500,000 tracked thus far

Foundation for End of Life Care, Inc. (Vitas Healthcare) *$13,500,000*

2000 $13,500,000 Duke University - Institute on Care at the End of Life *Founding grant to establish the Duke Institute on Care at the End of Life. (funds coordinated by Westbrook)*

The Duke Institute will incorporate spiritual, social and medical care for hospice patients. arranged by Hugh A. Westbrook, CEO, Vitas Healthcare Corp of Miami, FL.

Diane Eve Meier, M.D. — $14,861,893 tracked thus far

Robert Wood Johnson Foundation — *$13,429,596*

1998 35488 $449,658 Mount Sinai School of Medicine — *Promoting Excellence in End-of-Life Care (Chronic Health Conditions)*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___115
Mount Sinai School of Medicine's Henry L. Schwartz Department of Geriatrics and Adult Development is collaborating with Franklin Health, Inc., a national medical case management service, to integrate palliative care protocols into the disease management system used for patients in community-based settings, who are nearing the end of their lives. The project will: (1) develop training modules for case management nurses on palliative care assessment and care plan implementation, and approaches to physician feedback; and (2) utilize formal palliative care assessment with structured feedback, recommendations, and implementation support for physicians in the context of community-based case management. To determine the impact of the program, the quality of care of the dying, their quality of life, and the cost-effectiveness of the new strategy will be assessed.

1999 37515 $4,742,893 Mount Sinai School of Medicine - Center to Advance Palli *CAPC*

IMPORTANT: MEIER & CASSEL (DUPLICATE? - This grant amount is listed in Annual Report as #37515)
1999 Annual report, pg. 33, shows this grant, plus one to "Health Research & Educational Trust" in Chicago: "Improving Hospital-Based Palliative Care
Establishment of a National Resource Center for Palliative Care that will increase the number of hospitals that have the capability to provide quality palliative care; create sufficient momentum that hospital-based palliative care becomes a standard practice in comprehensive patient care; and provide leadership in the development of standards for palliative care programs (for the periods indicated)."
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___491
Summary Title: Improving Hospital-Based Palliative Care
Project Title: Center to Advance Palliative Care
Project Director: Christine K. Cassel and Diane E. Meier Degree: MD
Phone No.(Work): 212-241-1446
Fax (Work): 212-426-5054
Email: diane.meier@mssm.edu
Grantee Institution: Mount Sinai School of Medicine
Address: One Gustave L. Levy Place
Box 1070
New York New York United States.
Start Date: 11/01/1999 End Date: 10/31/2003
Amount: $4,742,893 Web Site:
This grant will establish a National Resource Center for Hospital-Based Palliative Care. The Center's core functions will be to: (1) provide and/or arrange for technical assistance to emerging established palliative care programs; (2) convene and network palliative care clinical leaders nationally and regionally; (3) track the number and characteristics of hospital-based palliative care programs; (4) document and communicate successes and failures, as well as approaches that could promote success; (5) identify strategic national opportunities to promote palliative care programs, such as encouraging the modification of criteria used in selecting U.S. News and World Report's "Best Hospitals;" (6) address barriers to palliative care, such as financing and reimbursement; and (7) catalyze the field to develop standards for palliative care programs. The goal of the program would be to: (1) increase the number of hospitals that have the capability to provide quality palliative care; (2) create sufficient momentum that hospital-based palliative care becomes standard practice in comprehensive patient care; and (3) provide leadership in the development of standards for palliative care programs.

1999 $5,182,582 Mount Sinai School of Medicine - Center to Advance Palli — *CAPC - National Program (Improving Hospital-Based Palliative Care) with Christine Cassel (Note "strategy" in comments section)*

IMPORTANT: MEIER & CASSEL (Duplicate? This grant amount does not appear in Annual Report, but is similar to 37515)
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___483
This program is for the establishment of the Center to Advance Palliative Care. The goals of the program are to: (1) increase the number of hospitals that have the capability to provide quality palliative care; (2) create sufficient momentum that hospital-based palliative care becomes standard practice in comprehensive patient care; and (3) provide leadership in the development of standards for palliative care programs. The program also includes funding for grants to selected organizations, that could help leverage the technical assistance component of the Resource Center. These grants will enable organizations such as the American Hospital Association to: (1) establish regional capability and networking among clinical and administrative leaders; (2) include palliative care program topics on the agendas of their annual meetings and in their regular publications; and (3) provide/arrange for technical assistance to member organizations. In addition, the program includes a Special Opportunities Fund that will be used to fund projects that fulfill the aims of the program. Examples of projects that may be funded include an in-depth survey of the characteristics of palliative care programs and a seed grant to stimulate the development of accreditation standards by the Joint Commission on Accreditation of Healthcare Organizations. The strategy employed by this program to establish palliative care capability will identify the early adopters, create a critical mass of palliative care programs, and communicate the message to key influential audiences that palliative care is part of comprehensive patient care.

2001 43952 $661,040 Mount Sinai School of Medicine - Center to Advance Palli — *CAPC - Expanding technical assistance and outreach services into the community*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___742
This technical assistance grant will fund four specific activities: (1) an expert panel; (2) a norms of palliative care

practice consensus process; (3) a social marketing study; and (4) a hospital liaison and marketing activities. The expert panel will be comprised of leaders in the field of palliative care who will provide a range of customer services and to act as adjunct professionals to the full-time staff. The norms of palliative care practice consensus process will be led by CAPC to advance the field and clarify the roles and responsibilities of pallaitive care professionals in the U.S. The social marketing study would serve to define further the Center's key audiences and develop strategies and tactics for communicating with these audiences. The hospital liaison would foster awareness of palliative care among key hospital decision makers and leaders throughout the industry.

2002	46969	$289,190	Mount Sinai School of Medicine - Center to Advance Palli	*Supplemental technical assistance and direction for the Center to Advance Palliative Care*
2003	47117	$2,104,233	Mount Sinai School of Medicine - Center to Advance Palli	*Technical assistance and direction for the Center to Advance Palliative Care*

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995	$140,000	Mount Sinai School of Medicine	*Development of faculty from clinical departments to be palliative care consultants and role models.*

OSI Scholar (http://www2.soros.org/death/1995_osi_fs.htm)
Amount of grant is approximate, and based on statement that faculty scholars receive up to $150,000 for two years.
http://www2.soros.org/death/prMay29-96.htm

National Institutes of Health - National Cancer Institute (NCI) *$648,000*

2003	$324,000	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Medicine Fellowship Training*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6574897&p_grant_num=1R25CA095302-01A1&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=100&p_audit_numfound=7&p_keywords=palliative
Grant Number: 1R25CA095302-01A1
PI Name: MEIER, DIANE E.
PI Email: diane.meier@mssm.edu
PI Title: DIRECTOR, LILLIAN AND BENJAMIN HERTZBERG
Project Title: Palliative Medicine Fellowship Training

Abstract: The primary aim of this proposal is to meet the manpower needs for physicians trained in palliative care by establishing an integrated palliative care fellowship experience in two medical specialties: hematology/oncology and geriatrics. Through development of new potential faculty rigorously trained in both palliative care and their primary disciplines, this training model will bring the core competencies of palliative care to those medical specialties with greatest responsibility for seriously ill and dying persons, and will promote the stability and sustainability of academic palliative care as an area of continued and central importance in medical education As important as establishing rigorous postgraduate training opportunities in palliative care, is the need to know if such programs are effective at achieving their stated aims. Therefore a central aim of this proposal is to evaluate the impact of the fellowship training program on outcomes of importance for the strength of the academic discipline of palliative care. These include: retention of graduates in academic posts; quality and number of their teaching and research activities in palliative care in general as' well as within their primary specialty; evidence of leadership in palliative care in general and within their primary specialty; and application of valid and feasible measures of trainees' knowledge, attitudes, and skills in the care of chronically, seriously, and terminally ill patients and their families.

Institution: MOUNT SINAI SCHOOL OF MEDICINE OF NYU
OF NEW YORK UNIVERSITY
NEW YORK, NY 10029
Fiscal Year: 2003
Department: MEDICINE
Project Start: 01-AUG-2003
Project End: 31-JUL-2008
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

2004		$324,000	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Medicine Fellowship Training*

National Institutes of Health - National Institute on Aging (NIA) *$644,297*

1999	$106,760	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Care and the Elderly*

http://grants.nih.gov/grants/award/state/fy1999.new.york.txt

1999	$106,760	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Care and the Elderly*
2000	$106,777	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Care and the Elderly*
2001	$108,000	Mount Sinai School of Medicine	*Palliative Care and the Elderly*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=2821146&p_grant_num=1K07AG000903-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=12&p_audit_numfound=257&p_keywords=palliative+care
Grant Number: 1K07AG000903-01
PI Name: MEIER, DIANE E.
PI Email: diane.meier@mssm.edu

PI Title: DIRECTOR, LILLIAN AND BENJAMIN HERTZBERG
Project Title: PALLIATIVE CARE AND THE ELDERLY

Abstract: The purpose of this Geriatric Leadership Academic Award is to promote the ability of Dr. Diane E. Meier to build a strong program of research and training in palliative medicine and aging at Mount Sinai School of Medicine. Abundant evidence of the need for academic leadership is evident in the almost total lack of research and education in this area, despite the obvious demographic and clinical forces mandating such attention. The award will permit the development of a stable program of clinical research and training, and provide critical validation of the importance of faculty leadership of this work both within Mount Sinai as well as in academic medicine. There is a critical mass of established interest in research and training in palliative medicine and aging, as demonstrated by the number and diversity of research initiatives, clinical programs, and educational efforts already in place at Mount Sinai. In order to organize and enhance these efforts, development of a formal support infrastructure and training process is necessary. To these ends Dr. Meier will establish a program that fosters clinical research, collaboration between investigators, and mentorship and training of new investigators through the 3 specific aims of this proposal: 1) Conduct of collaborative multispecialty clinical research in palliative medicine and aging; 2) Establishment of a research training program and mentorship for new investigators with database, programming, and statistical infrastructure support; and 3) Leadership of a medical school-wide educational effort designed to bring effective teaching in palliative medicine to trainees at all levels, and to evaluate and disseminate these models.

Thesaurus Terms:
education evaluation /planning, geriatric medicine, health science research analysis /evaluation, human old age (65+), terminal patient care, training
aging, health care model, interdisciplinary collaboration, medical education, role model
health services research tag, human data, statistics /biometry

Institution: MOUNT SINAI SCHOOL OF MEDICINE OF NYU
OF NEW YORK UNIVERSITY
NEW YORK, NY 10029
Fiscal Year: 1999
Department: GERIATRICS & ADULT DEVELOPMENT
Project Start: 01-MAY-1999
Project End: 30-APR-2004
ICD: NATIONAL INSTITUTE ON AGING
IRG: NIA

2002		$108,000	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Care and the Elderly*
2003		$108,000	Mount Sinai School of Medicine - Center to Advance Palli	*Palliative Care and the Elderly*

Melanie Pratt Merriman, Ph.D., M.B.A. — $734,960 tracked thus far

Robert Wood Johnson Foundation *$734,960*

2000	38540	$734,960	Touchstone Consulting	*Community-State Partnerships: Evaluation*

Evaluation of Community-State Partnerships to Improve End-of-Life Care Program: Phase I
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http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=csp.htm&iaid=142
Evaluation. Melanie Merriman, of Touchstone Consulting in North Bay Village, Fla., carried out a partial evaluation (under RWJF grant ID# 038540) during the second and third years (2000 and 2001) of the four-year program. RWJF conceived of the evaluation as a two-phase process.

In these two years, Merriman gathered baseline data using surveys her firm commissioned in 28 states, and end-of-life care indicators from existing U.S. databases. She also assisted program sites in evaluation work, and provided case studies to RWJF. RWJF decided against funding the evaluation beyond its data-gathering phase.

Richard E. Merritt — $1,617,846 tracked thus far

Robert Wood Johnson Foundation *$1,617,846*

1996	30342	$303,120	National Conference of State Legislatures	*Expanded Information Program for State Health Policy*

http://www.rwjf.org/reports/grr/037549.htm (see also George Washington University)
These grants from The Robert Wood Johnson Foundation (RWJF) supported the continuation and expansion of the pre-existing Intergovernmental Health Policy Project (IHPP), which provides nonpartisan information on health-care policy to state legislators, and created a forum in which legislators could share ideas and develop leadership in the field.

1997	32334	$149,486	National Conference of State Legislatures	*Research and information services for state policymakers in end-of-life care issues (for 1 year).; Washington, DC*

The National Conference of State Legislatures (NCSL) received the grant from RWJF to assist state policymakers on end-of-life care issues.
 # NCSL produced a five-chapter guidebook on end-of-life initiatives at the state level. The guidebook, State Initiatives in End-of-Life Care: Policy Guide for State Legislatures, was written in collaboration with The Center to Improve Care of the Dying at George Washington University, a research and advocacy organization.
 # A panel of end-of-life experts and legislators discussed key issues at an educational seminar held at NCSL's annual health care meeting in Scottsdale, AZ, in December 1997. The panel's discussion was edited into an 80-minute audiotape

entitled State Initiatives in End-of-Life Care. A second seminar, "State Initiatives on End-of-Life Care," was held in July 1998, at NCSL's 24th annual meeting in Las Vegas, NV, resulting in a 56-minute follow-up audiotape. (see Appendices for rosters of participants at both seminars.)
 # NCSL's Health Policy Tracking Service (HPTS) provided online services and printed issue reports on a wide array of legislative and regulatory developments. In addition to following official bills, statutes, and regulations, HPTS tracked information from relevant state-sponsored commissions, task forces, and executive branch working groups. Issues covered included physician-assisted suicide, intractable pain, palliative care financing, education and licensing, training of health professionals, advance directives, and do-not-resuscitate orders.
 # State Health Notes, NCSL's flagship health care bimonthly newsletter, included five featured articles on end-of-life issues and other briefer coverage.

1997 31569 $702,120 National Conference of State Legislatures *Expanded Information Program for State Health Policy Leaders*

http://www.rwjf.org/reports/grr/037549.htm (see also George Washington University)
These grants from The Robert Wood Johnson Foundation (RWJF) supported the continuation and expansion of the pre-existing Intergovernmental Health Policy Project (IHPP), which provides nonpartisan information on health-care policy to state legislators, and created a forum in which legislators could share ideas and develop leadership in the field.

1999 35554 $229,684 National Conference of State Legislatures *Creation of the Institute for Professional Health Staff Development*

The Robert Wood Johnson Foundation (RWJF) funded the National Conference of State Legislatures (NCSL) to create the Institute for Professional Health Staff Development. The institute's purpose is to conduct annual seven-day conferences that educate professional state legislative staff members on the basics of health policy.
A division of the NCSL, the Forum for State Health Policy Leadership, a major research and educational initiative funded principally by RWJF (ID# 030342), conducted this project. The forum subcontracted with the University of North Carolina at Chapel Hill (UNC) to develop the curriculum and to cosponsor and host the seminars. The grantee organization, in collaboration with UNC, conducted the first two annual seminars of the Institute, "Understanding the Fundamentals of State Health Policy," in Chapel Hill, NC, August 7-13, 1999, and August 5-11, 2000.

1999 37549 $233,436 National Conference of State Legislatures *Planning an Expanded Information Program for State Health Policy Leaders*

http://www.rwjf.org/reports/grr/037549.htm (see also George Washington University)
These grants from The Robert Wood Johnson Foundation (RWJF) supported the continuation and expansion of the pre-existing Intergovernmental Health Policy Project (IHPP), which provides nonpartisan information on health-care policy to state legislators, and created a forum in which legislators could share ideas and develop leadership in the field.

Frederick J. Meyers, M.D **$313,545** tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$313,545*

University of California - Davis *Simultaneous Care: Linking Palliation to Clinical Trials*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6464518&p_grant_num=1R25CA095260-01&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=24&p_audit_numfound=209&p_keywords=palliative
Grant Number: 1R25CA095260-01
PI Name: MEYERS, FREDERICK J.
PI Email: fred.meyers@ucdmc.ucdavis.edu
PI Title:
Project Title: Simultaneous Care: Linking Palliation to Clinical Trials

Abstract: DESCRIPTION (provided by applicant): This project will implement a Simultaneous Care Educational Intervention (SCEI) for patients and caregivers and evaluate related outcome variables in three cancer centers. The project has four aims and ten objectives. Aim 1 includes the implementation phase of the proposal and evaluates process outcomes that will guide future dissemination of the SCEI into the nation?s cancer centers. Aim 2 involves measurement of the impact of the intervention on patients. Aim 3 is the measurement of effect of the SCEI on families. Aim 4 addresses the dissemination of results of the SCEI and implementation in other cancer treatment settings. The specific aims will be accomplished using a quasiexperimental design with repeated measures. The assessments will be obtained using two pre-education measures, and assessments every thirty days for six months. The assessment points following the intervention will provide data regarding the effectiveness of the educational intervention on patients and family caregivers outcomes. The SCEI uses the COPE model (Creativity, Optimism, Planning and Expert Information) developed by D?Zurilla and Nezu, as one of its key components, for cancer patients on Phase I and II clinical trials, and combined it with a structured coaching model with the patient and caregiver to reinforce the educational intervention. The SCEI teaches patients and caregivers a problem solving approach for dealing with issues and problems common with advanced disease, and sets up a system for coaching the patient and caregiver for reinforcement of the new skills. Patients and family caregivers are taught a standardized, strategic approach to problemsolving, learn and practice new communication skills and receive periodic reinforcement and guidance from staff educators. The model uses patient/family caregiver education as file vehicle to support and sustain the patient/family constellation through the clinical trial while raising critical end-of-life and palliative issues. By applying this approach to the full range of difficulties encountered in the advanced illness and clinical trials arenas, patients and families can obtain crucial services and support while simultaneously planning for and working through difficult decisions. Based on prior individual and collaborative work, the investigators anticipate that patients and family caregivers will experience reduced distress, good symptom control, and improved quality-of-life. In addition, the enhanced communication skills of both patients and caregivers will lead to earlier identification and intervention with protocol-related complications and will promote improved recruitment and retention on clinical trials, more appropriate resource utilization, and increased frequency and duration in the use of hospice/supportive care. Having introduced and evaluated the intervention, we will disseminate the findings of the SCEI implementation and evaluation by hosting a national training program for 50 cancer centers. We will also monitor implementation of SCEI by these 50 cancer centers in their own settings. A comprehensive plan for the dissemination of the model and results to community and comprehensive cancer centers with follow-up to measure durable change completes this project.
Institution: UNIVERSITY OF CALIFORNIA DAVIS
SPONSORED PROGRAMS, 118 EVERSON HALL
DAVIS, CA 956165200
Fiscal Year: 2002
Department: INTERNAL MEDICINE
Project Start: 25-JUL-2002
Project End: 30-JUN-2007
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

1994 $92,627 University of California - Davis *WEST COAST CENTER FOR PALLIATIVE MEDICINE EDUCATION*

Grant Number: 5R25CA067068-02
PI Name: MEYERS, FREDERICK J.
PI Email: fred.meyers@ucdmc.ucdavis.edu
PI Title:
Project Title: WEST COAST CENTER FOR PALLIATIVE MEDICINE EDUCATION

Abstract: DESCRIPTION: (Applicant's Description) This application satisfies the criteria of the RFA including the six special requirements. In addition, our application offers three unique circumstances which enhance the intent of the RFA: the cultural diversity of our patient population, our geographic setting and the configuration of health care economics in this region. Our current census reflects the cultural, ethnic, socioeconomic, linguistic, life-style and diagnostic diversity of the patients we serve. On the West Coast, we are the only university-based hospice that provides palliative care education and thus serves as a natural magnet for such education throughout this area. The concentration of managed care in Sacramento affords the opportunity to provide palliative education in a context that closely resembles the future configuration of health care delivery. We have extensive experience spanning fifteen years providing palliative care education to a variety of health care providers and professionals in training. This application extends the University of California Davis Medical Center Hospice educational program by increasing the number of students and standardizing the core learning experience for trainees. We have in place plans to effectively publicize and recruit participants and have secured substantial commitments for participation from a multiplicity of disciplines and educational sites.The methodology and evaluation of our program are covered in depth. The role modeling provided by our interdisciplinary team will be replicated as our trainees graduate and enter their unique practice environments.

Further dissemination will occur through the publication of research initiated by the grant recipients. The content and scope of our educational activities are described in detail. Comprehensive didactic treatment of relevant palliative medicine topics is included, as well as substantial in milieu experience. Students will be paired with members of the hospice interdisciplinary team delivering direct care in homes, congregate living environments and clinics. Quality palliative medicine blends the science of effective symptom relief with the art of support and presence for the patients, the caregivers, the treatment team, and for the very process of dying. This program will educate health care professionals in the palliative arts; show up, listen, provide witness and support patients who are in the process of dying. Our aim then is straightforward: educate role models, those most able to disseminate the art and science of palliative care to the current and future generation of health care providers and consumers.

Thesaurus Terms:
health care personnel education, hospice, neoplasm /cancer education, neoplasm /cancer palliative treatment, terminal patient care
cancer pain, caregiver, death, education evaluation /planning, information dissemination, patient professional relations, physician, role model, sign /symptom, training

Institution: UNIVERSITY OF CALIFORNIA DAVIS
SPONSORED PROGRAMS, 118 EVERSON HALL
DAVIS, CA 956165200
Fiscal Year: 1995
Department: INTERNAL MEDICINE
Project Start: 30-SEP-1994
Project End: 31-AUG-1997
ICD: NATIONAL CANCER INSTITUTE
IRG: SRC

1996	$100,186	University of California - Davis	*WEST COAST CENTER FOR PALLIATIVE MEDICINE EDUCATION*

http://grants.nih.gov/grants/award/state/FY1996.californ.txt

1996	$120,732	University of California - Davis	*Southwest Oncology Group*

http://grants.nih.gov/grants/award/state/FY1996.californ.txt

Steven H. Miles, M.D.

$140,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995	$140,000	University of Minnesota - Center for Bioethics	*Faculty Scholar*

http://www2.soros.org/death/1995_fs.htm
Assessment of current end-of-life care practices in managed care organizations and development of a curriculum on end-of-life care issues with a managed care framework.

Galen Miller

$113,280 tracked thus far

Robert Wood Johnson Foundation *$113,280*

1997	30077	$113,280	National Hospice Organization - See National Hospice an	*Project to Train Residents in End-of-Life Care (Train the Trainers Program)*

The goal of this project funded by The Robert Wood Johnson Foundation (RWJF) was to help fill the gap in medical education regarding the care and treatment of dying patients through the national "Train-the Trainers" program. The objectives were to learn how to use the "Care Beyond Cure" educational kit as part of a self-study component of a physician's residency program curriculum and to strengthen the use of local hospice organizations as educational and consultative resources that physicians could easily access.

John B. Moeschler, M.D.

$30,917 tracked thus far

Robert Wood Johnson Foundation *$30,917*

1997	31118	$30,917	Dartmouth-Hitchcock Medical Center	*Conference on End-of-Life Decision Making for People with Chronic Disabling Conditions*

Dartmouth Medical School, Hanover, NH
John Moeschler, M.D.
This project supports a two-day conference entitled, 'End-of-Life Decision Making by People with Disabilities' (June 1997) which will convene national leaders from medicine, ethics, and the disability community. The hoped for outcomes of the conference are:

1. a set of guiding principles to improve end-of-life decision making by people with disabling conditions;
2. suggested actions to educate the medical, legal, ethical communities, and the general public about end-of-life care for the disabled;
3. outreach strategies for people with disabling chronic conditions to inform them about advance care planning and palliative care; and
4. action steps for the members of the leadership group.

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This grant from The Robert Wood Johnson Foundation (RWJF) supported two conferences on physician-assisted suicide and what it means to persons with disabilities, along with two training sessions that focused on developing ways of educating people with disabilities on the subject. According to the project director, people with disabilities are likely to suffer unduly and disproportionately from a social policy of legalized physician-assisted suicide and active voluntary euthanasia.

The first conference — entitled "End of Life Decision Making for People with Disabilities: The Problem of Physician-Assisted Suicide and Active Voluntary Euthanasia" — was held in Chicago, IL, on June 27-28, 1997. Eighteen national leaders from law, medicine, ethics, social policy, and disability research and advocacy attended. The second conference, held on March 2, 1998 in Manchester, NH, was cosponsored by the New Hampshire Governor's Commission on Developmental Disabilities and planned by a conference planning committee (see the Appendix for a complete list of committee members and affiliation). It brought together some 260 people with disabilities (along with some of their family members), legislators, attorneys, physicians, and professionals working in the field of disability services. Two sponsors of proposed legislation for physician-assisted suicide presented proponents' perspectives, and other speakers addressed the concerns of people with disabilities. Six other organizations contributed a total of approximately $10,000 to the funding of the conference: New Hampshire Developmental Disabilities Council; Disabilities Rights Center; Granite State Independent Living Foundation; Institute on Disability/University Affiliated Program - University of New Hampshire; New England ADA Technical Assistance Center; and University Affiliated Program at Dartmouth Medical School. Project staff produced a report on the project and distributed it through the Institute on Disability/UAP at the University of New Hampshire.

The training on disability and legalized assisted suicide was piloted in two one and a half-hour sessions in Chicago, IL, in the spring of 1998. Twelve 12 people with various disabilities attended the first session; seventeen people with multiple sclerosis attended the second. Before the start of the sessions, participants completed questionnaires concerning their beliefs and attitudes toward legalized assisted suicide, and then listened to a panel presentation, including two speakers endorsing legislation for assisted suicide and two opposing it. Following the presentation, participants completed the same questionnaire. Comparisons of the two sets of questionnaires suggested that a balanced educational presentation on disability and legalized assisted suicide had a limited effect on the knowledge and attitudes of either group of participants. In general, those who came to the presentation with strong views on the subject changed very little compared to those initially expressing neutrality. Among attendees, it appeared that women with disabilities were more likely to be opposed to legalized assisted suicide than men, and persons of color were more likely to be opposed than white persons. African-American and Latina women with disabilities expressed the most opposition to legalized assisted suicide.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Mary K. Mologne, MBA — $153,989 tracked thus far

Robert Wood Johnson Foundation — *$153,989*

2000 38339 $153,989 American Hospital Association - HRET (Chicago) — *Establishment of a National Resource Center for Palliative Care*

http://web.archive.org/web/20020319102336/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___506
Summary Title: Improving Hospital-Based Palliative Care
Project Title: Supporting activities for improving hospital-based palliative care program
Project Director: Mary K. Mologne Degree:
Phone No.(Work): 202-626-2960
Fax (Work): 202-626-2255
Email: mmologn1@aha.org
Grantee Institution: Health Research and Educational Trust
Address: Liberty Place, Suite 700
325 Seventh Street, NW
Washington District of Columbia United States.
Start Date: 01/01/2000 End Date: 12/31/2000
Amount: $153,989 Web Site:
Description: This grant will provide support to the American Hospital Association (AHA) for staff to identify and deploy AHA resources that will help advance the goals of the Foundation's program on hospital-based palliative care. This project will give visibility within the AHA and its members to the importance of building capacity to provide palliative care in the nation's hospitals.

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1999 Annual Report; pg. 33.
Improving Hospital-Based Palliative Care
Establishment of a National Resource Center for Palliative Care that will increase the number of hospitals that have the capability to provide quality palliative care; create sufficient momentum that hospital-based palliative care becomes a standard practice in comprehensive patient care; and provide leadership in the development of standards for palliative care programs (for the periods indicated).

Marilyn Moon, Ph.D. — $500,508 tracked thus far

Commonwealth Fund — *$500,508*

1999 $500,508 Urban Institute — *The Commonwealth Fund Program on Medicare's Future Support for Program Direction and Policy Analysis, 1999-2000*

In the next year, policymakers are expected to enter into broad discussions about the future of Medicare. Program direction staff will continue to provide authoritative analyses of major options for reform, and emphasis will be placed on the impact of policy changes on vulnerable beneficiaries. Work will include an examination of the specific needs of low-income and chronically ill elderly people, as well as the structure of benefits for this Medicare population. Additional analyses will focus on changes in enrollment in managed care plans and the geographic implications of reform proposals.

Vincent Mor, Ph.D. — $1,233,480 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) — *$979,834*

1995 $494,997 Brown University - School of Medicine — *BREAST CANCER MANAGEMENT IN OLDER WOMEN*

http://silk.nih.gov/silk/brownbooks/research/detail/fy95E

1995 $484,837 Brown University - School of Medicine — *HOME CARE TRAINING FOR YOUNGER BREAST CANCER PATIENTS*

http://silk.nih.gov/silk/brownbooks/research/detail/fy95E

National Institutes of Health - National Institute on Aging (NIA) — *$253,646*

1995 $5,000 Brown University - School of Medicine — *DO GOOD NURSING HOMES ACHIEVE GOOD OUTCOMES?*

http://silk.nih.gov/silk/brownbooks/research/detail/fy95E

1995 $248,646 Brown University - School of Medicine — *DO GOOD NURSING HOMES ACHIEVE GOOD OUTCOMES?*

http://silk.nih.gov/silk/brownbooks/research/detail/fy95E

Jane Morris, R.N. — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$70,000*

1995 $70,000 Mount Sinai Medical Center — *Faculty Scholar, 1995 (estimated funding; might be part of Diane Meier's grant)*

Development of faculty from clinical departments to be palliative care consultants and role models.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

[Rolfe] Sean Morrison, M.D. — $1,550,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

1995 $50,000 Mount Sinai School of Medicine — *Faculty Scholar (c. 1995) (Grant amount is estimated.)*

Agency for Health Care Policy and Research (see AHRQ) — *$1,500,000*

$1,500,000 Mount Sinai School of Medicine — *Pain management in hospital acute care*

http://adsr13.mssm.edu/domains/dept/facultyInfo.epl?objname=geriatrics&user=morrir01
Dr. Morrison is currently the principal investigator of a $1.5 million Agency for Healthcare Research and Quality grant designed to improve the detection and management of pain in acute care hospitals.

Ray E. Moseley, Ph.D. — $557,650 tracked thus far

National Institutes of Health - National Human Genome Research Institute — *$557,650*

1992 $263,559 University of Florida - College of Medicine - Community He — *INSURANCE IMPLICATIONS OF A COMPLETE HUMAN GENOME MAP*

5 R01HG000402-02

1993 $294,091 University of Florida - College of Medicine - Community He — *INSURANCE IMPLICATIONS OF A COMPLETE HUMAN GENOME MAP*

5 R01HG000402-03

Anne C. Mosenthal, M.D., FACS — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$70,000*

2000 $70,000 University of Medicine and Dentistry of New Jersey, New J — *Faculty Scholar, 2000-2002 (amount of funding is estimated)*

Benjamin W. Moulton, J.D., M.P.H. — $495,450 tracked thus far

Mayday Fund — *$495,450*

1997 $262,000 American Society of Law, Medicine, and Ethics — *Mayday Scholars program*

http://www.painandhealth.org/mayday/previous-grants.html
American Society of Law, Medicine and Ethics
Boston, Massachusetts
"American Society of Law, Medicine and Ethics"
$116,000, the final payment in a two year grant of $262,000 in support of ASLME's work to improve the law and regulations affecting the delivery of effective pain treatment and, in particular, the "Mayday Scholars" program.
Contact: Ben Moulton, Executive Director, ASLME
E-mail: aslme@bu.edu

2000 $233,450 American Society of Law, Medicine, and Ethics — *Mayday Scholars program*

http://www.painandhealth.org/mayday/previous-grants.html
American Society of Law, Medicine and Ethics
Boston, MA
USA
$233,450.00 in support of the Mayday Scholars program and to develop an interactive website to list, discuss and disseminate information about developing law relevant to the management of pain.
Contact: Benjamin W. Moulton, JD, MPH
Email: info@aslme.org
Web Site: www.aslme.org

Bill Moyers — $3,290,000 tracked thus far

Robert Wood Johnson Foundation — *$2,750,000*

1999 35477 $2,750,000 Public Affairs Television, Inc. — *On Our Own Terms - Bill Moyers*

Grantee organization is "Public Affairs Television, Inc., 356 West 58th Street, New York, NY: Production, promotion, and outreach for a public television series on the end of life (for 2 years).
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___186
This project supports the production of a four-part television documentary on death and dying in America that explores: (1) how Americans of different ethnic, cultural, religious, and socioeconomic backgrounds think about and experience death; (2) the movement within the health system to change care for the terminally ill, highlighting health care institutions that train for and practice state-of-the-art palliative care and debunking myths about pain management; (3) the stories of doctors and their patients who are wrestling with complex issues of death and dying, ranging from withdrawal of life support to euthanasia and physician-assisted suicide; and (4) the spiritual aspect of dying. An extensive outreach campaign intended to expand viewership for the program and increase its utility through organized community and informal educational activities is also planned. The outreach will occur simultaneously through local public television stations and through national organizations that have a demonstrated interest in end-of-life issues and outreach capacity.

Nathan Cummings Foundation, Inc. — *$540,000*

1997 $40,000 Educational Broadcasting Corporation *Living with Dying*

To conduct research for a four- or five-part television series on "Living with Dying" with Bill Moyers.

1998 $500,000 Educational Broadcasting Corporation *Living with Death*

To produce a four-part series for public television, "Living with Death" with Bill Moyers.

J. Cameron Muir, M.D., FAAHPM — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

2000 $70,000 Northwestern University *Faculty Scholar (grant amount is estimated)*
Palliative Care and Home Hospice Program - Northwestern University Medical School

Development of Interdisciplinary Outpatient Palliative Care Services: Enhancing the Continuum of End-of-Life Care. Given the current economic environment in health care, there is increased emphasis on the delivery of efficient, cost-effective medicine. The goal of this project is to seek funding to develop an interdisciplinary outpatient clinic for the management of palliative care issues including pain and symptom management, advance care planning, and coping with advanced disease. The project seeks to evaluate and implement the development of an interdisciplinaryoutpatient palliative care clinic that will not only provide direct palliative care but will enhance the continuum of whole person care provided by the other well established aspects of this program.

Lynne M. Mulder, M.S. — $449,960 tracked thus far

Robert Wood Johnson Foundation *$449,960*

1999 37917 $449,960 Florida Hospices and Palliative Care, Inc. *C-SP2: Community-State Partnerships - Florida Partnership for End-of-Life Care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___322
The Florida Partnership on End-of-Life Care will pursue the following initiatives: (1) engage the public through community leader coalitions to disseminate information about end-of-life care issues and facilitate policy and regulatory changes; (2) ensure advance directives and DNR orders are implemented and honored; and (3) promote adequate pain management and palliative care through education and training programs.

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years).
========
The Florida program will be carried out by the Florida Partnership to Improve EndofLife Care. Florida Hospice and Palliative Care, Inc. (FHPC) of Tallahassee will direct the projects. Samira K. Beckwith, president of FHPC and president of Hope Hospice and Palliative Care of Ft. Myers will lead the project. Lynne M. Mulder, executive director of FHPC, will be in charge of day-to-day direction of grant activities.
Other lead members of the Florida Partnership include the University of Florida College of Medicine's Department of Medical Ethics, Law and the Humanities, Florida Department of Health and Florida Department of Elder Affairs. These and several other organizations also were represented on the Panel for the Study of EndofLife Care constituted by the 1998 Florida Legislature. The 22-member Panel looked at the issues of pain management, advance care planning and financial and regulatory incentives the influence the quality of endoflife care.
"This is a tremendous opportunity to build on the work accomplished and relationships established by the Panel," said Samira Beckwith.
The grant will provide the statewide structure to carry out this important work.
Building on the Panel's recommendations and other state endoflife policy activities, the Florida Partnership has outlined six diverse initiatives. The first is to establish a network of community-based coalitions throughout the state to give Floridians access to practical, reliable information about endoflife care options and issues. Other initiatives will:
** Develop palliative care and pain management training programs for doctors, nurses, pharmacists and other health care professionals,*
** Assist state agencies in developing a portable do-not-resuscitate order and model advance care directive documents,*
** Develop training for EMS providers and emergency room personnel,*
** Train clergy on endoflife issues, and*
** Develop community outreach materials, community events and a speaker's bureau.*
====
Did some of the money go to Univ. of Florida's Program on Bioethics, Law, Medical Professionalism (PBLMP)?
See this from the Department of Community Health & Family Medicine:
http://www.chfm.ufl.edu/programs/blmp/blmp_activities.shtml
"On October 1999, the Program [PBLMP] received a substantial Robert Wood Johnson (RWJ) End-of-Life Care Grant as an integral part of the Florida Partnership for End-of-Life Care. Bill Allen is co-principal investigator and Ray Moseley is an investigator on this grant, which establishes a statewide partnership with a goal to improve end-of-life care through coordination of activities and education, and through impact on state policy. The primary role of the Program in this effort is to coordinate professional and public education activities in the state."

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

John Mullahy, Ph.D. — $4,626,114 tracked thus far

Robert Wood Johnson Foundation *$4,626,114*

2002 45825 $4,626,114 University of Wisconsin - Madison Medical School *The Robert Wood Johnson Foundation Health & Society Scholars Program*

http://www.rwjf.org/programs/grantDetail.jsp;jsessionid=BhB1UFPLh4ldAzUqk1Zqq49uI7Wt0Hc8rtAIbKL8o1rB4mnO0J4B!904486059?id=045825

Patricia A. Murphy, Ph.D., R.N., C.S., FAAN — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

2000 $70,000 University of Medicine and Dentistry of New Jersey, New J *Faculty Scholar, 2000-2002: Palliative Care in an Inner-City Trauma Service*

Alvin I. Mushlin, M.D., Sc.M. — $640,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$640,000*

2001 $640,000 Cornell University - Weill Medical College *Faculty Associates Program in Medical Ethics*

This grant supports the first year of a three-year project that seeks to bridge the gap between ethical theory and clinical practice by providing part-time support for an "internship" for practicing physicians to be more formally trained in medical ethics and to eventually build the capacity of the Division of Bioethics to better serve the patients of the New York Hospital Health System. Through conferences and bedside mentoring this program is designed to insure that elderly patients have access to doctors trained in clinical ethics to help them and their families with critical healthcare decisions. This grant funds the first year of the project, funding for years two and three will be contingent on the project's ability to successfully meet its interim objectives. Total expected costs for the entire three years would be $640,000

Naomi Nalerman, M.P.A. — $269,118 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$269,118*

$80,000 American Hospice Foundation *Grief at School*

http://www2.soros.org/death/report/pdia98-00report_8.pdf
Grief-at-School Training Program
Each year, millions of children and adolescents grieve over the death of a loved one. It is well documented that most Americans are not comfortable talking about death and grief, and this discomfort can have grave consequences for children who may receive little help developing constructive coping skills from the adults around them. For all children, school plays a vital role in shaping social skills; for a growing number of children, school fills the void left by family breakups. School personnel understand the burdens that children bring to school, but they are not adequately trained to respond. This project will expand an existing program by training members of national associations of school-based professionals. The program offers a 15-hour workshop to prepare schoolteachers, counselors, psychologists, nurses, and social workers to help grieving children in the classroom and after school. Participants learn to identify grieving children, conduct ageappropriate classroom lessons on loss and grief, establish school-based grief support groups, and use hospices as a local resource for grief expertise.

$52,876 American Hospice Foundation *Grief at School*

The American Hospice Foundation will design and pilot test a model for school-based grief program in 14 schools in Phoenix, Arizona and then replicate the model in Oklahoma City and Washington D.C. The model will include training workshops for school personnel, after-school support programs for grieving students, and comprehensive curricula focusing on age-appropriate grief concepts.

2001 $136,242 American Hospice Foundation *Grief at School Training Program in Collaboration with the National Association of School Psychologists will support leadership training for a new cohort of teams from*

http://www2.soros.org/death/newsletter10/selected_grants.html
The Grief at School Program trains schoolteachers, counselors, psychologists,nurses,and social workers to help grieving children in the classroom and in after-school programs.Workshops prepare participants to identify grieving children,conduct age-appropriate lessons on loss and grief,establish school-based grief support groups,and collaborate with local hospices.n 1999 PDIA supported the Grief at School 's 3-city pilot program.n response to the success of the pilot program,PDIA awarded a grant in 2000 to expand the program nationally by training members of national associations of school-based professionals via workshops at national and regional conferences.This third grant will make the model Grief at School training program available to members of the National Association of School Psychologists at national and state conferences.The goal is to facilitate the rapid expansion of the train-the-trainer workshops,both to school psychologists and graduate students.

Judith Eve Nelson, M.D., J.D. — $165,845 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$60,000*

$60,000 Mount Sinai School of Medicine *Faculty Scholar (amount of grant is estimated)*

PDIA Report 1998-2000: Integrating Palliative Care in the Intensive Care Unit
Patients admitted to Intensive Care Units arrive with the hope, shared by their caregivers, of reversing at least the immediate illness, if not the underlying disease. Nevertheless, 15 to 20 percent of adult patients admitted to an ICU in the United States do not survive hospital discharge. Often, death is impossible to anticipate in time to permit a shift from cure-oriented to comfort-oriented care. This project aims to examine and improve the experience of critically ill cancer patients and their families in the ICU. This new model will demonstrate that palliative care is not simply a sequel to intensive care but an essential component of comprehensive intensive care, provided concurrently to all patients.

National Institutes of Health - National Institute on Aging (NIA) *$105,845*

2004 $105,845 Mount Sinai School of Medicine *Improving Palliative Care in Chronic Critical Illness*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6817367&p_grant_num=1K02AG024476-01&p_query=%28palliative%29&ticket=14332762&p_audit_session_id=65197762&p_audit_score=100&p_audit_numfound=10&p_keywords=palliative
Grant Number: 1K02AG024476-01
PI Name: NELSON, JUDITH E.
PI Email: judith.nelson@mountsinai.org
PI Title:
Project Title: Improving Palliative Care in Chronic Critical Illness

Abstract: DESCRIPTION (provided by applicant): A large and growing population of patients survives acute critical illness only to become "chronically critically ill," with profound debilitation and often permanent dependence on life-sustaining technology. Despite intensive care, outcomes for these patients remain poor: mortality rates are high and extreme functional dependence is typical for survivors. Evidence suggests substantial patient suffering during care. Chronic critical illness is a serious health problem for the nation and especially for older adults; the majority of these patients are over age 65. The Candidate for this K02 award brings expertise in critical care and palliative medicine to this important new area for aging research. Overall goals of her research program are: I. To assess palliative care needs of chronically critically ill older adults; II. To evaluate the influence of unmet palliative needs on important clinical/utilization outcomes of chronic critical illness; and III. To test targeted interventions to improve palliative care/associated outcomes of older adults with chronic critical illness. She recently received her first R01 award for research with these specific aims: 1) To assess symptom distress during chronic critical illness; and 2) To analyze associations between symptom experience and other outcomes including success in/time to liberation from mechanical ventilation, functional status and survival. Here, the Candidate presents a plan for further career development/research that will enhance the current R01 and facilitate her transition from newly independent investigator to leader of a strong, expansive, and sustainable program that continues to inform and improve palliative care for older adults with chronic critical illness. Whereas she currently carries substantial non-research responsibilities, a K02 award would protect the Candidate's time to: 1) Advance her skills/knowledge/experience in clinical research methods/project leadership, palliative medicine and geriatrics; 2) Use her ongoing observational research as a platform for successful applications for federal funding of interventional studies; and 3) Establish herself as an investigator of international stature. The environment is a renowned center for research in geriatric palliative care and chronic critical illness and for clinical research training; the institution offers enthusiastic support.
Institution: MOUNT SINAI SCHOOL OF MEDICINE OF NYU
OF NEW YORK UNIVERSITY
NEW YORK, NY 10029
Fiscal Year: 2004
Department: MEDICINE
Project Start: 01-SEP-2004
Project End: 31-AUG-2009
ICD: NATIONAL INSTITUTE ON AGING
IRG: NIA

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Kaye Norris, Ph.D. — $699,146 tracked thus far

Robert Wood Johnson Foundation *$699,146*

1999 36677 $699,146 Missoula Demonstration Project / Life's End Institute *Missoula Demonstration Project*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___495
The Missoula Demonstration Project (MDP) was established in March 1996, to research the experience of dying persons and their families and to demonstrate that a community-based approach of excellent medical care and psychological, social, and spiritual support can consistently improve the quality of life among those who are dying and their families. Over the past year, the MDP has focused on administration and data analysis of the surveys it has conducted, including a retrospective clinical profile of 250 deaths, a faith community leaders survey, a Native American experience assessment, and administration of community and physicians' surveys in a comparison city of Laramie, Wyoming. Additional results are being finalized for the prospective and retrospective clinical profiles, family bereavement interviews, community focus groups, and patient and family caregiver surveys. As the project details the lessons learned, the focus will turn to communication and dissemination of the findings. The development of a strategic communications plan will enable the MDP to share its research tools, methodology, and community engagement strategies (with families, institutions, and agencies) with national and local colleagues.

Laurence J. O'Connell, Ph.D. — $21,559 tracked thus far

Robert Wood Johnson Foundation *$21,559*

1996 29559 $21,559 Park Ridge Center for the Study of Health, Faith and Ethic *Conference on Rituals and End-of-Life Care in Institutional Settings*

Summary
This grant from The Robert Wood Johnson Foundation supported a one-day seminar in which experts, practitioners, and lay people explored the role of rituals in End-of-Life care in institutionalized settings. The goals of the seminar were: (1) to explore the nature and role of rituals in human life, especially during situations of transition; (2) to analyze End-of-Life care and uncover the critical moments of the dying, their families, and medical personnel; (3) to explore types of rituals and their appropriateness at the end of life in institutionalized settings; and (4) to suggest program areas designed to address meaning and ritual in End-of-Life care. Fifteen persons, including theologians, anthropologists, sociologists, administrators, gerontologists, ethicists, and a dramaturge/ritualist attended the conference on April 25, 1997. Participants presented position papers, heard responses, and engaged in group discussions. A summary of the working group's findings was produced by the Park Ridge Center after the seminar. A key observation was that the "rituals" of technological medical care often clashed with the religious and/or cultural rituals patients and families drew upon to find meaning at the time of death. The group recommended: (1) social science study of medical rituals; (2) evaluation and reconstruction of religious rituals to improve care of the dying; (3) identification, collection, and dissemination of stories that undergird rituals; (4) study of the interaction of various rituals; and (5) collection and creation of innovative rituals. Project findings will inform ongoing Foundation initiatives for improving the care of dying persons

Jonathan Oberlander, Ph.D. — $148,391 tracked thus far

Greenwall Foundation *$148,391*

2002 $148,391 University of North Carolina - Chapel Hill *Rationing Medicine:The Oregon Health Plan and the Search for Justice In Health Policy*

http://ww*http://www.greenwall.org/2k4MedList.htm*
University of North Carolina at Chapel Hill
Research support: Rationing Medicine:The Oregon Health Plan and the Search for Justice In Health Policy (three-year grant:$148,391, awarded in 2002)
==========
$50,118
[WPD] CURRICULUM VITAE Jonathan B. Oberlander Personal Information ...
File Format: Corel WordPerfect 6.1 - View as HTML
... July 2002-June 2005, "Rationing Medicine: The Oregon Health Plan and the Search for Justice in Health Policy," Principal Investigator. ...
www.med.unc.edu/wrkunits/2depts/ soclmed/FACULTY&STAFF/oberlandercv.wpd - Similar pages

Margo Okazawa-Rey, Ed.D. — $30,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$30,000*

2000 $30,000 San Francisco State University *Social Work Leader, 2000 (Amount of grant is estimated)*

(With Norma del Rio) This project combines a grass roots program in northern California for minority and disadvantaged terminally ill individuals with the San Francisco State Multicultural Institute. Project goals are to 1) develop cross-cultural/cross ethnic assessment guidelines for the terminally ill and bereaved; 2) design and implement a curriculum for graduate social work students that integrates end-of-life care and multiculturalism and 3) test the application of available measures of professional cultural competency developed for other areas to end-of-life care.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Frank Ostaseski — $95,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation)

Zen Hospice Project — *Cultivating Compassion workshop and educational materials*

To initiate a broad-based experiential community, professional, and client education program. Written materials that bring a new perspective to the care of the dying and to ways of approaching death will be developed. In addition, six three-day "Cultivating Compassion" workshops will be offered. The aim of the workshop is to de-mystify the caregiving process, investigate our response to suffering, and clarify our intention in service.

Nathan Cummings Foundation, Inc. — *$95,000*

2000 $95,000 Zen Hospice Project — *A Capacity Building Initiative*

To build the capacity of the Zen Hospice Project to respond to the high volume of inquiries it receives about its work.

Steven Z. Pantilat, M.D. — $1,629,640 tracked thus far

Robert Wood Johnson Foundation — *$750,000*

2003 49042 $750,000 University of California - San Francisco — *Palliative Care Leadership Center*

Open Society Institute / Project on Death in America (Soros Foundation) — *$153,000*

1998 $153,000 University of California - San Francisco — *Faculty Scholar, 1998-2000: A Palliative Care Curriculum for Medicine Residents and Hospitalist Trainees (Grant amount is estimated.)*

Sixty-three percent of patients die in hospitals and many die in pain. Hospitalists, internists who spend at least 25 percent of their time caring for inpatients in place of a patient's primary care provider, provide much of the care for these patients, but are largely untrained in palliative care. Dr. Pantilat will develop, implement, and evaluate a palliative care curriculum for medicine residents and fellows training to specialize as hospitalists at UCSF.
http://medicine.ucsf.edu/hospitalists/people/steven_pantilat_cv.html
This faculty development award funded the development, implementation and evaluation of a curriculum focused on improving end-of-life care. The curriculum is designed for medical residents, including those pursuing careers as hospitalists.

National Institutes of Health - National Institute on Aging (NIA) — *$726,640*

2000 $726,640 University of California - San Francisco — *Improving Inpatient Palliative Care for Older Adults*

1 K23 AG01018-01
This grant supports a controlled, clinical trial to determine whether a multidisciplinary palliative care consultation will improve management of two physical symptoms, pain and dyspnea, one psychological symptom, anxiety, advance care planning and spiritual care for seriously ill, hospitalized older adults. It also provides for ongoing mentorship and professional development.

Steven D. Passik, Ph.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

1999 $50,000 Indiana Community Cancer Care Foundation — *Faculty Scholar, 1999-2001: The Oncology Symptom Control and Research Program: Creating a Palliative Care Clinical, Educational, and Research Initiative in a Community-Based, Rural, Oncology Setting (Grant amount is estimated.)*

In order to improve the quality of cancer treatment for rural patients in their own communities, this project will establish a palliative care service. The service will develop educational ties, especially with mental health programs throughout the state, to expose trainees in psychology, psychiatry, and social work to palliative care early in their careers. Through research and education, the project will increase oncologists' palliative care skills, train new practitioners, make promising palliative care research treatments available to rural communities, and contribute to the evidence base supporting palliative care interventions by monitoring patients throughout their care.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Richard Payne, M.D. — $838,214 tracked thus far

Robert Wood Johnson Foundation — *$446,990*

2002 43073 $446,990 North General Hospital — *EPEC2 Project: End-of-life care education for African-American health care professionals*

http://www.rwjf.or *PROJECT*
The EPEC2 Project: End-of-life care education for African-American health care professionals

GRANTEE
North General Hospital
1879 Madison Avenue
New York , NY 10035-2709

GRANT DETAIL
$446,990 (21 months, awarded on 07/16/2002, starting 07/15/2002 ending 04/30/2004) ID# 043073

CONTACT INFORMATION
Richard Payne M.D. (Project Director)
payner@mskcc.org
212-639-8031

Open Society Institute / Project on Death in America (Soros Foundation) — *$241,224*

2002 $166,224 North General Hospital — *To North General Hospital to establish a national program office for Initiative to Improve Palliative Care for African-Americans*

http://www2.soros.org/death/general_grants_01-03.shtml
The Initiative to Improve Palliative Care for African-Americans (IIPCA) is defining and promoting an agenda in research, education, and policy to improve care for African American patients facing serious illness. This grant supports the infrastructure of a national program office (NPO) that will be located at North General Hospital in Harlem. IIPCA will have four main objectives: 1) to serve as a resource center for the collection, evaluation, and dissemination of information about palliative and end-of-life care in the African-American community; 2) to facilitate networking and a national dialogue across various disciplines in the African-American community regarding palliative and end-of-life care; 3) to propose, review, and coordinate targeted areas of research that will increase our understanding of the needs of African-Americans in palliative and end-of-life care, and to increase the understanding of the socio-economic, legislative and regulatory barriers to improved palliative and end-of-life care; and 4) to advocate for changes in health policy, legislation and standards of care that impact the availability, utilization, and quality of palliative and hospice services for African-Americans.

2002 $75,000 North General Hospital — *Initiative to Improve Palliative Care for African-Americans - National Conference Jan 3-4, 2002*

http://www2.soros.org/death/general_grants_01-03.shtml
The Initiative to Improve Palliative Care for African-Americans (IIPCA) is an interdisciplinary working group of African American scholars, professionals, and community leaders who have gathered to delineate the historical, social, cultural, ethical, economic, legal, health policy, and medical issues that appear to affect African Americans' attitudes towards, acceptance of, access to, and use of palliative and hospice services. The Initiative's objective is to work collectively to define and promote a research, education, and policy agenda to improve care for African American patients facing death. This grant supports a national leadership meeting to take place on January 3rd and 4th, 2002 in Harlem, New York. Through the theme of this conference, "Heritage, Health, and Hope," the initiative acknowledges the positive strengths and hopes derived from the rich African-American heritage and the desire to employ those strengths toward improving the health of the African-American community. The goal is to use this event to engender suggestions for demonstration projects and other efforts that would point toward solutions for improving palliative care for African Americans.

Kornfeld / PDIA (Soros) collaborative — *$150,000*

2003 $150,000 Memorial Sloan Kettering — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Samuel K. Payne, M.D. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1998 $50,000 University of Iowa

Faculty Scholar, 1998-2000: The Development and Evaluation of Telemedicine Applications in Palliative Care (Grant amount is estimated.)

The population of Iowa is spread out over a large, mostly rural area, and ranks first in the nation in the percentage of its population over 85 years old. Advances in communications technology provide new opportunities for health care providers to extend care from the hospital to patients' homes. Using telemedicine to enhance hospice and palliative care may help improve health care service to remote areas of the state. Dr. Payne will create a series of interactive telemedicine seminars in palliative care for physicians, nurses, and allied health providers throughout the state. He will evaluate telemedicine as a tool to allow clinicians to follow patients after they are discharged from the hospital into the home, and to monitor the challenges of home care for the patient, the family, and the health care team.

Robert A. Pearlman, M.D., M.P.H. — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1999 $50,000 University of Washington

Faculty Scholar, 1999-2001: Evaluating and Ameliorating End-of-Life Suffering (Grant amount is estimated.)

(With Anthony Back) At the end-of-life, suffering has special resonance for patients and physicians, and relief of suffering becomes the fundamental goal of medicine. Yet physicians rarely evaluate suffering or discuss it explicitly with patients. This two part project aims to improve medical evaluation and amelioration of suffering for patients in the last year of life. The project team will conduct a qualitative study of patient experiences in the last year of life, involving longitudinal patient interviews, to characterize suffering and its evolution over time. These patient narratives will then be integrated in an education program for faculty physicians with inpatient medicine attending responsibilities to improve patient-physician communication and will add to the growing body of medical research of suffering and its treatment.

Kendra Peterson, MD — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1998 $50,000 Stanford University School of Medicine

Faculty Scholar, 1998-2000: medicine is increasing. Dr. Muir will develop an
Quality of Life / Quality of Death: Living and Dying with a Malignant Brain Tumor (Grant amount is estimated.)

Little is known about the experience and needs of patients dying with malignant brain tumors. Dr. Peterson will characterize the experience of such patients and their caregivers in order to facilitate the development of improved models of care. This study is expected to generate novel insights about patient and caregiver experience and positively effect the future practices of trainees and faculty at Stanford Medical Center and providers around the country.

Susan Foley Pierce, Ph.D., R.N. — $129,694 tracked thus far

Robert Wood Johnson Foundation *$129,694*

1996 30101 $100,000 University of North Carolina - Chapel Hill

Monograph for nurses on care of the dying: "Notes on a Peaceful Death"

1996 Annual Report. (2 years)

1999 $29,694 University of North Carolina - Chapel Hill

Monograph on Care of the Dying for Nurses--supplemental support

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_user_view_html__468
In 1997, the Foundation provided funding to develop a monograph titled, "Notes on a Peaceful Death," and to disseminate the information contained therein to members of the nursing profession. This grant will extend and expand that work. The previous grant resulted in the development of a manuscript suitable for publication and the convening of a group of nursing influentials to discuss and assist in disseminating the precepts of a peaceful death (December 1998). The group reached two principal conslusions: (1) nurses have a primary role in instituting care that will lead to a peaceful death; and (2) nurses, with the leadership of symposium participants, will lead the effort to improve patient care, starting with an effort to add a fifth vital sign, pain assessment, to the routine taking of vital signs (temperature, pulse, respiration, and blood pressure).

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

James D. Plumb, M.D. — $150,000 tracked thus far

Robert Wood Johnson Foundation *$150,000*

1993 $150,000 Jefferson Medical College — *JeffCARES: Community Action, Research, Education, and Service*

http://www.rwjf.org/reports/grr/healthpublice-r06.htm
The Health of the Public (HOP) project funded by The Robert Wood Johnson Foundation (RWJF) at Thomas Jefferson University expanded coverage of topics concerning population health in the Jefferson Medical College curriculum and established university-community partnerships to promote the health of individuals living in and around Center City Philadelphia. The partnerships involved the medical college, the College of Allied Health Sciences, Thomas Jefferson University Hospital, other area medical schools, and community organizations. The JeffCARES project worked in collaboration with other RWJF initiatives, including the Pennsylvania Generalist Physician Initiative at Pennsylvania State University Medical School in Hershey, PA, (a site of RWJF's Generalist Physician Initiative, a national program to challenge schools of medicine — in collaboration with state governments, private insurers, HMOs, hospitals, and community health centers — to increase the supply of generalist physicians); and the Bridging the Gaps: Philadelphia Community Health Internship Program, a local initiative that also involved the University of Pennsylvania HOP project. It places medical students from all of the city's medical schools in community health-related projects.

Russell K. Portenoy, M.D. — $519,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1998 $50,000 Beth Israel Medical Center - NYC — *United States Cancer Pain Relief Committee, Inc./ NIH Conference, March, 1998*

(I am guessing that Beth Israel was the grant recipient, as I believe he was there at the time.) Project: Co-sponsored by The National Institutes on Health (U.S.), and The United States Cancer Pain Relief Committee, this conference, to be presented March 12 - 14, 1998 and will provide an open forum for an exchange of new research findings and methods of investigation relevant to palliative care Prior to this conference's commencement, current information pertaining to research methodologies relevant in symptom control and palliative care will be collated and critiqued; a monograph will be created that defines the current state of affairs; and an agenda for future research will be decided. The abstracts will be published in the Journal of Pain and Symptom Management.

Mayday Fund *$5,000*

2003 $5,000 Beth Israel Medical Center - NYC — *Recognition of Russell Portenoy*

Beth Israel Medical Center, Department of Pain Medicine and Palliative Care
New York, NY
A grant of $5000 in recognition of all the work that Dr. Russell K. Portenoy does to help educate the broader public about pain and the myths that surround the use of pain medication.
Web Site: http://www.stoppain.org/

Fan Fox and Leslie R. Samuels Foundation *$414,000*

1999 $50,000 Beth Israel Medical Center - NYC — *The First International Conference on Geriatric Palliative Care.*

http://www.samuels.org/hc1999.htm

2003 $364,000 Beth Israel Medical Center - NYC — *The Palliative Care Home Care Service*

The Department of Pain Medicine and Palliative Care (PC) will hire two advance practice nurses to develop a model approach to improve medical and psycho-social support services for elderly home care pts. in need of PC. The program will improve appropriate use of hospice services, assist caregivers, and provide education to home care nurses and physicians.

Commonwealth Fund *$50,000*

1998 $25,000 Beth Israel Medical Center - NYC — *Longitudinal Outcomes Assessment for a New Model of Palliative Care: Pilot Phase*

Longitudinal Outcomes Assessment for a New Model of Palliative Care: Pilot Phase

1998 $25,000 Beth Israel Medical Center - NYC — *Establishing the New York Quality of Care at the End of Life Research Consortium*

Establishing the New York Quality of Care at the End of Life Research Consortium

Thomas J. Prendergast, M.D. — $225,110 tracked thus far

Robert Wood Johnson Foundation *$85,110*

2003 42705 $85,110 Dartmouth-Hitchcock Medical Center — *Survey of critical care fellows on palliative and end-of-life care training*

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1999 $140,000 Dartmouth-Hitchcock Medical Center — *PDIA Faculty Scholar, 1999-2001*

Amount of grant is estimated.
Physicians specializing in critical care medicine require training in the philosophy and practice of palliative care. This project will develop a curriculum for teaching health care professionals who work in the ICU about the principles of palliative care with an emphasis on negotiation and conflict resolution techniques.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Christina M. Puchalski, M.D. — $72,982 tracked thus far

Robert Wood Johnson Foundation *$72,982*

1998 31236 $72,982 George Washington University — *Enhancing the role of national religious organizations in improving end-of-life care (Home Care Research Initiative; Chronic Health)*

Washington, DC: Enhancing the role of national religious organizations in improving end-of-life care (for 1 year).
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___41
This project will support a conference of chaplains and physicians to discuss the role that religious organizations can play in improving end-of-life care. Chaplains will inform physicians on the spiritual needs of the dying, and physicians will inform chaplains on the significant medical issues in end-of-life care. Two resource guides will be developed: (1) a guide for health care institutions to begin to understand and address the spiritual component of end-of-life care; and (2) a policy resource book for religious organizations as they examine their role in caring for individuals at the end of life.

Kathleen Puntillo, R.N., DNSc, FAAN — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1998 $50,000 University of California - San Francisco — *Faculty Scholar, 1998-2001: Improving Symptom Assessment and Management during Palliative Care of Dying Patients in Intensive Care Units (Grant amount is estimated.)*

People who die in Intensive Care Units suffer greatly from distressing symptoms, such as pain, difficulty breathing, and agitation. Despite advances in symptom control in other medical settings, limited research in end-of-life care in the ICU and the incomplete application of palliative care practices to this setting contribute to poor symptom control. This project will describe symptom assessment and management practices for dying patients in ICUs and use this information to design, implement, and evaluate an academic course in symptom assessment and management in the ICU.

Timothy E. Quill, M.D. — $115,000 tracked thus far

Mayday Fund *$115,000*

1999 $115,000 ViaHealth - Greater Rochester Health Care System — *Pain as Fifth Vital Sign*

http://www.painandhealth.org/mayday/previous-grants.html
Greater Rochester Health Care System (ViaHealth)
Rochester, New York
$60,000, the first of two payments in a two year $115,000 grant to ViaHealth to support measuring and treating pain in the acute, chronic and home care programs run by a health care organization with 400,000 subscribers in upstate New York.
Contact: Timothy Quill, M.D.
E-mail: timothy.quill@viahealth.org

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http://yaledailynews.com/articlefunctions/Printerfriendly.asp?AID=10834
"The Mayday Fund, in conjunction with the Kornfeld Foundation, recently [1998] awarded $115,000 to ViaHealth -- a coalition of health care organizations -- to do research on pain as the fifth vital sign"

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Michael W. Rabow, M.D. — $450,000 tracked thus far

Robert Wood Johnson Foundation — *$450,000*

1998 35486 $450,000 University of California - San Francisco — *Comprehensive Care Team: A Controlled Trial of Care at the Beginning of End of Life - Promoting Excellence in End-of-Life Care*

Annual Report: San Francisco, CA: (3 years).
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http://web.archive.org/web/20020309215816/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___117
Summary Title: Promoting Excellence in End-Of-Life Care
Project Title: The Comprehensive Care Team: A Controlled Trial of Care at the Beginning of End of Life
Project Director: Michael W. Rabow Degree: M.D.
Phone No.(Work): 415-353-7918
Fax (Work): 415-353-7901
Email: mrabow@medicine.ucsf.edu
Grantee Institution: University of California at San Francisco
Address: 1701 Divisadero Street
Fifth Floor
San Francisco California United States.
Start Date: 10/01/1998 End Date: 09/30/2001
Amount: $450,000 Web Site:
Description: Researchers at UC San Francisco's Collaborative Innovation in Primary Care Program and the Hospice by the Bay are collaborating to address the problem that dying patients often feel forced to make a decision between life-prolonging medial care and hospice support for themselves and their families. The project will employ a randomized study to assess the feasibility, impact and cost-effectiveness of removing this dichotomy. Patients may receive state-of-the-art medical care and at the same time, hospice or palliative care. An interdisciplinary team of doctors, nurses, and social workers will provide comprehensive care and family caregiver support for seriously ill outpatients who are nearing the end of their lives. Using a case management model, the program will draw heavily on local volunteer support services, faith communities and social agencies. The project will assess the team's impact on patient quality of life, level of symptom control, psychosocial and spiritual well being, advance care planning and health care utilization.

Open Society Institute / Project on Death in America (Soros Foundation)

University of California - San Francisco — *Faculty Scholar*

http://www.medschool.ucsf.edu/teachingscholars/scholarlist/rabowm.aspx

Gloria C. Ramsey, R.N., B.S.N., J.D. — $190,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation — *$190,000*

2002 $190,000 New York University — *Working with the African American Church Community to Encourage End of Life Planning and Proxy Form Completion*

This project seeks to establish an ongoing program of educational activities in the Convent Avenue Baptist Church aimed at encouraging African Americans to complete advance directives and appoint healthcare agents. A simple evaluation will measure whether people actually complete the forms as a result of the intervention. [ISW: EPEC2?]

Martha Ramsey — $560,000 tracked thus far

Robert Wood Johnson Foundation — *$560,000*

2000 38964 $560,000 American Association of Retired Persons (AARP) — *Modern Maturity special section for "On Our Own Terms"*

The American Association of Retired Persons (now known as AARP) produced an eight-page pullout special section called "Start the Conversation: The Modern Maturity Guide to End-of-Life Care" for the September/October 20002 issue of its Modern Maturity magazine. The Robert Wood Johnson Foundation (RWJF) provided grant support for the effort.

The pullout appeared in the September/October 2000 issue of Modern Maturity, to coincide with the Bill Moyers PBS series "On Our Own Terms: Moyers on Dying" (partially supported by RWJF grant ID# 035477) and was part of RWJF's Targeted End-of-Life Projects Initiative (ID#s 034625, 041076). The purpose of the guide was to heighten readers' awareness of end-of-life issues and provide information on four aspects of end-of-life decision making: physical, emotional, financial and legal. The guide also listed resources for medical and emotional care and for legal and financial help, and it contained information on hospice care and caregiver concerns.
http://www.rwjf.org/reports/grr/038964.htm

David F. Ransohoff, M.D. — $1,899,014 tracked thus far

Robert Wood Johnson Foundation — *$1,899,014*

1998 34655 $599,996 University of North Carolina - Chapel Hill — *Clinical Scholars Program*

http://www.rwjf.org/reports/grr/034655.htm and the 1998 Annual Report

1998 34448 $1,299,018 University of North Carolina - Chapel Hill — *Clinical Scholars Program*

http://www.rwjf.org/reports/grr/034655.htm and the 1998 Annual Report

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Edward Ratner, M.D. — $445,140 tracked thus far

Robert Wood Johnson Foundation — *$445,140*

1999 37635 $445,140 Metropolitan Area Agency on Aging, Inc. — *C-SP2: Community-State Partnerships – Minnesota*

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years).

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___325
The Minnesota Partnership to Improve End-of-Life Care includes the Allina Health System, Fairview Health Services/BlueCross BlueShield of Minnesota, and HealthPartners, providing a unique opportunity to reach 85 percent of the population of Minnesota. The partnership will work in three critical areas: (1) to reduce public policy barriers through formation of a highly visible, state-sponsored commission in collaboration with the Minnesota Commissioner of Health that will focus on state funding, education, and licensure issues; (2) to coordinate curriculum development; and (3) to increase incentives for palliative care through design and implementation of a palliative care benefit package for health plans.

Mary Raymer, M.S.W. — tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation)

PDIA Social Work Leader

Burton Reifler, M.D., M.P.H. — $28,482,273 tracked thus far

Robert Wood Johnson Foundation — *$24,861,866*

1987 $6,300,000 Wake Forest University School of Medicine — *Dementia Services*

1988 $3,900,000 Wake Forest University School of Medicine — *Dementia Care and Respite Services Program (DCRSP)*

http://www.rwjf.org/reports/npreports/partnerse.htm
In 1987, to address the need for community-based, nonresidential programs that can meet the needs of demented individuals and their caregivers, RWJF created the Dementia Care and Respite Services Program (DCRSP). With a $3.9-million commitment from RWJF and $625,000 each from the national Alzheimer's Association and the federal Administration on Aging, this program, which ran from 1988 to 1992, was the first national adult day services demonstration program. Technical assistance and direction were provided by a National Program Office at the Wake Forest University School of Medicine, Winston-Salem, NC, under the direction of Burton V. Reifler, MD.

1998 24202 $1,900,000 Wake Forest University School of Medicine — *PIC - Partners in Caregiving - Promoting Excellence in End-of-Life Care (Chronic Health Conditions)*

Winston-Salem, NC: Technical assistance for the dissemination of the adult day service programs (30 months). Program to provide technical assistance and grant support to help adult day centers develop and strengthen innovative center-based,in-home, and other respite programs for people with chronic cognitive disorders (for the period indicated).

2000 37535 $401,083 Wake Forest University School of Medicine — *Chronic Health*

[I'm guessing that Reifler is the contact.] Adult day services census (for 8 months).

2002 43798 $4,250,223 Wake Forest University School of Medicine — *Technical assistance and direction for Faith in Action*

2003 46128 $4,729,778 Wake Forest University School of Medicine — *Technical assistance and direction for Faith in Action*

2004 48407 $3,380,782 Wake Forest University School of Medicine — *Technical assistance and direction for Faith in Action*

From the Grants database

Alzheimer's Disease & Related Disorders Assn. — *$625,000*

1988 $625,000 Wake Forest University School of Medicine — *Dementia Care and Respite Services Program (DCRSP)*

http://www.rwjf.org/reports/npreports/partnerse.htm
In 1987, to address the need for community-based, nonresidential programs that can meet the needs of demented individuals and their caregivers, RWJF created the Dementia Care and Respite Services Program (DCRSP). With a $3.9-million commitment from RWJF and $625,000 each from the national Alzheimer's Association and the federal Administration on Aging, this program, which ran from 1988 to 1992, was the first national adult day services demonstration program. Technical assistance and direction were provided by a National Program Office at the Wake Forest University School of Medicine, Winston-Salem, NC, under the direction of Burton V. Reifler, MD.

US DHHS - Administration on Aging (AoA) — *$625,000*

1988 $625,000 Wake Forest University School of Medicine — *Dementia Care and Respite Services Program (DCRSP)*

http://www.rwjf.org/reports/npreports/partnerse.htm
In 1987, to address the need for community-based, nonresidential programs that can meet the needs of demented individuals and their caregivers, RWJF created the Dementia Care and Respite Services Program (DCRSP). With a $3.9-million commitment from RWJF and $625,000 each from the national Alzheimer's Association and the federal Administration on Aging, this program, which ran from 1988 to 1992, was the first national adult day services demonstration program. Technical assistance and direction were provided by a National Program Office at the Wake Forest University School of Medicine, Winston-Salem, NC, under the direction of Burton V. Reifler, MD.

National Institutes of Health - National Institute of Mental Health (NIMH) *$2,370,407*

1992 $1,500,000 Wake Forest University School of Medicine *Psychiatric Problems in a General Health Settings*

http://www.wfubmc.edu/psychiatry/grants.html

1996 $432,407 Wake Forest University School of Medicine *Psychiatric problems in general health settings*

5 R24MH051552-04 Psychiatry and Behavioral Med

1997 $438,000 Wake Forest University School of Medicine *Psychiatric problems in general health settings*

5 R24MH051552-05 Psychiatry and Behavioral Med

Nancy Reller — $2,541,526 tracked thus far

Robert Wood Johnson Foundation *$2,541,526*

2002 45919 $1,448,890 Sojourn Communications *Last Acts campaign–Phase II (1 year)*

2002 44944 $1,092,636 Sojourn Communications *Last Acts campaign–Phase II (1 year)*

Anne Rhome, M.P.H., R.N. — $1,049,824 tracked thus far

Robert Wood Johnson Foundation *$1,049,824*

2000 40766 $846,999 American Association of Colleges of Nursing (AACN) *ELNEC support*

ELNEC (http://www.rwjf.org/reports/grr/032829.htm)
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___643
This supplement grant addresses the overwhelming response to the End of Life Nursing Education Consortium (ELNEC) project that provides an educational opportunity in end-of-life care for nursing school faculty. Funds will be used to increase enrollment in already scheduled courses; add three additional courses for undergraduate faculty to provide training for current and future applicants; add one additional course for continuing education providers; and support faculty to present an abridged ELNEC course in conjunction with five Last Acts regional meetings.

2002 $202,825 American Association of Colleges of Nursing (AACN) *ELNEC: Evaluation of nursing faculty development in end-of-life care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___746
AACN, in partnership with City of Hope National Medical Center, will perform a knowledge asessment of 1,110 nursing students to evaluate student knowledge pre and post End-of-Life Nursing Education Consortium Project (ELNEC) implementation into their nursing school curriculum. The results from the student evaluation will provide valuable information on the implementation of end-of-life curriculum into nursing programs, that can be used to inform future program development. Funds will support the ELNEC staff, psychometric testing, and pre and post test administration, and statistical analysis.

Tamara E. Robinson — $639,705 tracked thus far

Robert Wood Johnson Foundation *$639,705*

1996 29469 $639,705 Educational Broadcasting Corporation *Multi-Media Curriculum on End-of-Life Issues for Grassroots Organizations (Before I Die)*

See also grant #29929
The Foundation-sponsored SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) on care for seriously ill and dying patients revealed that death is a subject rarely discussed by most Americans. This project produced a multi-media curriculum to be used by grassroots organizations to promote the exploration of attitudes toward end-of-life issues. The project's centerpiece, a one-hour television broadcast, Before I Die, aired on Public Broadcasting Service stations April 22, 1997 and was rebroadcast September 19, 1997. The program featured a panel of experts in medicine, journalism, ethics, and religion who debated three hypothetical scenarios: a young mother dying from advanced breast cancer; a 65-year-old man who, in peak health, signs an advanced directive; and a young man with AIDS who seeks control over his death. The project also developed a "Viewer's Guide for Before I Die" and other educational materials for individuals and groups to further explore issues around end-of-life. The project held a pre-broadcast videoconference for 40 local stations or organizations designed to generate interest in organizing discussion groups following the actual broadcast. A World Wide Web site (www.wnet.org/bid) was also developed on end-of-life issues, which provided facts and figures, profiles of individuals confronting end-of-life issues, and on-line support groups. More than 646,000 viewers saw the original broadcast. Reviews of the program were featured in publications including The New York Times and The Washington Post. More than 30 newspapers and guides listed it as a recommended program. The Web site continues to promote the Before I Die videos and educational materials. The project produced an educational, interactive tool for bringing end-of-life issues to consumers, and it complements the Foundation's Last Acts initiative, a national program that seeks to better manage end-of-life care.

Walter M. Robinson, M.D., MPH — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1996 $50,000 Harvard Medical School *Faculty Scholar, 1996-97 (Grant amount is estimated.)*

An examination of the medical and ethical aspects of end-of-life care for chronically ill children and their families and development of a specialized team of physicians, nurses, and other caregivers to meet their particular needs.

New York, NY -- 29 May 1996

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Susan Rogers, MS, BSN, CHPN

tracked thus far

US DHHS - Agency for Healthcare Research and Quality (AHRQ)

2002 Americans for Better Care of the Dying (ABCD) *EPEC, ELNEC conference: "Making Change Happen in Palliative Care"*

http://www.gold.ahrq.gov/GrantDetails.cfm?GrantNumber=R13%20HS12090
Grant Number: R13 HS12090
RFA/PA:
PI Name: ROGERS, SUSAN
Project Title: Meeting People Where They Are: Palliative Care Across H

Abstract:

In 2000 and 2001, Americans for Better Care of the Dying joined with the D.C. Partnership to Improve End-of-Life Care to conduct dinner conferences focused on improving end-of-life care. The conferences: Incorporating End-of-Life Care into Your Curriculum and Effective Interdisciplinary Teams: An End-of-Life Model, drew over 135 people to meet and discuss much of the current research in end-of-life care training, including the American Medica! Association's EPEC (Education for Physicians in End-of-Life Care) curriculum, and the corresponding American Association of Colleges of Nursing's ELNEC (End-of-Life Nursing Education Consortium) curriculum. The planned half-day conference set for September 13, 2002, at Georgetown University, "Making Change Happen in Palliative Care," will broaden the focus to build on national research, as well as on the success of these two pervious conferences.

** disseminate and expand findings from the Institute of Medicine's 2001 report, Improving Palliative Care for Cancer*
** document and present effective models of palliative care throughout the region and the nation*
** enhance the collaboration that has resulted from the formation of the Community-State Partnerships to Improve End-of-Life Care, funded in part by the Robert Wood Johnson in 19 states and the District of Columbia, and foster increased interdisciplinary care of dying patients and their families.*

Among those who will attend the September conference will be leaders of hospice, hospital palliative care, and nursing home palliative care programs. In addition, health professionals from emergency rooms, intensive care units, nursing home chronic care units, transplant programs, and various pediatric programs will be invited. All health professional disciplines, including physicians, nurses, social workers, chaplains, therapists, ethicists and other allied health staff will be included as speakers and participants. Approximately 200 participants are expected.

Based on information gleaned from the two dinner programs and the poster session, as well as a brief survey conducted with a small group of attendees at the 2001 program, the half-day conference will include two plenary sessions: (1) the 10M report and how that information can be expanded to cover patients with a variety of diagnoses; and (2) the special needs of minority populations, including the difficult questions of access to care.

Fiscal Year: 2002
Department: AMERICANS FOR BETTER CARE OF THE DYING
Project Start: 07/01/2002
Project End: 06/30/2003
Accession Number: PB2005-102772 (http://www.ntis.gov)
IRG: ZHS1

David L. Rosenbloom, Ph.D.

$19,215,553 tracked thus far

Robert Wood Johnson Foundation *$19,215,553*

1991 18713 $1,931,002 Boston University - School of Public Health *Join Together program - National Technical Assistance Project for Substance Abuse Initiatives*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)

1993 19307 $8,782,509 Boston University - School of Public Health *Join Together program - National Technical Assistance Project for Substance Abuse Initiatives*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)

1993 22578 $102,346 Boston University - School of Public Health *Join Together Program*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)
Community Substance Abuse Indicators Conference

1996 26942 $5,499,212 Boston University - School of Public Health *Join Together Program*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)
National Resource for Community Substance Abuse Initiatives

1996 29585 $383,122 Boston University - School of Public Health *Join Together Program*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)
Community Effects of Local Substance Abuse Initiatives

1996 30686 $138,404 Boston University - School of Public Health *Join Together Program*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)

Coordinating Community Coalition Participation Outreach Activities Around HBO substance Abuse Specials

1999 27954 $2,378,958 Boston University - School of Public Health *Join Together Program*

http://www.rwjf.org/reports/grr/035347.htm (Steve Heilig is on National Board)
National Resource for Community Substance Abuse Initiatives

Kenneth E. Rosenfeld, M.D. — $187,738 tracked thus far

Robert Wood Johnson Foundation *$137,738*

2001 $137,738 Greater Los Angeles Health Care System *Wit film project to teach medical students about end-of-life care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___745
The Pulitzer Price-winning play, "Wit," presented a creative teaching opportunity for medical schools. "Wit" is the story of a woman who received a late stage diagnosis of overian cancer and her journey as she faces her cancer and her mortality. Several medical schools have hosted the performance of the play as part of their educational activities, and the response of faculty and students has been very positive. Under this project, the videotape of HBO's production of "Wit" would be distributed to allopathic and osteopathic schools of medicine in the United States and Canada, accompanied by the training manuals developed for the stage productions. This includes: materials for a pre-performance lecture that primes the trainees to important themes in the play, and a program guide for facilitated small group discussions following the film. Funds for this project will be used to engage the American Association of Medical Colleges and medical schools and to encourage long-term inclusion of the play in curriculum.

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

2000 $50,000 University of California - Los Angeles, School of Medicine *Faculty Scholar, 2000-2002: Pathways: An Institutional Quality Improvement Program in End of Life Care (Grant amount is estimated.)*

(Grant amount is estimated.) Recent SUPPORT studies have demonstrated the quality of care that United States' hospitals provide to patients near the end of life has been slow to improve. The goal of this project is to implement and evaluate the implementation process and impact of an institution-wide quality improvement program to provide continuous coordinated and comprehensive palliative care to patients with poor-prognosis conditions at the Greater Los Angeles Healthcare System.

Cynda Hylton Rushton, D.N.Sc., R.N. — $594,163 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$594,163*

$200,000 Johns Hopkins *Nursing Leadership Academy for End-of-Life Care*

To develop a National Nursing Leadership Institute on End of Life Care to advance the profession's agenda to improve care at the end of life by increasing leadership capacity of nurses in this arena. The project builds on the priorities developed by the Nursing Leadership Consortium on End of Life Care and the commitment and strength of nursing specialty organizations representing over 600,000 nurses.

2001 $394,163 Johns Hopkins *Nursing Leadership Academy for End-of-Life Care*

This project is a continuation and extension of the PDIA-funded Nursing Leadership Academy for End-of Life Care. The original Academy provided leadership training for participant teams from twenty-two nursing specialty organizations who have gone on to develop projects within their own organizations designed to give palliative care and end-of-life care a higher priority within the specialty. Academy mentors have monitored and supported the teams during the post-training period. This grant will allow for a replication of the leadership training for an additional cohort of teams from twenty-five nursing specialty organizations. Initial training and skill-building will be similar; the new cohort will also be mentored and monitored as they develop their projects. This grant also provides funding for ongoing development of www.palliativecarenursing.net designed to provide a vehicle for Academy members and others to access nursing resources related to palliative and end-of-life care.

Kornfeld / PDIA (Soros) collaborative

1999 Johns Hopkins *Kornfeld Fellow in end-of-life, ethics and palliative care*

James E. Sabin, M.D. — $681,128 tracked thus far

$88,363

1995 $88,363 Harvard Pilgrim Health Care, Inc. *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

[Recipient organization and contact are only a guess on my part, based on the info in RWJF grant report at http://www.rwjf.org/reports/grr/026732s.htm]

Robert Wood Johnson Foundation *$188,661*

1996 26732 $188,661 Harvard Pilgrim Health Care, Inc. *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

http://www.rwjf.org/reports/grr/026732s.htm
This grant from supported a study by Harvard Pilgrim Health Care (HPHC) of how insurers, employers, and other purchasers of health care decide which medical technologies should be provided to consumers under resource constraints. During this project, also funded by three other foundations and HPHC, the investigators conducted a detailed study of how one managed care organization, HPHC, made its decisions about the use of medical technologies.

 # The investigators concluded that managed care plans and other insurers faced a "legitimacy" problem and needed to persuade a skeptical public and practitioners that they should retain the authority to make limit-setting decisions about new technologies. To resolve the legitimacy problem, the investigators proposed the concept of "accountability for reasonableness." To achieve such accountability, managed care plans and other insurers would have to meet four conditions:

** Publicity: Decisions regarding coverage for new technologies (and other limit-setting decisions) and their rationales must be publicly accessible.*
** Reasonableness: The rationale for coverage decisions should aim to provide a reasonable explanation of how the organization should provide "value for money" in meeting the varied health needs of a defined population under reasonable resource constraints.*
** Appeals: There must be a mechanism for challenge and dispute resolution regarding limit-setting decisions, including the opportunity to revise decisions in light of further evidence or arguments.*
** Enforcement: There must be either voluntary or public regulation of the process to ensure that the first three conditions are met. The investigators promoted the concept of "accountability for reasonableness" to numerous health care and health policy organizations. This included submitting a proposal to the National Committee for Quality Assurance (NCQA) to modify its standards for making policy about the use of new technologies. NCQA is an independent, nonprofit organization that assesses and reports on quality of care delivered by managed care organizations.*

Harvard Pilgrim Health Care, Inc. *$38,851*

1995 $38,851 *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

[Recipient organization and contact are only a guess on my part, based on the info in RWJF grant report at http://www.rwjf.org/reports/grr/026732s.htm]

Greenwall Foundation *$212,500*

1995 $212,500 Harvard Pilgrim Health Care, Inc. *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

[Recipient organization and contact are only a guess on my part, based on the RWJF grant report info at http://www.rwjf.org/reports/grr/026732s.htm]

National Science Foundation *$88,363*

1995 $88,363 Harvard Pilgrim Health Care, Inc. *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

Retirement Research Foundation *$64,390*

1995 $64,390 Harvard Pilgrim Health Care, Inc. *Project on Insurer Decision Making Regarding Coverage of Medical Technologies*

[I'm only guessing at the recipient, based on RWJF grant report at http://www.rwjf.org/reports/grr/026732s.htm

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Ronald Schonwetter, M.D.

tracked thus far

US DHHS - Agency for Healthcare Research and Quality (AHRQ)

2003 University of South Florida *Charting the Course in End-of-Life Care*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6785764&p_grant_num=1R13HS014416-01&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=98&p_audit_numfound=19&p_keywords=palliative+care
Grant Number: 1R13HS014416-01
PI Name: SCHONWETTER, RONALD S.
PI Email: rschonwe@hsc.usf.edu
PI Title:
Project Title: Charting the Course in End-of-Life Care

Abstract: DESCRIPTION: Palliative care is a therapeutic model that can address the physical, psychosocial, spiritual, and practical needs of dying patients and their families. Progress in a broad field such as this is dependent upon developing and improving the scientific foundation for palliative care (Portenoy & Bruera, 2003). The Center for Hospice, Pallative Care and End-of-Life Studies at the University of South Florida (USF) is a research center that has as its focus the health care issues of individuals near the end of life and their families and caregivers. The Center is a unique community-academic partnership of multidisciplinary faculty from the University, and the H. Lee Moffitt Cancer Center and Research Institute, and researchers, administrators, and care providers from two of the largest hospices in the world: The Hospice of the Florida Suncoast, and LifePath Hospice and Palliative Care Inc. Center members work collaboratively to conduct research that informs cutting-edge practice in palliative care, to develop and refine research methodologies that are effective in end-of-life research, and to ensure that research is responsive to the needs and constraints of providers of hospice palliative care services. The proposed conference, 'Charting the Course in End-of-Life Care: From Research to Policy and Practice,' will bring together researchers, care providers, administrators, graduate students, and policy makers representing various disciplines and sites of care to evaluate the current state-of-the-art of this emergency field, to disseminate current research and best-practices, and to generate recommendations for future research in the field. The one-day conference will feature nationally and internationally known researchers in end-of-life and palliative care, as well as provide a forum for new investigators to showcase their research through the submission of research abstracts. The conference will be unique in that interactive 'think tank' sessions will allow academic researchers in end-of-life and palliative care hospice and palliative care providers and representatives of federal funding agencies whose priorities include end-of-life populations and issues, including AHRQ, to mutually create an agenda for the field.

Thesaurus Terms:
health care quality, meeting /conference /symposium, terminal patient care

Institution: UNIVERSITY OF SOUTH FLORIDA
4202 E FOWLER AVE
TAMPA, FL 33620
Fiscal Year: 2003
Department: INTERNAL MEDICINE
Project Start: 15-SEP-2003
Project End: 14-SEP-2004
ICD: AGENCY FOR HEALTHCARE RESEARCH AND QUALITY
IRG: ZHS1

Marlan Gray Secundy, Ph.D.

$100,305 tracked thus far

Robert Wood Johnson Foundation *$100,305*

2000 37552 $100,305 Tuskegee University *Targeted End of Life Projects [EPEC2 ?]*

http://www.rwjf.org/reports/grr/037552.htm and
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___465
Notes from my web site: June 5-6: RWJF awards $100,000 to Marian Gray Secundy, PhD, at Tuskegee University's Center for Bioethics in Research and Health Care, to host a Roundtable Discussion on African-American Perspectives on End-of-Life Care. The forum commissioned nine papers that "would serve as the framework for a future national conference." On 2/27/01, ten of the participants met to finalize plans for the national conference ("Last Miles" -- held in Atlanta in February, 2004). Marian Gray Secundy had suffered a stroke in 2000. She left Tuskegee and moved to Washington, DC. in mid-2002. On December 17, 2002 she died of a heart attack while visiting her daughter in New York. Subsequent grants for the work went to Richard Payne, MD, at North General Hospital in New York, and it would be Dr. Payne and his organization -- IIPCA -- that would host "Last Miles."

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Peter A. Selwyn, M.D., M.P.H. — $220,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1997 $70,000 Albert Einstein College of Medicine - Montefiore Medical — *Faculty Scholar, 1997 (estimated funding); Care of Patients with Late-Stage AIDS in a Skilled Nursing Facility*

http://www2.soros.org/death/1997_fs.htm
A model center will be developed for clinical, palliative and end-of-life care, teaching, and research at a dedicated, skilled nursing facility for people with HIV/AIDS. The goal of the model is to improve clinical outcomes for patients and their families and to create a greater understanding among care providers of the unique end-of-life issues faced by this population in our community and elsewhere.

Kornfeld / PDIA (Soros) collaborative *$150,000*

2004 $150,000 Albert Einstein College of Medicine - Montefiore Medical — *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12
NOTE: Selwyn co-directs the fellowship with SEAN O'MAHONY, MD

Myles N. Sheehan, S.J., M.D. — $120,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$120,000*

1999 $120,000 Loyola University (Chicago) — *Improving Care of the Dying in the American Catholic Community*

(Dollar amount is approximate; news story says each recipient receives up to $150,000 for two years.)
http://www2.soros.org/death/news6.htm and http://www2.soros.org/death/allgrants_8.htm
Catholic hospitals are one of the major providers of health care in the United States. This project focuses on improving care of the dying through a community educational program for parishes and physicians. The curriculum will discuss the Catholic tradition of death and dying, respect for human dignity, pain and symptom relief, and recognizing the inevitability of natural death.

Deborah Witt Sherman, PhD, APRN, ANP, BC, FAA — $330,387 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$60,000*

1998 $60,000 Mount Sinai Medical Center — *Faculty Scholars Program (Amount estimated)*

Not certain whether this grant went to NYU or to Mount Sinai. PDIA 1998-2000 report lists her as faculty scholar, Mt. Sinai/NYU.

National Institutes of Health - National Cancer Institute (NCI) *$270,387*

2001 $138,451 New York University — *Interventions and Quality of Life in Cancer and AIDS*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6409431&p_grant_num=1R21CA085227-01A2&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=24&p_audit_numfound=149&p_keywords=palliative+care
Grant Number: 1R21CA085227-01A2
PI Name: SHERMAN, DEBORAH W.
PI Email: das1@is.nyu.edu
PI Title:
Project Title: Interventions and Quality of Life in Cancer and AIDS

Abstract: DESCRIPTION (provided by applicant): Cancer and AIDS impose long-term stress suffering for individuals with these diseases and their families. The SUPPORT study focuses national attention on quality of life across the illness/dying trajectory and the need to examine the disease specific interventions, and the palliative interventions that are offered across the continuum of care. The objectives of this pilot study are to: 1) test the feasibility of conducting a longitudinal study of 40 patient/family caregiver dyads experiencing advanced cancer or AIDS given the vulnerability of this population; 2) obtain preliminary data regarding the changes/patterns in quality of life of patients with advanced cancer or AIDS and their family caregivers from the time of diagnosis with advanced disease, until death, and into the bereavement period for family caregivers (illness/dying trajectory); 3) explore whether patients or family caregivers experiencing advanced cancer and AIDS are comparable based on contextual/demographic factors, and in terms of changes/patterns in their quality of life; 4) evaluate the sensitivity and reliability of measures to examine quality of life of the patient/family dyads; and 5) pilot test the Continuum of Palliative Care Intervention Inventory (CPCII) to evaluate its ability to document palliative care interventions for patients and family caregivers across the illness/dying trajectory, and develop descriptive aggregate profiles of interventions across the illness/dying trajectory. This pilot study will use a longitudinal, prospective design, in which patients with advanced cancer or AIDS and their family caregivers are followed from the time of diagnosis with advanced disease for approximately one year or until death, and into the bereavement period for family caregivers. Quality of life of patients and family caregivers will be measured by multidimensional instruments, and unidimensional, self-report measures. The CPCII will be pilot tested to obtain information regarding the physical, emotional, social, and spiritual interventions that are offered, received, or desired across the illness/dying trajectory by patients and family caregivers. For preliminary evaluation of the changes/patterns in the quality of life of patients and family caregivers, and evaluation of the sensitivity of the instruments, a model for repeated measurement data, specifically a random coefficient model will be used. Cronbach's alpha coefficients will be calculated for each instrument to determine their reliability with each group. The CPCII will be evaluated for its comprehensiveness regarding intervention information, and ability to develop descriptive aggregate profiles of

interventions. Pearson correlations or one-way ANOVAs will be used to examine the relationship of contextual/demographic factors to quality of life and interventions provided.

Institution: NEW YORK UNIVERSITY
15 WASHINGTON PLACE
NEW YORK, NY 10003
Fiscal Year: 2001
Department: DIVISION OF NURSING
Project Start: 09-JUL-2001
Project End: 30-JUN-2003
ICD: NATIONAL CANCER INSTITUTE
IRG: ZRG1

2002 $131,936 New York University *Interventions and Quality of Life in Cancer and AIDS*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6409431&p_grant_num=1R21CA085227-01A2&p_query=%28palliative+care%29&ticket=14351191&p_audit_session_id=65239250&p_audit_score=24&p_audit_numfound=149&p_keywords=palliative+care
Grant Number: 1R21CA085227-01A2
PI Name: SHERMAN, DEBORAH W.
PI Email: das1@is.nyu.edu
PI Title:
Project Title: Interventions and Quality of Life in Cancer and AIDS

Abstract: DESCRIPTION (provided by applicant): Cancer and AIDS impose long-term stress suffering for individuals with these diseases and their families. The SUPPORT study focuses national attention on quality of life across the illness/dying trajectory and the need to examine the disease specific interventions, and the palliative interventions that are offered across the continuum of care. The objectives of this pilot study are to: 1) test the feasibility of conducting a longitudinal study of 40 patient/family caregiver dyads experiencing advanced cancer or AIDS given the vulnerability of this population; 2) obtain preliminary data regarding the changes/patterns in quality of life of patients with advanced cancer or AIDS and their family caregivers from the time of diagnosis with advanced disease, until death, and into the bereavement period for family caregivers (illness/dying trajectory); 3) explore whether patients or family caregivers experiencing advanced cancer and AIDS are comparable based on contextual/demographic factors, and in terms of changes/patterns in their quality of life; 4) evaluate the sensitivity and reliability of measures to examine quality of life of the patient/family dyads; and 5) pilot test the Continuum of Palliative Care Intervention Inventory (CPCII) to evaluate its ability to document palliative care interventions for patients and family caregivers across the illness/dying trajectory, and develop descriptive aggregate profiles of interventions across the illness/dying trajectory. This pilot study will use a longitudinal, prospective design, in which patients with advanced cancer or AIDS and their family caregivers are followed from the time of diagnosis with advanced disease for approximately one year or until death, and into the bereavement period for family caregivers. Quality of life of patients and family caregivers will be measured by multidimensional instruments, and unidimensional, self-report measures. The CPCII will be pilot tested to obtain information regarding the physical, emotional, social, and spiritual interventions that are offered, received, or desired across the illness/dying trajectory by patients and family caregivers. For preliminary evaluation of the changes/patterns in the quality of life of patients and family caregivers, and evaluation of the sensitivity of the instruments, a model for repeated measurement data, specifically a random coefficient model will be used. Cronbach's alpha coefficients will be calculated for each instrument to determine their reliability with each group. The CPCII will be evaluated for its comprehensiveness regarding intervention information, and ability to develop descriptive aggregate profiles of interventions. Pearson correlations or one-way ANOVAs will be used to examine the relationship of contextual/demographic factors to quality of life and interventions provided.

Institution: NEW YORK UNIVERSITY
15 WASHINGTON PLACE
NEW YORK, NY 10003
Fiscal Year: 2001
Department: DIVISION OF NURSING
Project Start: 09-JUL-2001
Project End: 30-JUN-2003
ICD: NATIONAL CANCER INSTITUTE
IRG: ZRG1

Amadeo Shije — $157,050 tracked thus far

Robert Wood Johnson Foundation *$157,050*

2000 40480 $157,050 All Indian Pueblo Council, Inc. *Promoting Excellence in End-of-Life Care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail_Ala_res_grant_region_summ_list_html_601
Talking Circle: Palliative care networks for Native Americans

This project will fund a national forum on Improving End-of-Life Care for Native Americans. The specific objectives are to: (1) initiate conversation around improving excellence in end-of-life issues in tribal communities; (2) exchange Native-American views on end-of-life care; (3) train tribal/Indian Health Service clinicians in the principles of palliative care; (4) introduce Education for Physicians in End-of-Life Care (EPEC) curriculum; and (5) explore the creation of regional networks for rural palliative care for Native Americans.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

John Lee Shuster, Jr., M.D. — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1996 $70,000 University of Alabama - Birmingham *Faculty Scholar, 1996-97 (estimated funding amount)*

Development of clinical and educational programs focusing on psychiatric issues in terminal care such as anxiety, confusion, and delirium.

Bruce Siegel, M.D., M.P.H. — $3,350,000 tracked thus far

Robert Wood Johnson Foundation *$3,350,000*

2000 46225 $3,350,000 George Washington University *Urgent Matters (Reducing Racial and Ethnic Disparities in Chronic Care)*

Technical assistance and direction for Urgent Matters. Awarded on 8/30/2002.

Terry Simonette — $6,499,913 tracked thus far

Robert Wood Johnson Foundation *$6,499,913*

1999 36072 $6,499,913 NCB Development Corporation (NCBDC) *Coming Home: Affordable Assisted Living*

To undertake the development of rural community-based systems of chronic care (for 5 years).

Kelley M. Skeff, M.D., Ph.D. — $831,931 tracked thus far

Robert Wood Johnson Foundation *$831,931*

1998 35017 $831,931 Stanford University *Development of a train-the-trainer faculty development program in end-of-life care*

http://v *PRINCETON, N.J., April 5, 1999 -- Two ground-breaking programs to train doctors and nurses in providing better care* Foundation *for the dying are being launched by universities on opposite sides of the country. Stanford University and Harvard Medical School will start their programs to train medical and nursing faculty with funds from the Princeton, N.J.-based Robert Wood Johnson Foundation.*

The four-year, $831,931 grant to Stanford University will be used to establish an end-of-life care curriculum for medical faculty. Stanford's Faculty Development Program, co-directed by Kelley M. Skeff, M.D., Ph.D,. and Georgette A. Stratos, Ph.D., trains medical faculty from across the United States in its special month-long programs. These individuals, in turn, become resources for other faculty and for residents back in their home institutions, using formal training courses and large workshops to spread the word.

The Stanford project expects to train 18 faculty members directly. Each subsequently will train an additional 360 faculty members and residents during a three-year period.

"We like the "train-the-trainer" model because it's a quicker way to reach a great many doctors?much quicker than working with one medical school at a time," said RWJF Senior Program Officer Rosemary Gibson.

Thomas J. Smith, M.D., FACP — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$50,000*

1995 $50,000 Virginia Commonwealth University *Faculty Scholar, 1995-96 (Grant amount is estimated.)*

Evaluation of the efficacy and cost-effectiveness of end-of-life care, development of clinical practice guidelines, and randomized controlled trials of financing alternatives for palliative care.

New York, NY -- 29 May 1996

Rev. Walter J. Smith, S.J., Ph.D. — $150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 HealthCare Chaplaincy *HealthCare Chaplaincy*

circa 1999: Project: To develop and offer a community education program on death, dying, and bereavement to local clergy, laypeople, volunteers in local agencies and bereaved people. Following a series of focus groups, the education programs will be designed, offered, and evaluated. Also will promote the concept and necessity of pastoral education for clergy and laypeople on death, dying, and bereavement through planning and participating in a national forum on issues in death education and bereavement.

Lois Snyder, J.D. — $25,000 tracked thus far

Greenwall Foundation *$25,000*

$25,000 American College of Physicians - ACPS-ASIM *End-of-Life Care Consensus Panel*

Produced report in Annals of Internal Medicine, March 2000

Ralph Snyderman, M.D.

$25,000 tracked thus far

Commonwealth Fund *$25,000*

2000 $25,000 University of North Carolina - Chapel Hill — *Project: Medical Education's Fred Friendly Seminar on the Health of American Medical Education*

http://www.cmwf.org/grants/grantdetail.asp?id=522&pid=11&link=5

Mildred Z. Solomon, Ed.D.

$4,121,020 tracked thus far

Robert Wood Johnson Foundation *$1,584,069*

1996 28037 $297,600 Education Development Center, Inc. (EDC) — *Support for a National Task Force on End-of-Life Care for Patients in Managed Care and a Report of Recommendations for Improvement*

These grants from The Robert Wood Johnson Foundation (RWJF) funded the Education Development Center (EDC), a nonprofit research and development organization, to convene the interdisciplinary National Task Force on End-of-Life Care in Managed Care and to publish and disseminate a report to help prepare managed care organizations to meet the needs of patients who develop terminal illnesses. To provide background to the task force, the EDC's Center for Applied Ethics and Professional Practice conducted an extensive nationwide survey of managed care organizations, with follow-up interviews. The task force recommendations and a series of specific action steps were published in an 85-page report entitled Meeting the Challenge: Twelve Recommendations for Improving End-of-Life Care in Managed Care. The recommendations and action steps focused on three areas: (1) improvement of access to humane and effective End-of-Life care, (2) strengthening of accountability on the part of plans and providers, and (3) development and evaluation of payment methods that would properly compensate plans and providers for the costs of caring for gravely ill patients without compromising access or quality. The recommendations and action steps were directed to managed care leaders, policymakers, and purchasers of managed care, such as private employers and government agencies. Recommendations included provision of managed care insurance products that cover humane and effective End-of-Life care for patients and families, the focusing of continuous quality improvement efforts on End-of-Life care, and the testing of new methods for aligning financial incentives with the provision of humane and effective care.

1998 36375 $48,032 Education Development Center, Inc. (EDC) — *Support for a National Task Force on End-of-Life Care for Patients in Managed Care and a Report of Recommendations for Improvement*

The task force recommendations and a series of specific action steps were published in an 85-page report entitled Meeting the Challenge: Twelve Recommendations for Improving End-of-Life Care in Managed Care.

1999 36037 $383,275 Education Development Center, Inc. (EDC) — *Innovations (?)*

Probably for "Innovations"

2000 38962 $467,806 Education Development Center, Inc. (EDC) — *Innovations*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___507
This renewal grant provides continued support for the online international end-of-life journal, "Innovations in End-of-Life Care." "Innovations" is published bi-monthly and addresses important topics in the delivery of high-quality end-of-life services. Unlike traditional journals, "Innovations" focuses on how an innovation was accomplished, rather than just its results. The issues include many tools and resources for other providers who may want to replicate all or part of an innovation and a discussion board. The content of "Innovations" has been deemed of such high quality that a commercial publisher will be reprinting highlights in an annual yearbook, starting in 2000, and the "Journal of Palliative Medicine" will include material from "Innovations" in its bimonthly publication. Ideas suggested for treatment by "Innovations" are reviewed by an international editorial committee.

2002 44641 $387,356 Education Development Center, Inc. (EDC) — *Innovations in End-of-Life Care, an online jounal*

Open Society Institute / Project on Death in America (Soros Foundation) *$449,951*

1997 $149,951 Education Development Center, Inc. (EDC) — *(Date and Title are approximate) "Focus on Cancer Care" Leadership Training Conference*

Maybe same as this: http://caepp.edc.org/dnel.html
"In 1996-97, through a generous grant from the Open Society Institute's Project on Death in America, [Decisions Near the End of Life] was adapted for interdisciplinary teams of clinicians working in comprehensive and community cancer centers. Decisions Near the End of Life: Focus on Cancer Care was piloted in 19 cancer centers nationwide."
=======
Project: To educate health professionals in order to enhance the care that cancer patients receive near the end of their lives. The program will seek to improve health care professionals' knowledge, attitudes, and practices in ethics, law, and pain management; help them to resolve conflicts between the goals and values of aggressive cancer treatment and those of palliative care; and address the impact of cultural diversity on treatment decision making.
Awarded sometime between 1994 and 2000; for two-year period.
===
Maybe the same as this? http://www2.soros.org/death/news2.htm
January 9-11, 1997 "Focus on Cancer Care" Leadership Training Conference offered by the Education Development Center, Inc. and sponsored by PDIA. This national training initiative is designed to assist cancer specialists in caring for their patients near the end of life. Contact: 617/969-7100.

2002 $300,000 Education Development Center, Inc. (EDC) — *Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions, Phase II: Moving to Action*

(date approx; between 2001-2003) There is growing empirical evidence that the health care system is failing children

confronted by a life-threatening condition and their families. Working in close collaboration with the National Association of Children's Hospitals and Related Institutions, the Society of Pediatric Nurses, and the New York Academy of Medicine, Education Development Center, Inc. will develop educational resources and a framework for improvement that children's hospitals across the United States will be able to use to make a difference in the lives of gravely-ill children and their families. To ensure the relevance and feasibility of these resources and strategies, six leading hospitals will pilot test program materials, undertake innovative practices and policies, and measure progress toward establishing new quality indicators for family-centered pediatric palliative care.

US DHHS (US Department of Health and Human Services *$937,000*

1999 $937,000 Education Development Center, Inc. (EDC) *Increasing Organ Donation by Enhancing End-of-Life Care: A Family-Centered, Quality Improvement Program*

http://www.transweb.org/news/news/archive/gore9909/gore9909.htm
Vice President Gore Announces Additional Support for Organ Donation

On Friday, September 24, 1999, in the Old Executive Office Building near the White House, Vice President Al Gore held a discussion about the importance of organ and tissue donation, and announced several major developments, including a major new public service ad campaign and a $13 million grant program designed to increase donation. Vice President Gore also announced that that afternoon President Clinton would be signing a Organ Donor Leave Act.

"These projects will help us break new ground in organ donation," said Secretary Shalala. "Most people support the idea of donation, but only about 50 percent of families and others consent to donation of their loved one's organs when asked. These grants will help us develop new strategies encouraging more families to agree to donation."

These awards are part of the Clinton Administration's National Organ and Tissue Donation Initiative, a comprehensive plan targeting the donor shortage launched by Vice President Gore and Secretary Shalala on Dec.17, 1997. The program is administered by HHS' Health Resources and Services Administration's Division of Transplantation in the Office of Special Programs. . . . Grantees are required to be part of a consortium consisting of at least one agency with transplant experience and one with research expertise. Grantees will evaluate the effectiveness of new or existing strategies based on how well they work in increasing organ procurement, improving consent rates for organ donation, and/or increasing the number of individuals who declare their intent to donate and notify their families of their wishes. . . .

Education Development Center/New England Organ Bank, Newton, Mass.
Increasing Organ Donation by Enhancing End of Life Care: A Family-Centered Quality Improvement Program

The grantee will collaborate with hospitals in Rhode Island, Massachusetts, and New Hampshire to increase health professionals' comfort and skills in end-of-life care, discussions about death and dying, and family support to improve the donation request process. Contact: Mildred Z. Solomon, (617) 969-7100, x2404.
one-year award: 408,611
three-year award: 937,892
=========
http://main.edc.org/newsroom/features/donation2.asp

EDC and the New England Organ Bank have launched a $937,000, three-year project to develop and evaluate a program that will build public and hospital commitment to participating in organ donation and educate intensive care unit staff. Funded by the U.S. Department of Health and Human Services, the program is part of a $13 million nationwide effort to test promising new ways of increasing organ donation.

Nathan Cummings Foundation, Inc. *$1,150,000*

2000 $900,000 Education Development Center, Inc. (EDC) *Enhancing Family Centered Care (FCC) for Children Living with Life Threatening Conditions*

To enable hospitals to provide children living with life-threatening illness and their families the quality of care necessary to support their physical, emotional and spiritual well-being.

2001 $250,000 Education Development Center, Inc. (EDC) *Children with life-threatening illness ($ paid in 2001)*

reference: Cummings' Form 990-PF 2001 "To enable hospitals to provide quality care to children with life-threatening illnesses."

Lynn Hill Spragens, M.B.A. — $760,545 tracked thus far

Robert Wood Johnson Foundation *$560,545*

2001 $335,000 Bard Group, LLC *CAPC - Building business tools to support sustainable palliative care programs*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___743
The purpose of this project is to provide clinicians and hospital administrators with the tools they need to assess the impact of palliative care programs on their institutions. Special emphasis will be given to the financial implications of palliative care that can arise from shorter lengths of stay in the hospital, increased revenue from inpatient hospice beds, and other changes in care provided to patients at the end of life. This project will be successful if it identifies design features of palliative care programs and strategies that result in successful introduction and sustainability of palliative care. The Bard Group will engage the Healthcare Financial Management Association and other organizations in the process to encourage mainstream buy-in from health care institutions' leadership.

2002 46432 $225,545 Bard Group, LLC — *CAPC - Consulting services for the Center to Advance Palliative Care (1 year)*

Commonwealth Fund *$200,000*

2003 $200,000 Spragens and Associates, LLP — *Wellspring Innovative Solutions: Replicating the Model*

Many nursing homes are looking for evidence-based models to improve the care they provide to their frail elderly residents. Wellspring is one such model. But if replication of this model is to proceed, Wellspring Innovative Solutions will require support to build its capacity to recruit nursing homes and serve new and existing members. This Picker Program Grant will provide the crucial support needed to attract an able leader for the dissemination effort, develop professional education and training capabilities, establish a formal mentoring program for new alliance leaders, and develop marketing capacities. If the project is successful, a program-related investment will be contemplated for next year to help the organization reach a goal of 18 alliances, of about 10 nursing homes each, by 2005. This level of activity will enable Wellspring to function as a financially independent, nonprofit service business in the field of nursing home quality improvement. Cofunding is being sought.

Barbara K. Spring, Ph.D. — $10,000 tracked thus far

Nathan Cummings Foundation, Inc. *$10,000*

1995 $10,000 Missoula Demonstration Project / Life's End Institute — *Missoula Demonstration Project*

http://www.missoulian.com/specials/dying/challenges.html
In the fall of 1995, a funder came to town. Andrea Kydd of the Nathan Cummings Foundation became a "fairy godmother." She asked Byock, "What can I do?" and he asked her to fund Barbara Spring for three months. The fledgling effort got its first $10,000 on Dec. 10.

Judith A. Spross, Ph.D., R.N. — $403,971 tracked thus far

Mayday Fund *$403,971*

1995 $303,971 Education Development Center, Inc. (EDC) — *PainLink*

http://main.edc.org/Search/projectView.asp?bcn=1&bcl=Project+Information&projectID=2412
This project is inactive. Follow the links below to explore the project's outcomes and publications.
A Project of: Center for Applied Ethics and Professional Practice (CAEPP)
PainLink was a virtual community of health professionals working in institutions committed to alleviating pain. An initiative of Education Development Center, Inc., PainLink was established in 1995 with funding from The Mayday Fund of New York City, which funded PainLink through 1999. From 1995 through 2001, EDC's PainLink staff worked with staff in over 60 hospitals and nursing homes. Participating institutions received technical assistance (TA) which included administration of the Pain Management inventory (a clinician survey of knowledge, attitudes, institutional barriers, and pain management learning needs), teaching cases, consultation with EDC staff, a listserve discussion, and access to a variety of pain management resources. The Mayday PainLink site is now an archived site—pages with many resources for improving pain management continue to be available to the public.
Duration: 1995 to 1999
Director(s): Judith A. Spross, R.N., Ph.D.
Mildred Z. Solomon, Ed.D.
Funder(s):Participant fees
Project Web site: http://www.edc.org/PainLink/

1998 $100,000 Education Development Center, Inc. (EDC) — *EDC/Mayday Pain Link*

http://www.painandhealth.org/mayday/previous-grants.html
Education Development Center
Newton, Massachusetts
$100,000, the second of three payments in a grant of $303,971 to support the EDC/Mayday Pain Link, a "technical Assistance" project that provides free practical help to institutions seeking to improve the management of pain. Technical assistance includes a survey, conference calls, topically focused mailings, an email discussion and an informative website <www.edc.org/PainLink>.
Contact: Judy Spross, PhD., RN
E-mail: JSpross@edc.org

John M. Stanley, Ph.D. — $254,440 tracked thus far

Robert Wood Johnson Foundation *$254,440*

1997 30299 $254,440 American Health Decisions — *Research (focus groups) on Americans' values regarding end-of-life care (for 11 months).; Atlanta, GA*

http://web.archive.org/web/19970208142148/http://www.ahd.org/
he Robert Wood Johnson Foundation has awarded a grant of $254,440 to American Health Decisions to conduct a research project aimed at a better understanding of Americans' values, concerns, hopes, and fears regarding end of life care. Thirty-eight focus groups will be conducted in cities and towns across the country to discover what Americans want from their care givers and the barriers they see to getting what they want carried out. In addition to the focus group discussions, the AHD research project will include in depth telephone interviews with individuals who have recently, or are currently, facing end of life decisions for themselves or a family member. The findings of the research project will be released in July at an opportune time to benefit two other iniatives: a project being conducted by the American Medical Association to enhance American physicians understanding of, and attention to, a wide range of options for end of life care and a national education program that will parallel the AMA's project. Information on how to get copies of the AHD report on this project will be posted here when they are available.
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http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___130
Summary Title: American Health Decisions, Inc.
Project Title: Research on Americans' values regarding endoflife
care
Project Director: Beverly A. Tyler Degree:
Phone No.(Work): 4049749327
Fax (Work): 4048749372
Email: jhdatl@atlanta.com
Grantee Institution: American Health Decisions
Address: 1720 Peachtree Street
Suite 1029
Atlanta Georgia United States.
Start Date: 02/01/1997 End Date: 12/31/1997
Amount: $254,440 Web Site:
Description: This project documented Americans' opinions and attitudes regarding endoflife
care. Nationally representative focus groups and indepth interviews were conducted nationwide in order to reach both urban and rural residents and various subpopulations defined by age, ethnicity, and religion. Copies of the report can be obtained from American Health Decisions.
Products: The Quest To Die With Dignity

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http://www.lawrence.edu/dept/public_affairs/media/release/9697/stanley.txt

According to John Stanley, current chairman of the board of AHD and director of Lawrence University's biomedical ethics program, the grant will fund a six-month national study aimed at "mapping" people's opinions and values regarding health care near the end of life.

Starting in March, 38 focus groups representing a cross section of Americans will be assembled in cities across the country -- large metropolitan areas as well as rural and small-town locations -- to discuss their opinions and attitudes regarding the end-of-life care they would want for themselves and their loved ones.

In addition to focus group discussions, the AHD research project will include in-depth telephone interviews with individuals who have recently, or are currently, facing end-of-life decisions for themselves or a family member.

"Focus groups are an extremely effective tool that will allow us to move beyond surface opinion and uncover the core values and perspectives Americans have on health care at the end of life," Stanley said. "The additional telephone interviews should provide an even deeper understanding of the conflicts and tensions of individuals who have faced these decisions in their own lives."

Stanley said the findings of the research project will be released in July and at an opportune time to benefit two other initiatives: a project conducted by the American Medical Association to enhance American physicians' understanding of, and attentiveness to, a wide range of options for end-of-life care and a national public education program that will parallel the AMA's project.

Among the goals of the AMA project are respect for the patients' perspective in advance care planning and a greater emphasis on palliation-- control of pain and compassionate comfort care.

R. Knight Steel, M.D. — $49,285 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$49,285*

$36,285 University of Medicine and Dentistry of New Jersey, New J — *A Program to Improve Palliative Care and End of Life Services for Individuals Requiring Long Term Care (over 30 months)*

http://www.samuels.org/hc_archive_99-96.htm

1999 $13,000 American Federation for Aging Research (AFAR) — *Palliative care in elderly*

http://www.samuels.org/hc1999.htm
An Advisory Group Meeting: Exploring the Feasibility of a Palliative Care Initiative in Long Term Care Settings.

Gary L. Stein, M.S.W., J.D. — $982,219 tracked thus far

Robert Wood Johnson Foundation — *$922,219*

1996 $240,220 New Jersey Health Decisions — *NJ Citizens' Committee on Biomedical Ethics – Broaden Scope*

Google cache of:
http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_region_summ_list_html___66

Summary Title: New Jersey Health Decisions, Inc.
Project Title: New Jersey Comfort Care Coalition
Project Director: Gary Stein Degree:
Phone No.(Work): 9738575552
Fax (Work): 9738578083
Email: healthdec@aol.com
Grantee Institution: New Jersey Health Decisions
Address: 13 Rockland Terrace
1st Floor
Verona New Jersey United States.
Start Date: 05/01/1996 End Date: 07/31/1998
Amount: $249,229 Web Site:
Description: The intent of this project was to help the New JerseyCitizens' Committee on Biomedical Ethics broaden the scope of its activities from its historical focus on
endoflife
decision making to the larger arena of health care policy. One of the activities conducted under this project was a daylong
meeting for New Jersey health
care leaders on the topic of improving endoflife
care.

1998 $231,999 New Jersey Health Decisions — *Demonstration of a new interdisciplinary model of palliative care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___124
This is a hospital-based initiative to organize an interdisciplinary team of medical and social service professionals to develop comprehensive care plans for individuals and families facing end-of-life decisions. Special emphasis is placed on pain and symptom management, as well as spiritual and emotional support. Educating physicians and other healthcare providers in the practice of palliative care medicine will be an important component of this project.

1999 38219 $450,000 New Jersey Health Decisions — *C-SP2: Community-State Partnerships--New Jersey*

Program to support the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for people at the end of life (3 years).

Open Society Institute / Project on Death in America (Soros Foundation) — *$60,000*

2000 $60,000 New Jersey Health Decisions — *2000 Social Work Leaders*

http://www2.soros.org/death/swlda_2000.shtml
$60,000
The Excellence in End of Life Care Fellowship for Social Workers will develop, pilot, evaluate, and disseminate a model palliative care curriculum for training social workers in working with the elderly and people with disabilities. This collaborative effort will create New Jersey's first comprehensive initiative to educate social work practitioners in end of life care.

Marguerite M. Stevens, Ph.D. — $100,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$100,000*

$100,000 Dartmouth-Hitchcock Medical Center — *Dying experience of seriously ill adults*

Project: A multi-method, cross disciplinary analyses will be developed to understand more about the dying experience of seriously ill adults through analyzing patient and family reports of severe pain and developing descriptive models of "good" and "bad" dying experiences from the viewpoints of the patient and family. With this new level of understanding and descriptions of pain and dying, NCI hopes to change the quality of dying and the existing culture of the dying experience through public and professional education. These analyses, once completed and integrated, will contribute to the books which The Center to Improve Care of the Dying is committed to writing for the public.

Jill O'Mahony Stewart — $4,765,958 tracked thus far

Robert Wood Johnson Foundation — *$4,765,958*

1996 30257 $283,847 Stewart Communications — *Last Acts task force management, outreach, and continuing communications (for 18 months)*

1996 Annual Report; Chronic conditions

2000 38722 $3,820,201 Stewart Communications — *Last Acts (contract)*

2001 $661,910 Stewart Communications *Rallying Points (first conference) – Outreach summit for community coalition leaders following the Moyers' series on end-of-life care*

More than three hundred state and local coalitions have formed in response to the airing of "On Our Own Terms: Moyers on Dying in America." This solicited program contract supports an outreach summit for the coalition leaders, entitled, "Rallying Points: Sustaining a Community Network." The objectives of the meeting are to: (1) motivate their continued efforts by celebrating their accomplishments; (2) stimulate their creativity by helping them learn from each other; (3) strengthen their network by exposure to other coalition leaders; (4) improve their skills by providing targeted technical assistance; and (5) solidify their commitment by laying out doable future projects.

Eric M. Storch, Psy.D. — $5,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$5,000*

$5,000 Catholic Hospice, Inc. *General support*

http://www2.soros.org/death/allgrants_2.htm
Catholic Hospice is a not-for-profit organization in Miami, Florida whose members include the Archdiocese of Miami, Mercy Hospital, and St. Francis Medical and Health Care Services. The Hospice was organized in order to deliver palliative end-of-life care and related services for terminally-ill patients and their families.

C. Porter Storey, M.D. — $1,883,698 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$1,200,000*

2004 $1,200,000 American Academy of Hospice and Palliative Medicine (A *developing a College of Palliative Care*

http://www.hopva.org/VA1200-complete.pdf and http://www.aahpm.org/about/history.html
The Academy received a $1.2MM grant from the Open Society Institute's Project on Death in America to be used for hiring a part-time physician executive, providing part-time compensation to the President of the Academy, expanding staff, and developing a College of Palliative Care that will serve as a focal point for multi-disciplinary research and education

National Institutes of Health - National Cancer Institute (NCI) *$683,698*

1994 $94,490 Academy of Hospice Physicians see American Academy *PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS*

http://silk.nih.gov/silk/brownbooks/research/detail/fy94B
http://grants.nih.gov/grants/award/state/FY1994.florida.txt

1995 $93,487 American Academy of Hospice and Palliative Medicine (A *PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS*

GAINESVILLE, AMERICAN ACADEMY/HOSPICE & PALLIATIVE MD
5 R25CA066771-02 STOREY, C PORTER
PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS
93,487

1997 $202,737 American Academy of Hospice and Palliative Medicine (A *PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS*

http://grants.nih.gov/grants/award/state/FY1997.florida.txt

1998 $143,571 American Academy of Hospice and Palliative Medicine (A *PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS*

http://grants1.nih.gov/grants/award/state/fy1998.florida.txt

1999 $149,413 American Academy of Hospice and Palliative Medicine (A *PHYSICIAN HOSPICE/PALLIATIVE CARE TRAINING--UNIPACS*

http://grants.nih.gov/grants/award/state/FY1999.florida.txt

Brad Stuart, M.D. — $449,994 tracked thus far

Robert Wood Johnson Foundation *$449,994*

1998 35494 $449,994 Sutter Visiting Nurse Association and Hospice *Promoting Excellence in End of Life Care – Comprehensive home-based options for informed consent about end-of-life services*

Emeryville, CA: (3 years). Self-Determination for Persons with Developmental Disabilities (Chronic Health Conditions)
SUMMARY
The Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care initiative is intended to foster long-term changes in health care institutions that will improve care for the dying. This project will demonstrate how end-of-life care of capitated Medicare beneficiaries at high risk of acute decompensation can be managed compassionately and cost-effectively throughout the uncertain trajectory of advanced chronic illness. Primary care physicians will be trained to assess patient risk and make referrals. A multidisciplinary team will continuously assess evolving patient and family medical, psychosocial, materials, and spiritual needs, and determine patient/family preferences.

Jeremy Sugarman, M.D. — $9,975 tracked thus far

Greenwall Foundation *$9,975*

2001 $9,975 Duke University - Medical School *[unknown]*

reference: Greenwall Foundation Form 990-PF 2001

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

M. C. (MaryCarroll Sullivan, RN, M.T.S., J.D — $230,748 tracked thus far

Robert Wood Johnson Foundation *$230,748*

1998 35054 $230,748 Midwest Bioethics Center (aka Center for Practical Bioeth *Compassion Sabbath*

http://web.archive.org/web/20020322055606/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___88
This is a pilot project that will provide clergy in metropolitan Kansas City the tools to engage members of all faiths in end-of-life discussions. The goal is to create a national model with national partners who will assist with dissemination of this important educational program. The project has four phases: (1) "A Matter of Life and Death" - a one-day conference for clergy to offer tools to use in providing spiritual support to seriously ill and dying congregants and to assist them in exploring and understanding the meaning of death; (2) "Train the Trainer Workshops" - workshops to assist clergy and adult educators in customizing Action/Reflection Tool Kits designed to stimulate congregants' discussions about death and dying; (3) "Compassion Sabbath Weekend" - including sermons delivered directly congregants and rebroadcast to an others about duties and obligations to seriously ill and dying people; and (4) the introduction of a series of educational programs and activities in every participating faith community in the area. The impact of the project will be assessed and results will be disseminated nationally.

Daniel P. Sulmasy, O.F.M., M.D., Ph.D. — $302,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1996 $140,000 Georgetown University *Faculty Scholar*

Dollar amount is approximate. http://www2.soros.org/death/prMay29-96.htm
Development of measurements of the quality of care rendered to medical inpatients at the end of life including attention to patient care needs and patient and family satisfaction.

Fan Fox and Leslie R. Samuels Foundation *$162,000*

1999 $162,000 St. Vincent's Hospital and Medical Center *The Natural History of End-of-Life Decision-Making (over 3 years).*

http://www.samuels.org/hc1999.htm

Ronald H. Sunderland, Ed.D. — $126,826 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$126,826*

$126,826 Foundation for Interfaith Research & Ministry *Care Teams*

Project: Using the innovative "Care Team" model, the project will develop community-based programs to provide coordinated grief support and grief education programs for terminally ill child, adolescent, and adult populations. The Foundation for Interfaith Research & Ministry is the recipient of the 1997 Rosalynn Carter Caregiving Award. For more about the award and the Rosalynn Carter Institute please visit their Web site http://rci.gsw.peachnet.edu/
Awarded sometime between 1994-2000.

Sharyn M. Sutton, Ph.D. — $683,784 tracked thus far

Robert Wood Johnson Foundation *$683,784*

2000 $283,634 Sutton Group, LLC *Marketing analysis for a program to train physicians in end-of-life care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___541
This contract supports an assessment of the Education for Physicians in End-of-Life Care (EPEC) project, which originated from a grant to the American Medical Association and is currently at Northwestern University. This information will be provided to the EPEC team for incorporation into a strategic plan for future EPEC activities. Specifically, this assessment will: (1) document the number of physicians who received EPEC training; (2) profile EPEC participants and any changes in practice they may have made as a result of their training; (3) gauge satisfaction with and utilization of EPEC products (e.g., training, technical assistance, Web site, faculty development conference); (4) evaluate strengths and weaknesses of the EPEC team; and (5) document potential audiences for any ongoing EPEC activities. In addition, this assessment will explore ideas for EPEC's long-term sustainability.

2002 46285 $400,150 Sutton Group, LLC *CAPC - Consulting services for the Center to Advance Palliative Care (1 year)*

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Eric Swanson — $39,900 tracked thus far

Robert Wood Johnson Foundation *$39,900*

1997 $39,900 Radio and Television News Directors Foundation *Journalists' Resources on End-of-Life Care*

http://web.archive.org/web/20030704171633/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___72
Summary Title: Radio and Television News Directors Foundation
Project Title: Journalists' resources on end-of-life issues
Project Director: Eric Swanson Degree:
Phone No.(Work): 202-659-6510
Fax (Work): 202-223-4007
Email: ericS@rtnda.org
Grantee Institution: Radio and Television News Dir
Address: 1000 Connecticut Avenue NW
Suite 615
Washington District of Columbia United States.
Start Date: 05/15/1997 End Date: 11/14/1997
Amount: $39,900 Web Site:
Description: The first part of this project allowed the Radio and Television News Directors Foundation to research, write, produce and disseminate The Journalist's Resource Guide on End-of-Life Issues to reporters. This guide is a concise yet comprehensive reference that spells out end-of-life issues and provides story ideas, related articles, contacts, suggested questions and a glossary. Topics addressed include hospice, care for the terminally ill, the emotional and financial choices families face, and physician-assisted suicide. The second part of the project was a chapter on end-of-life issues that was included in The Health Reporter's Handbook, a general resource for reporters.

Claire Tehan, M.A. — $10,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$10,000*

$10,000 Hospice Foundation (California) *Japanese hospice*

Project: One of the greatest challenges in hospice work is the importance of supporting patient and family beliefs and practices around death and dying, regardless of one's own values or the obstacles of language or cultural barriers posed in today's diverse societies. In an effort to meet this challenge in Los Angeles and Orange Counties, a hospice will be created for Japanese nationals and Japanese Americans. Accompanying the hospice development, will be an education program for hospice and health care professionals caring for Japanese patients. Both approaches will enable health care professionals to overcome the language and cultural barriers that too often stand between the patient and quality end-of-life care.

Joan M. Teno, M.D.

$4,333,737 tracked thus far

Robert Wood Johnson Foundation *$4,014,649*

29719 $43,770 George Washington University — *Developing a Toolkit to Help Hospitals Measure Quality of Care at the End of Life*

Developing a Toolkit to Help Hospitals Measure Quality of Care at the End of Life: This grant provided funds to George Washington University to convene experts in the measurement of quality of care at the end of life and to establish a consensus on the elements of a "toolkit" to help health care providers assess the quality of the care they provide to terminally ill patients. The grant had four objectives: (1) critically evaluate known measurements regarding the quality of care at the end of life using the framework proposed by the Medical Outcomes Trust's Scientific Advisory Committee of the Medical Outcomes Trust, (a US-based, nonprofit repository of health care measurement tools), and create a comprehensive resource guide to current measures; (2) reach consensus on a recommended set of measures and procedures — a user-friendly toolkit — that institutions can use now to measure quality of care at the end of life; (3) disseminate available and recommended measures to health care institutions and researchers through direct mail, professional publications, professional organizations, and the World Wide Web; and (4) identify priorities for future research to improve measures that reflect the needs of the public, health care providers, and policymakers.

In order to accomplish objectives one, two, and four, the center held a conference on Measuring Care at the End of Life on August 27 and 28, 1996, in Woods Hole, MA. RWJF supported the attendance of 15 out of 31 multidisciplinary experts (participants are listed in the Appendix). The center received the remaining support needed from the Nathan Cummings Foundation, and from the Institute of Medicine, (IOM) through a grant from The Commonwealth Fund. Before the conference, researchers at the Center to Improve Care of the Dying completed comprehensive literature reviews of available measurement instruments, examining the 11 domains proposed by the American Geriatrics Society: advance care planning, continuity of care, emotional symptoms, functional status, grief, family burden, pain and physical symptoms, quality of life, satisfaction, spirituality, and survival time and aggressiveness of care. As planned, they used criteria proposed by the Medical Outcomes Trust's Scientific Advisory Committee. These literature reviews were sent to the conference participants and their input was incorporated into a briefing book. During the conference, the experts agreed that measures must be: (1) clinically meaningful and manageable in their application; (2) focused on the middle manager who wants to assess the institution's quality of care for dying patients, strengths, and opportunities for improvement; and (3) responsive to both the patient and family; in addition, medical record review of people who have died must be considered as another important perspective. In addition, rapid cycles of improvement in measurement should occur, with the first toolkit quickly becoming outdated with research and further development of guidelines. They also drafted a set of research priorities. This project did the groundwork for developing tools and measures of quality of end-of-life care, and — in purposefully addressing patient and family perspectives — represented a first step in developing measures relevant to the needs and expectations of the dying and their families.

1997 32208 $69,286 Brown University Center for Gerontology & Health Care Re — *Developing a Toolkit – Developing measurement tools to assess quality of care at the end of life (for 6 months).; Providence, RI*

Developing a toolkit - Developing measurement tools to assess quality of care at the end of life (for 6 months).

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___182
This project responded to the deficit found with existing quality and outcome measures for end-of-life care that were identified in an earlier grant to establish valid, clinically meaningful, and practical measures to help health care providers assess how well they care for dying patients and their families. It captured elements of a "good" death as defined by the Institute of Medicine (IOM) report, Approaching Death. A major activity of this project was a conference that established a consensus statement on a research agenda in collaboration with leaders in clinical research and palliative care. The activities of this project were consistent with one of the main recommendations of the IOM report on end-of-life care that called for improving methods to measure the quality of care for the terminally ill.

1997 32557 $244,985 Brown University Center for Gerontology & Health Care Re — *SUPPORT - Program on the Care of Chronically Ill Hospitalized Adults Study of regional variation in intensive care unit use (3 years).; Providence, RI*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___508
This project will examine regional variation in intensive care unit (ICU) resource utilization at the end of life, drawing on both quantitative data (ie, national Medicare administrative claims files and the SUPPORT database) and qualitative data (ie, narratives written by intervention nurses). The research team will investigate: (1) whether ecological factors (eg, hospital bed capacity) preduct ICU resource utilization, even after adjustment for patient preferences, disease severity, and other characteristics; and (2) whether the observed regional variation is explained by differences in process measures (eg, communication about prognoses, understanding of prognoses, and physician understanding of patient preferences).

1998 33491 $498,337 Brown University Center for Gerontology & Health Care Re — *Developing a toolkit*

Providence, RI: (2 years).

1999 37188 $2,390,000 Brown University Center for Gerontology & Health Care Re — *Monitoring national, state, and local indicators of end-of-life care*

(5 years)
http://www.ahcpr.gov/research/jan00/0100RA26.htm
Joan Teno, M.D., was recently awarded a $2.4 million grant from the Robert Wood Johnson Foundation to assess progress at the national, State, and local levels in improving end-of-life care for dying patients and their families.

2000 38225 $380,161 Brown University Center for Gerontology & Health Care Re — *C-SP2: Community-State Partnerships to Improve End-of-Life Care (Chronic Health Conditions)*

Providence, RI: (3 years)

2000 $388,110 Brown University Center for Gerontology & Health Care Re *C-SP2: Community-State Partnerships to Improve End-of-Life Care*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___361
Rhode Island's consortium will focus on improving pain management in long-term care. They will work with their Department of Health on the development of quality indicators focused on end-of-life care for nursing homes, provide them to each of the 105 nursing home facilities in the state prior to their public release, and assist nursing homes to improve their quality of care. This assistance will be in the form of interventions that will provide nursing homes with the needed knowledge, skills, and tools to improve and enhance the quality of pain management in nursing homes. The goal of this three year effort is to ensure that persons dying in nursing homes will receive their desired level of pain control.

Open Society Institute / Project on Death in America (Soros Foundation) *$119,944*

$119,944 Center for Palliative Care Studies (CPCS) *Center to Improve Care of the Dying, now known as CPCS*

Project: Advanced care planning for improved care at the end of life in managed care settings. Using focus groups, an expert panel with consumer input, and quality improvements, this project will: 1) obtain consumers' and health care providers' preferences for content and design of advance care planning about care near the end of life; 2) assemble an expert panel to articulate practical and ethically justified guidelines for advance careplanning in managed care; 3) collect benchmark data regarding advance care planning and care of dying patients in an HMO; and 4) design and pilot an intervention to facilitate communication and enhance the care of the dying. Principal Investigator: Joan M. Teno, M.D., M.S. Co-Principal Investigators: Bradley Owen Boekeloo, Ph.D. and Jacqueline J. Glover, Ph.D.

Nathan Cummings Foundation, Inc. *$50,000*

1996 $50,000 George Washington University *Toolkit*

Toolkit for assessing and enhancing end-of-life care, Center to Improve the Care of the Dying, George Washington University, Washington, DC

Mayday Fund *$124,166*

2002 $42,363 Brown University Center for Gerontology & Health Care Re *Medical School; Pain Management Services*

http://www.painandhealth.org/mayday/previous-grants.html
Brown Medical School, Center for Gerontology and Health Care Research; Providence, RI
$42,363 to support Phase I of Auditing Pain Management Among Palliative and Pain Management Services.
Contact: Joan Teno, MD, MS
Web Site: http://www.chcr.brown.edu

2004 $81,803 Brown University Center for Gerontology & Health Care Re *Web Based Resources to Aide Nursing Homes in Improving Pain Management*

http://www.painandhealth.org/mayday/previous-grants.html
Brown University, Center for Gerontology and Health Care Research, Providence, Rhode Island, "Web Based Resources to Aide Nursing Homes in Improving Pain Management"
A grant of $81,803 representing the first payment in a two-year grant in the amount of $178,247 to support the project, which will make available tools and resources to better address the care of pain in nursing homes. Contact: Joan Teno
Web Site: http://www.chcr.brown.edu/Contents.htm

Commonwealth Fund *$24,978*

2000 $24,978 Brown University Center for Gerontology & Health Care Re *Comparison of the U.K. versus U.S. Dying Experience*

Comparison of the U.K. versus U.S. Dying Experience

Daniel Tobin, M.D. — $750,000 tracked thus far

Robert Wood Johnson Foundation *$400,000*

2000 $100,000 Life Institute *National advanced illness coordinated care program*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___602
This project will: (1) demonstrate the feasibility of implementing an Advanced Illness Care Coordination Program in a wide range of health settings; (2) evaluate the impact of the program on selected patient and surrogate outcomes; and (3) estimate the cost of the program.

2000 $300,000 Life Institute *Knight-Ridder Fifteen-part newspaper series on end-of-life issues*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___645
This project supports: (1) a 15-part series of articles on end-of-life issues that will be distributed by Knight Ridder/Tribune Information Services in September 2001; (2) a series of regional workshops and community forums focusing on the topics raised in the articles; and (3) publicity and public relations for the series. The articles will be written by national leaders focusing on their particular area of expertise and will reach nine million people through the Knight Ridder papers. They also will distribute the series over their newswire, which reaches papers with circulations of an additional 25 million.

Fan Fox and Leslie R. Samuels Foundation *$350,000*

2000 $200,000 Research Foundation of State University of New York *An Evaluation of Advanced Illness Care Coordination Program (AICCP)*

This project will evaluate AICCP, an innovative approach to caring for people with advanced illness. The AICCP

promotes peaceful dying by constructing an environment that allows patients to have responsibility (to the extent they wish) for their own dying process. This evaluation is part of a larger research strategy on the effectiveness of the AICCP model; this part will study the feasibility, process of care, and cost of care.

2001 $150,000 Partnership for Caring *Finding Our Way: Living and Dying in America*

With the Life Institute; 24 months: This four-part project explores the complex issues that face seriously ill Americans, their caregivers, and our communities. It is designed to provide information, insights, and tools needed to create better ways of caring for dying people and their caregivers. The component parts are: 1) a 15-week series of newspaper articles containing state of the art information from national leaders in medical, social, spiritual and cultural aspects of death and dying; 2) a promotional campaign by a network of almost 700 national and local organizations and community coalitions; 3) development of tie-in activities, such as discussion groups and follow-up stories, on the local level to increase awareness of and enlarge the impact of the newspaper series; 4) writing and publishing a textbook based on an expanded version of the essays in the newspaper series for use in colleges, adult education courses, university extension courses, etc.

Susan Tolle, M.D. — $848,351 tracked thus far

Robert Wood Johnson Foundation *$598,351*

1998 33903 $598,351 Oregon Health and Science University *Projects to Improve End of Life Care [Removing Barriers to good EOL Care; POLST for other states; Expand Hospice Coverage; Data-Driven Change for other states] (Tie in with Midwest Bioethics "State Initiatives")*

Portland, OR: (3 years). See: Death With Dignity 2002 report: "In 1998, the Robert Wood Johnson Foundation awarded Oregon Health & Science University nearly $600,000 to finance four projects with the goal of improving terminal care in Oregon and nationally. According to a representative of the Foundation, Oregon was selected because, "Oregon is providing a road map for a lot of other states in how they can improve care for patients who have life-limiting illnesses. Oregon has really taken this on."

http://www.willamette.edu/wucl/pas/pasupdatejuly98.htm
Oregon research projects on end-of-life care. Dr. Susan Tolle, director of the Center for Ethics in Health Care at Oregon Health Sciences University, and Virginia Tilden, associate dean for research at OHSU's School of Nursing, will lead several research projects to improve end-of-life care. Oregon Health Sciences University has received $598,351 from the Robert Wood Johnson Foundation and $100,000 from the Nathan Cummings Foundation to conduct four projects over a three-year period:

a. Removing barriers. Researchers will collect data about barriers to good end-of-life care for patients who die in hospice care, nursing homes, or hospitals. The project began with telephone surveys of almost 500 families and friends, completed in June 1998, which covered patient wishes about resuscitation measures, pain management, and issues involving communication with physicians, transportation, and finances. The personal stories will be published in a year and also will be discussed in forums statewide with health care professionals and others connected with hospitals, hospices, and nursing homes.

b. Hospice coverage. Researchers will compile a policy paper describing the population of uninsured terminally ill Oregonians and suggesting ways to expand coverage.

c. POLST form. Researchers will compile and present a guide for other states on how Oregon developed its Physician Orders for Life-Sustaining Treatment (POLST) form.

d. Data-driven change. Researchers will help other states' leaders learn to access their own statistical information on death and dying as a tool to change policies.

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_region_summ_list_html___84
06/01/1998 End Date: 05/31/2001
Amount: $598,351
Description: This project will focus on improving policies that influence how care of the dying is managed in the United States. The project has both a state and national focus. In Oregon, the aims are: (1) to facilitate changes in policies, protocols, and procedures of Oregon health care systems in order to overcome current barriers identified in research as impeding high-quality end-of-life care; and (2) to facilitate examination of Oregon state policy that governs funding for hospice care in order to achieve universal statewide access to hospice. Nationally, the aims are: (1) to guide and empower other state leaders in end-of-life care by providing consultation on improving methods to communicate orders to limit life-sustaining treatment; and (2) to assist other state leaders in end-of-life care to access and use existing state-based statistical data related to death and dying as a tool for policy change.

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 Oregon Health and Sciences University *To compare EOLC in three major settings ("The shaping of governmental and institutional policy")*

Project: A study to compare end-of-life care in the three major settings where death occurs in Oregon: acute care hospital, nursing homes, and home/hospice. Using death certificates of recently deceased adults, we will access families and providers and collect data on the following key variables related to the patients and their deaths: 1) advance directives; 2) the extent to which deaths followed advance planning; 3) access to hospice; 4) preference for location of death vs. location of actual death; 5) degree of pain and suffering vs. effectiveness of comfort care efforts; 6) decision

making about level of aggressiveness of treatment; 7) family satisfaction with care and identification of problems; 8) provider identification of barriers to compassionate care. Co-investigator: Virginia Tilden, R.N.

Nathan Cummings Foundation, Inc. *$100,000*

1998 $100,000 Oregon Health and Science University *Improving Care of The Dying - Overcoming Barriers & Advancing Gains in End-of-Life Care (Portland, OR)*

http://www.nathancummings.org/health_grants/000222.html
For improved care of the dying in Oregon and nationwide.
========
From Willamette U. web site on assisted suicide:
Oregon research projects on end-of-life care. Dr. Susan Tolle, director of the Center for Ethics in Health Care at Oregon Health Sciences University, and Virginia Tilden, associate dean for research at OHSU's School of Nursing, will lead several research projects to improve end-of-life care. Oregon Health Sciences University has received $598,351 from the Robert Wood Johnson Foundation and $100,000 from the Nathan Cummings Foundation to conduct four projects over a three-year period:

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b. Hospice coverage. Researchers will compile a policy paper describing the population of uninsured terminally ill Oregonians and suggesting ways to expand coverage.

c. POLST form. Researchers will compile and present a guide for other states on how Oregon developed its Physician Orders for Life-Sustaining Treatment (POLST) form.

d. Data-driven change. Researchers will help other states' leaders learn to access their own statistical information on death and dying as a tool to change policies.

Linda Torma, MSN, APRN, BC — $150,000 tracked thus far

Mayday Fund *$150,000*

1996 $150,000 Missoula Demonstration Project / Life's End Institute *Missoula Demonstration Project, Inc.*

http://www.painandhealth.org/mayday/previous-grants.html
Missoula Demonstration Project
Missoula, Montana
$39,048, the final payment in a three year $150,000 grant to improve the assessment and treatment of pain in the community of Missoula.
Contact: Linda Torma, RN, MSN
E-mail: LtormaMDP@aol.com

H. James Towey — $1,696,586 tracked thus far

Robert Wood Johnson Foundation — *$1,611,586*

1996 29110 $398,690 Aging With Dignity, Commission on — *Public Education to Promote a Health and Long-Term Care System to Allow Aging with Dignity*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___60
This grant supported a series of public forums on issues facing the state of Florida because of its growing proportion of elderly citizens. The forums examined how health and long-term care services could be structured and managed in such a way as to safeguard the dignity of people as they age. The forums involved leaders in government, private industry, the health and long-term care community, and the religious community, among others. The purpose was to foster greater public awareness and stimulate broad discussion on the many economic, social, and ethical dimensions of aging and dying. Some of the issues the forums focused on included financial security for the elderly and end-of-life care.
======
According to this description from the RWJF Grants Result Report, Towey laid the groundwork for RWJF's Community-State Partnerships with this project.

This project funded a series of five community forums in Florida on a variety of aging and end-of-life issues. The forums, conducted by the privately funded, nonprofit Florida Commission on Aging with Dignity, examined how health and long-term care services could be structured and managed to safeguard the dignity of people as they age and approach death. Topics of the first four forums were: (1) an overview on the aging of America; (2) the Medicaid program; (3) long- term care insurance and other financial planning; and (4) cultural barriers to discussing death and dying. During the final forum, Florida's governor, state supreme court justice, and their wives signed copies of "Five Wishes," an advance directive created by the project to help people discuss and make their wishes known about end-of–life care. The commission's advisory board consisted of high-level officials and executives who gave visibility to the project and participated in the forums. The forums generated substantial national media coverage, with articles in The New York Times, The Christian Science Monitor, and on National Public Radio, as well as more than 100 articles in state and local newspapers. The project helped shape a new Foundation national program, Community-State Partnerships to Improve End-of-Life Care, which supports organizations working to stimulate community dialogue and improve the quality of end-of-life care. The commission received a follow-up grant from the Foundation (ID# 033397) to disseminate the "Five Wishes" campaign in 33 states and the District of Columbia.

1998 33397 $492,003 Aging With Dignity, Commission on — *Five Wishes: Revision and national dissemination of advance directives*

http://web.archive.c*Annual report: Tallahassee, FL: (2 years).*
http://web.archive.org/web/20020322055308/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___91
Project Title: Revision and national dissemination of advance directives
Project Director: H. James Towey Degree:
Phone No.(Work): 850-681-2010
Fax (Work): 850-681-2481
Email: _fivewishes@aol.com
Grantee Institution: Aging with Dignity
Address: P.O. Box 11180

Tallahassee Florida United States.
Start Date: 05/01/1998 End Date: 04/30/2000
Amount: $492,003 Web Site:
Description: This project will: (1) revise the FIVE WISHES advance directive, originally developed in Florida, so that it can be used in other states; (2) conduct a nationwide communications campaign to maximize public interest around end-of-life care and patient rights; (3) construct a network of Last Acts members and interested health and long-term care providers, and religious and civic organizations to capture public interest in FIVE WISHES and help distribute the document; and (4) evaluate whether the educational and distribution efforts were successful in educating the public, changing behavior, and improving provider adherence to patient wishes.

2000 38914 $720,893 Aging With Dignity, Commission on — *Five Wishes at Work*

http://web.archive.org/web/20020319204100/http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___522
Project Title: Five Wishes at Work
Project Director: H. James Towey Degree:
Phone No.(Work): 850-681-2010
Fax (Work): 850-681-2481
Email: _fivewishes@aol.com
Grantee Institution: Aging with Dignity Inc.
Address: 215 South Monroe Street
Suite 620
Tallahassee Florida United States.
Start Date: 07/01/2000 End Date: 06/30/2003
Amount: $720,893 Web Site: www.agingwithdignity.org
Description: This project would promote and facilitate advance care planning by providing educational services in the workplace, building on the use of the Five Wishes advance directive and related materials. Five Wishes at Work emcompasses: distribution of the Five Wishes document itself, provision of information on how to complete other advance directives if some other form is preferred/required, use of a 30-minute training video, a toll-free line for

employers to contact Aging with Dignity's full-time health educators, Web services for employers to enable downloading of Five Wishes materials, a guide on advance care planning and patient self-determination, a book and checklist on "How to Talk with Your Doctor," and tips for promoting family discussion of one's wishes.

Pepper Foundation (Claude Pepper) *$85,000*

1996 $85,000 Aging With Dignity, Commission on *Project 2010*

this grant was mentioned in an RWJF grant report for Project 2010. http://www.rwjf.org/reports/grr/029110s.htm

Marie Trozzi — $75,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$75,000*

$75,000 Boston University School of Medicine

Located in Boston's South End, the Department of Pediatrics and its affiliated teaching hospital serve a predominantly minority constituency made up of primarily the city's underclass, working poor, and lower-middle class. The children living in this urban area are exposed to a disproportionately higher number of deaths than their peers in surrounding suburbs and are vulnerable to the pervasive stresses associated with poverty and their minority status. The CIRCLE will make available grief support for these children and their families, who face a multitude of loss, through peer support groups, trained volunteers, community outreach and clinical counseling services within individual neighborhoods of the city.

James A. Tulsky, M.D. — $778,531 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 Duke University - Medical Center *Faculty Scholar*

Grant amount is approximate. http://www2.soros.org/death/prMay29-96.htm
Development, implementation and evaluation of a model for teaching students and residents how to communicate better with dying patients.

National Institutes of Health - National Cancer Institute (NCI) *$638,531*

2003 $638,531 Duke University - Medical Center *Enhancing Patient-Oncologist Communication*

from NIH grants online: fy2003.north.carolina.txt

National Institutes of Health - Nursing Research (NINR)

2003 Duke University - Medical Center *Trajectories of Serious Illness: Patients and Caregivers*

http://crisp.cit.nih.gov/crisp/CRISP_LIB.getdoc?textkey=6682610&p_grant_num=1R01NR008249-01A1&p_query=%28hospice%29&ticket=14333335&p_audit_session_id=65197762&p_audit_score=14&p_audit_numfound=229&p_keywords=hospice
Grant Number: 1R01NR008249-01A1
PI Name: TULSKY, JAMES A.
PI Email: jtulsky@duke.edu
PI Title: ASSISTANT PROFESSOR OF MEDICINE
Project Title: Trajectories of Serious Illness: Patients and Caregivers

Abstract: DESCRIPTION (provided by applicant): Dying patients confront complex and unique challenges that threaten their physical, psychosocial and spiritual integrity. Despite recent interventions to improve palliative care, little is known about how dying patients and their families progress along the continuum from serious illness to death, and the most effective strategies for integrating curative and palliative care. The purpose of this research is to follow patients with three representative advanced chronic illnesses - metastatic cancer, NYHA Class IV congestive heart failure, and chronic obstructive pulmonary disease with hypercapnea - and their caregivers prospectively in order to describe multiple dimensions of the end-of-life experience. The specific aims of this proposal are to: 1. Describe patients' trajectories of physical symptoms, functional status, emotional function, quality of life, preparation for death, spirituality, and awareness of dying. 2. Describe caregivers' trajectories of anticipatory grief, caregiver burden and awareness of dying. 3. Examine the relationships between these trajectories (e.g., patient spirituality and functional status). 4. Determine the extent to which these trajectories are modified by patient and caregiver characteristics (e.g., ethnicity, disease type, coping style) and health services utilization (e.g., emergency department visits, hospitalizations, hospice enrollment). 5. Assess, in post-death interviews, timing of caregivers' realizations that the patient was dying, and locate disease time points along pre-death patient and caregiver trajectories. Two hundred forty patients and their primary caregivers living within a circumscribed geographic region will be enrolled. Key domains as listed in the specific aims will be assessed monthly until death, or for up to two years. Longitudinal variables will be analyzed using generalized growth mixture models and linear mixed effects models, and four hypotheses tested. The results from these analyses will be used to develop clinical profiles of patient and caregiver subgroups, identifying times of heightened need and potential targets for intervention. Knowledge of domain-specific trajectory patterns, such as abrupt versus progressive functional decline, and interactions between domains, such as physical symptoms, mood and awareness of dying, will illuminate our understanding of how seriously ill patients and their caregivers experience the transition from serious illness to death, and guide efforts to improve care of the dying.

Thesaurus Terms:
caregiver, chronic obstructive pulmonary disease, congestive heart failure, death, neoplasm /cancer palliative treatment, terminal patient care

awareness, coping, functional ability, gender difference, grief, health care model, health care quality, health care service utilization, hypercapnia, longitudinal human study, quality of life, racial /ethnic difference
behavioral /social science research tag, clinical research, human subject, interview, patient oriented research

Institution: DUKE UNIVERSITY
DURHAM, NC 27710
Fiscal Year: 2003
Department: MEDICINE
Project Start: 01-AUG-2003
Project End: 30-APR-2008
ICD: NATIONAL INSTITUTE OF NURSING RESEARCH
IRG: ZRG1

Wayne A. Ury, M.D. — $70,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$70,000*

1997 $70,000 St. Vincent's Hospital and Medical Center — *Faculty Scholar, 1997 (funding amount estimated); A Palliative Medicine Curriculum for an Internal Medicine Residency Program*

http://www2.soros.org/death/1997_fs.htm
In this project, an innovative palliative care curriculum will be developed, implemented, and evaluated. The curriculum will utilize case and problem-based learning techniques.

Patricia J. Volland, M.S.W., M.B.A. — $344,000 tracked thus far

Fan Fox and Leslie R. Samuels Foundation *$344,000*

1999 $344,000 New York Academy of Medicine — *A Model to Educate Social Work Students for Geriatric Practices in Health and Mental Health Care Settings (over 3 years).*

http://www.samuels.org/hc1999.htm

Charles F. von Gunten, M.D., PhD, FACP — $1,119,822 tracked thus far

Robert Wood Johnson Foundation *$285,700*

2000 38476 $285,700 San Diego Hospice — *Preparation of a Practical Guide to the Establishment of Palliative Care Services*

http://www.lastacts.org/scripts/la_res01.exe?FNC=grantDetail__Ala_res_grant_user_view_html___342
This National Program supports a National Resource Center at Mt. Sinai Hospital that is working to ensure that palliative care becomes a standard part of comprehensive patient care in the United States. The purpose of the Resource Center is to catalyze and facilitate the development of a new hospital-based palliative care program by serving as a clearinghouse and network to: quantify and describe existing programs, bring together existing organizations as resources, identify ways to encourage the development of programs in early stages, provide expert consultation on program development and staff training, and to convene a process for standard setting for hospital-based palliative care programs. This project will support the development of a practical guide to establishing palliative care services in hospitals. The guide will be based on the practical experience of pioneers who have established such services outside the current hospice model. This "how to" manual will provide a critical, descriptive, explanatory, and pragmatic synthesis of palliative care knowledge for a wide-reaching audience of health care providers, caregivers, and policymakers. It will address prime areas such as clinical services, financing, palliative care consultation services, inpatient palliative care units, and home care.

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 Northwestern University — *Faculty Scholar (EPEC? – "multi-disciplinary palliative medicine education program") Note: Amount of grant is estimated.*

Grant amount is approximate; http://www2.soros.org/death/prMay29-96.htm
Establishment of a multi-disciplinary palliative medicine education program for health care professionals.
========
http://www.northwestern.edu/univ-relations/media/observer/1995-96observer/faculty-news/vongunten-facnews.html
Von Gunten is among 13 scholars chosen to share approximately $3 million over the next three years to improve the care of the dying across North America. The scholars represent 12 major medical institutions in the United States and one in Canada. The role of the scholars is to participate in the project's overall goal of transforming the culture of dying through catalyzing change in the health care institutions they represent.

National Institutes of Health - National Cancer Institute (NCI) *$544,122*

1996 $93,774 Northwestern University — *CANCER PAIN EDUCATION--AN ANLGESIC DOSING SERVICE*

http://grants.nih.gov/grants/award/state/FY1996.illinois.txt

1996 $75,560 Northwestern University — *CLINICAL ELECTIVE IN HOSPICE/PALLIATIVE MEDICINE*

http://grants.nih.gov/grants/award/state/FY1996.illinois.txt

1996 $77,677 Northwestern University — *CLINICAL ELECTIVE IN HOSPICE/PALLIATIVE MEDICINE*

http://grants.nih.gov/grants/award/state/FY1997.illinois.txt (second year was this $77000 grant)

Grant Number: 5R25CA066933-02
PI Name: VON GUNTEN, CHARLES F.
PI Email: cvongunten@sdhospice.org
PI Title:
Project Title: CLINICAL ELECTIVE IN HOSPICE/PALLIATIVE MEDICINE

Abstract: DESCRIPTION: (Applicant's Description) We propose to create a curriculum-driven elective rotation to educate resident physicians training in primary care medicine in three separate medical training programs which are affiliated with the Northwestern University Medical School about Hospice and Palliative Care. The faculty in palliative medicine will be comprised of physicians with special expertise in hospice/palliative medicine (and the multidisciplinary team members of three hospice programs). There are two components to the one-month elective: direct patient care and didactic palliative medicine curriculum. Residents in their second and third years of training will serve as an integral part of established (multidisciplinary) Hospice/Palliative Medicine Services. They will evaluate and participate (with interdisciplinary team members) in the care of patients in general hospital, inpatient hospice/palliative care unit, and home-hospice settings. Concurrently they will receive instruction guided by an explicit curriculum in Hos-pice/Palliative Medicine. The educational objectives for residents completing the elective are 1) to improve knowledge and skill in cancer pain management, 2) to improve knowledge and skill in managing common symptoms of advanced disease, 3) to improve communication skills with patients about death and dying, and 4) to improve knowledge about the principles of palliative care, (the bio-psycho-social model of illness), optimal utilization of hospice programs, (and participation in a team approach to care). The specific aims of the proposal are, 1) to pilot a full-time curriculum-driven Hos-pice/Palliative Medicine elective for residents training in primary care, 2) to evaluate whether the educational objectives of the curriculum have been met, 3) to use a videotaped interview between resident and standardized patient to assess essential communication skills, and 4) to formalize a faculty of Palliative Medicine drawn, in part, from an affiliation of community hospice programs with the Lurie Cancer Center of Northwestern University. The educational outcome will be assessed with an evaluation of the knowledge base of the resident before and after the rotation.

Thesaurus Terms:
cancer pain, curriculum, medical education, neoplasm /cancer education, neoplasm /cancer palliative treatment communication behavior, death, education evaluation /planning, family, hospice, patient care management, patient care personnel relations, primary care physician, psychological aspect of cancer
human data, human subject, interview, videotape /videodisc

Institution: NORTHWESTERN UNIVERSITY
710 N. Lake Shore Drive
CHICAGO, IL 60611
Fiscal Year: 1997
Department: MEDICINE
Project Start: 01-SEP-1996
Project End: 30-JUN-1999
ICD: NATIONAL CANCER INSTITUTE
IRG: CRME

2003 $297,111 San Diego Hospice *Palliative Care Curriculum for 3rd-Year Medical Students*

http://grants.nih.gov/grants/award/state/state03.htm

2004 San Diego Hospice *Academic Palliative Care*

Grant Number: 1K05CA102582-01A1
PI Name: VON GUNTEN, CHARLES F.
PI Email: cvongunten@sdhospice.org
PI Title:
Project Title: Academic Palliative Care

Abstract: DESCRIPTION (provided by applicant): Charles F. von Gunten, MD, PhD is seeking support as an established investigator in palliative care, part of National Cancer Institute's prevention and control program. Palliative care can be summarized as the prevention and relief of suffering. As an established investigator with a track record of funded research, peer-reviewed publications and mentoring, he is now in a unique position to foster further development of the field as called for in the recent reports by the Institute of Medicine and National Cancer Policy Board. In roles as Director of the Center for Palliative Studies at San Diego Hospice & Palliative Care, a teaching and research affiliate of the University of California San Diego School of Medicine, member of the NCI-designated University of California San Diego Moores Comprehensive Cancer Center, Co-Principal of the EPEC Project, Senior Associate Editor of the Journal of Palliative Medicine and Chairman, American Board of Hospice and Palliative Medicine, the NCI is able to protect his abilities to conduct palliative care research and mentor trainees and leaders in the field. He has pursued research objectives to understand education (particularly physicians) and symptom control (particularly neuropathic pain) and as well as broad advocacy and leadership objectives to achieve his goals. Scientifically supported approaches to the prevention and relief of suffering are as important to the overall care of patients with cancer and their families as are approaches to the treatment of cancer itself. He needs protected time to continue a vital research program in the creation and dissemination of palliative care knowledge and reentering new physician scientists in the field. He is responsible for the educational and research developments in the largest department of subspecialist palliative medicine physicians in the USA. In addition, he is responsible for nurturing and developing nurse practitioners, nurses, social workers, and chaplains in a similar way. His personal research plan addresses the question "How is palliative care best taught?" This K05 will permit him to conduct educational research for resident physicians, physician fellows, nurses, social workers and chaplains. This K05 will permit him to mentor junior investigators in projects to test the ability of infusional

lidocaine to relieve severe refractory pain, to understand patient, family, staff communication in terminal illness, and to test the ability of acupuncture to relieve distress in patients with terminal illness. All reentered investigators are seeking NCI funding and have the potential to become independent investigators.
Institution: SAN DIEGO HOSPICE AND PALLIATIVE CARE
4311 3RD AVE
SAN DIEGO, CA 921031407
Fiscal Year: 2004
Department:
Project Start: 01-SEP-2004
Project End: 31-AUG-2009
ICD: NATIONAL CANCER INSTITUTE
IRG: NCI

Kornfeld / PDIA (Soros) collaborative *$150,000*

2004 $150,000 San Diego Hospice *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://www.soros.org/initiatives/pdia/articles_publications/publications/newsletter_20040310/pdia_newsletterfall2003.pdf

Jamie Von Roenn, M.D. — $536,984 tracked thus far

National Institutes of Health - National Cancer Institute (NCI) *$236,984*

1997 $236,984 Northwestern University *AIDS-ASSOCIATED MALIGNANCIES CLINICAL TRIALS MEMBER*

http://grants.nih.gov/grants/award/state/FY1997.illinois.txt

Kornfeld / PDIA (Soros) collaborative *$300,000*

2003 $150,000 Northwestern University *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

http://fdncenter.org/grantmaker/kornfeld/list.html
Institutional Post-Graduate Palliative Care Fellowships
For 2003 through 2005, the Kornfeld Foundation is funding institutional palliative care fellowships in collaboration with the Project on Death in America (Open Society Institute), with the goal of building capacity in the field through training physicians in the principles and practice of palliative care. The ultimate goal is to establish the field of palliative care as an accredited sub-specialty of medicine. We are encouraging other funders to join with us by developing a "Funders Consortium to Advance Palliative Medicine."

2004 $150,000 Northwestern University *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12

Edward H. Wagner, M.D., M.P.H., F.A.C.P. — $11,038,599 tracked thus far

Robert Wood Johnson Foundation *$11,038,599*

34794 $400,632 GroupHealth Cooperative of Puget Sound - ICIC *Improving Chronic Illness Center*

Seattle, WA: Technical assistance and direction for Improving Chronic Illness Care 4 months).

34984 $10,637,967 GroupHealth Cooperative of Puget Sound - ICIC *Improving Chronic Illness Center*

Seattle, WA: (21 months).

Florence Schorske Wald, M.N., M.S., FAAN — $18,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$18,000*

$18,000 National Prison Hospice Association *The shaping of governmental and institutional policy: To assess the need for adapting hospice care services for terminally ill patients under prison custody in the Connecticut State Department of Correction.*

http://www2.soros.org/death/governmental_policy.htm
Co-funded with the Center on Crime, Community and Culture ($18,000).
Six prison infirmaries serving the state's 23 correctional facilities, will undergo an evaluation of the health management practices, support services, and ancillary programs that provide terminal care for dying inmates.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Judy Waxman — $1,055,000 tracked thus far

Gerbode Foundation (Wallace Alexander) — *$55,000*

1999	$10,000	National Women's Law Center	*Hospital merger project*

Gerbode's form 990, pg 118
NOTE: Though I am not certain who was the NWLC contact, Waxman runs the Health section, so my guess is she was the contact.
Merger project is described at NWLC web site:
http://www.nwlc.org/details.cfm?id=252&section=health

Religiously affiliated hospitals, managed care companies, and insurers may refuse to provide or pay for services to which they have a religious objection. Catholic entities generally impose the most detailed and rigid limitations on the provision of women's reproductive and other health services. The prohibited services might include abortion, contraceptive services or counseling, emergency contraception (even in cases of rape), sterilization procedures, infertility treatment, counseling on the use of condoms to prevent the spread of HIV and STDs, research or treatment involving fetal or stem cells, and certain end-of-life care. Furthermore as religious health care facilities merge with, purchase, or otherwise affiliate with secular facilities, they often impose their religious restricitions on their new partners. Despite the pervasiveness of these restrictions, many health care consumers do not know about them, and many institutions do not provide notice of their religious restrictions. The National Women's Law Center has developed innovative and practical responses to protect the availability of these vital health care services and, where services are restricted, to ensure that health care entities provide adequate notice of those restrictions to consumers.

Launched in 1998, the NWLC Health Care Religious Restrictions Project is an ongoing campaign to develop and apply creative legal strategies to protect the availability of vital health services. NWLC offers assistance to community organizers, attorneys, health care providers, legislators, governmental agencies, and health care consumers, such as:

Providing direct technical assistance to individuals and organizations around the country who are challenging specific mergers. Center staff advise community activists and their attorneys on which officials to contact and how to present their concerns. Center staff members also contact these officials directly. NWLC helps locate attorneys throughout the country who are interested in assisting community advocates, and Center staff may work directly on cases as well.

2001	$20,000	National Women's Law Center	*"Health Care Provider Merger Project"*

from Gerbode's form 990, pg 42

2002	$25,000	National Women's Law Center	*"Health Care Provider Merger Project"*

from Gerbode's form 990, pg 275

Open Society Institute / Reproductive Health and Rights (Soros Foundation) — *$1,000,000*

1998	$1,000,000	National Women's Law Center	*NWLC Reproductive Rights and Health Program (1998-2004).*

http://www.soros.org/initiatives/repro/focus_areas/advocacy_litigation/grantees/grants_list
NOTE: Though I am not certain who was the NWLC contact, Waxman runs the Health section, so my guess is she was the contact.

Sharon M. Weinstein, MD — $50,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) — *$50,000*

1996	$50,000	University of Texas	*Faculty Scholar, 1996-97: Development and implementation of clinical care pathways to improve the care of dying cancer patients. (Grant amount is estimated.)*

Press Release: PDIA AWARDS $1.6 MILLION TO IMPROVE CARE OF THE DYING

New York, NY -- 29 May 1996

David E. Weissman, M.D. — $4,546,307 tracked thus far

Robert Wood Johnson Foundation — *$3,745,214*

	32598	$74,789	Medical College of Wisconsin, Inc.	*Workers' Compensation Health Initiative (Chronic Health Conditions)*

Milwaukee, WI: (1 year). (guessing that Weissman is contact.)

1999	36669	$669,043	Medical College of Wisconsin, Inc.	*Improving residency training in end-of-life care*

(guessing that Weissman is contact.)

1999	36547	$998,865	Medical College of Wisconsin, Inc.	*Improving residency training in end-of-life care*

(guessing that Weissman is contact.)

2001	41481	$378,749	Medical College of Wisconsin, Inc.	*Improving residency training in end-of-life care -- supplemental support*
2002	44826	$274,610	Medical College of Wisconsin, Inc.	*Improving residency training in end-of-life care*
2002	45195	$301,658	Medical College of Wisconsin, Inc.	*Development of the national resource center for end-of-life physician education*

2003 49036 $750,000 Medical College of Wisconsin, Inc. *Palliative Care Leadership Center*

August 21, 2003 - The Palliative Care Programs of the Medical College of Wisconsin, Froedtert Hospital and Children's Hospital of Wisconsin have been designated as one of the nation's six Palliative Care Leadership Centers by the Center to Advance Palliative Care, a national program of the Robert Wood Johnson Foundation.

http://www.mcw.edu/display/router.asp?DocID=729
As a result, the Palliative Care Leadership Program of the Medical College, Children's and Froedtert will receive a three-year, $750,000 grant to provide site visits and hands-on training in Milwaukee for clinicians and hospital administrators throughout the nation who are interested in developing palliative care programs.

2003 46547 $297,500 Medical College of Wisconsin, Inc. *Improving residency training in end-of-life care*

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1995 $140,000 Medical College of Wisconsin, Inc. *Faculty Scholar*

Amount of grant is approximate. http://www2.soros.org/death/prMay29-96.htm
Developmen of a death education curriculum for primary care.

National Institutes of Health - National Cancer Institute (NCI) *$661,093*

1992 $79,974 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

Grant Number: 5R25CA057786-06
PI Name: WEISSMAN, DAVID E.
PI Email: dweissma@mail.mcw.edu
PI Title:
Project Title: CANCER PAIN ROLE MODEL PROGRAM

Abstract: This grant application is a competitive renewal that seeks a five year extension of our existing cancer pain education grant, "Cancer Pain Role Model Program". Cancer pain remains a major public health problem in the United States. Inappropriate attitudes and knowledge deficits among health professionals contribute to poor pain management. Conventional education programs have made little impact on the cancer pain problem. This application seeks to continue the Cancer Pain Role Model Program, an education project of the Wisconsin Cancer Pain Initiative. 180 physicians and nurses involved in medical education will be recruited each year for 5 years. Physicians and nurses together with their clinical partners will attend one of three year model conferences each year. The conferences include didactic lectures, small group case-based workshops and an education workshop. Each physician and nurse-clinical partner team will complete an Action Plan detailing proposed education and clinical care activities in their clinical practice setting. 25 participants will be allowed to, come to Milwaukee and work for up to 3 days as a member of the Medical College of Wisconsin Palliative Care Service to augment their clinical skills and further develop their Action Plan. Pre-and post conference knowledge surveys, conference evaluations and one-year Action Plan surveys are used to assess the impact of the Role Model Program.

Thesaurus Terms:
cancer pain, education evaluation /planning, neoplasm /cancer education, nursing education, role model community health service, continuing education, continuing nursing education, health behavior, meeting /conference /symposium, neoplasm /cancer palliative treatment, nurse, patient care management, physician, training, workshop human data

Institution: MEDICAL COLLEGE OF WISCONSIN
PO BOX26509
MILWAUKEE, WI 532260509
Fiscal Year: 1997
Department: MEDICINE
Project Start: 10-SEP-1992
Project End: 31-AUG-2000
ICD: NATIONAL CANCER INSTITUTE
IRG: CRME

1993 $81,983 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

http://grants.nih.gov/grants/award/state/FY1995.wisconsi.txt

1994 $84,073 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

1994 $24,624 Medical College of Wisconsin, Inc. *Cancer Education Program*

1995 $26,180 Medical College of Wisconsin, Inc. *Cancer Education Program*

1995 $107,596 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

1996 $27,617 Medical College of Wisconsin, Inc. *Cancer Education Program*

http://grants.nih.gov/grants/award/state/FY1996.wisconsi.txt

1996 $111,901 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

http://grants.nih.gov/grants/award/state/FY1996.wisconsi.txt

1997 $116,378 Medical College of Wisconsin, Inc. *Cancer Pain Role Model Program*

1997 $767 Medical College of Wisconsin, Inc. *Cancer Education Program*

Michael A. Weitzner, M.D.

$150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 University of South Florida *Clinical Depression*

Although many health care professionals view clinical depression as an inevitable part of terminal illness, there are many other factors that play a role in the generation of clinical depression. This project will test the explanatory value of a social cognitive model of depression in home hospice cancer patients, and create improved screening assessment in hospice for clinical depression.

W. Peter Welch, Ph.D.

$426,509 tracked thus far

Robert Wood Johnson Foundation *$426,509*

1993 21243 $426,509 Urban Institute *Study of US/Canadian Differences in Use and Costs of Physician Services*

Washington, DC, Grant Results: The project found that Canadians receive a higher volume of services than US elderly, but the price per service is lower, resulting in lower overall expenditures for physician services in Canada; elderly Canadians receive fewer surgical procedures than their US counterparts and fewer procedures for which there is low clinical consensus on need; Canadian elderly receive more than four times as many home and nursing home visits as US elderly; the United States does not appear to spend more than Canada on physician services for the elderly in the last six months of their lives; and the number of Canadians seeking health care services in the United States to avoid Canadian queues is insignificant. Because the policy climate in the United States is so different today than it was at the height of planning for health care reform and because the Canadian health care system is no longer a model for the United States, the findings from this study are unlikely to inform the work of local, state, or federal governments in the near term. The study does provide useful insights into the rise in expenditures in the US Medicare program, which remains predominantly a fee-for-service program.

Alvin F. Wells, MD

$315,000 tracked thus far

Robert Wood Johnson Foundation *$315,000*

2000 $315,000 Duke University - Medical Center *award to minority physicians*

http://www.dukemednews.org/news/article.php?id=256

date : 1/7/2000
media contact : Tracey Koepke , (919) 684-4148 or (919) 660-1301
koepk002@mc.duke.edu

DURHAM, N.C. -- Dr. Alvin F. Wells, a senior rheumatology fellow at Duke University Medical Center, has been awarded a $315,000 grant by the Robert Wood Johnson Foundation to study the mechanisms of autoimmune diseases, such as rheumatoid arthritis.

The Robert Wood Johnson Foundation created the four-year award to increase the number of under-represented minorities on the faculty at medical centers throughout the United States. The award is presented to minority physicians who have demonstrated superior academic and clinical skills, and who show commitment to careers in academic medicine

Paul Wink, Ph.D.

$150,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$150,000*

$150,000 Wellesley College *Study of the diverse social contexts of social mobility, gender and war participation on bereavement, resiliency and healthy adaptation to the process of aging*

(over 2 years) At a time when increasing numbers of Americans are living well into their 80's, relatively little is known about the psychological processes that influence the role of the diverse social contexts of social mobility, gender and war participation on bereavement, resiliency and healthy adaptation to the process of aging. Drawing upon existing archival data from two longitudinal studies of men and women (The Oakland Growth (OGS) and Berkeley Guidance Studies (BGS)), which include a rich array of personality, cognitive and health data gathered in childhood, adolescence and at three points in adulthood; this project will investigate adaptation, influence of past and present religious beliefs and spirituality, long-term and interpersonal factors and integrity in health, old age, death and bereavement. Participants in the study are currently, on the average, between 68 - 76 years of age.

Underwriting: Listing by Project Director or Principal Investigator, in alpha order.
This lists only those grants where a project contact is known. See "Grants to Organizations" for a more complete list of funding.

Joanne Wolfe, M.D., M.P.H. — $290,000 tracked thus far

Open Society Institute / Project on Death in America (Soros Foundation) *$140,000*

1999 $140,000 Harvard Medical School - Dana Farber Cancer Insitute In *PDIA Faculty Scholar*

http://www2.soros.org/death/news7.htm
Wolfe: Balancing Curative Treatment with Palliative Care
Each year about 12,400 children in the United States are diagnosed with cancer, but in 1998 only 2,500 died of cancer-related causes (which still makes cancer the leading cause of non-accidental death in children ages 1 to 14 years).

"Since most children with cancer survive, the primary goal of the pediatric oncologist is to cure cancer," Joanne Wolfe, of the Dana-Farber Cancer Institute in Boston, said. "Considerations of toxicity of therapy and impingement on quality of life are usually secondary to this goal. This approach makes it difficult for physicians to redirect care when there is little hope for cure."

Faculty Scholar Joanne Wolfe conducted a study documenting the substantial suffering of dying children and the significant communications difficulties between physicians and the parents of these children. A pilot intervention will attempt to bring greater attention to the medical problems of children at the end of life, improve communication and understanding of family preferences, and reduce suffering.

The study involved 103 parents, one parent per family. The average duration of disease was 2.7 years, the average age at death was 10.8 years. Forty-four patients died at Children's Hospital, 45 percent of these on a ventilator in the last 24 hours. Seventy-nine percent of patients died as a result of progressive disease; the remainder experienced a toxic complication.

The study found that children who died of cancer experienced substantial suffering in the last month of life. Interviews with parents showed that 89 percent of the children experienced substantial suffering from at least one symptom, most commonly fatigue, pain or dyspnea. Treatment for these symptoms was seldom successful, even in the case of symptoms that are typically considered to be amenable to treatment. The data suggests that many physicians may be unaware that much end-of-life suffering can be alleviated through palliation.

Kornfeld / PDIA (Soros) collaborative *$150,000*

2004 $150,000 Harvard Medical School - Dana Farber Cancer Insitute In *Kornfeld/PDIA Institutional Post-Graduate Palliative Care Fellowship*

PDIA Newsletter, Fall, 2003, No. 11, pg. 12
NOTE: Galanos and Tulsky co-direct the fellowship

Jay Wolfson, Dr. P.H., J.D. — $4,842,454 tracked thus far

National Institutes of Health - Department of Clinical Bioethics *$700,000*

2000 $700,000 *Adolescent Clinical Trials for HIV/AIDS*

US DHSS - Health Resources and Services Administration (HRSA) *$4,142,454*

200 $1,064,364 *Florida Family AIDS Network*

1992 $1,500,000 *Tampa Bay Pediatrics AIDS Project*

From Health Resources and Services Administration within DHHS
Reference his c.v. at http://hsc.usf.edu/publichealth/eoh/jwolfson/index.html

1995 $350,000 *Tampa Bay Pediatrics AIDS Project*

From Health Resources and Services Administration within DHHS
Reference his c.v. at http://hsc.usf.edu/publichealth/eoh/jwolfson/index.html

2001 $1,228,090 *Florida Family AIDS Network*

From Health Resources and Services Administration within DHHS
Reference his c.v. at http://hsc.usf.edu/publichealth/eoh/jwolfson/index.html