

A CADRE OF PROFESSIONALS

Some key people in the end-of-life movement.

Note: This information has been verified as best as time and resources permit. Corrections are welcomed and may be sent to joynlife@earthlink.net

Kimberly D. Acquaviva, Ph.D., MSW

Affiliations:

Hospice of the Florida Suncoast: Hospice Institute of the Florida Suncoast
Research Director
University of Pennsylvania
Alumna; PhD, MSW

Conferences, research papers, task forces, ev

- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."
- 2004 NHPCO 2004 Clinical Team Conference
Concurrent sessions

Known funding:

Elizabeth Mayfield Arnold, Ph.D., LCSW

Affiliations:

Duke University - Institute on Care at the End of Life
Core Faculty
Open Society Institute / Project on Death in America (Soros Foundation)
grant recipient
University of North Carolina - Chapel Hill
Assistant Professor, The Graduate School of Social Work

Conferences, research papers, task forces, ev

- 2000 Soros's Project on Death in America announces second round of grants for their \$2 million Social Work Leaders Program -- \$419,400.
- 2002 Social Work Summit on End-of-Life and Palliative Care co-sponsored by the Last Acts Provider Education Committee, The Duke Institute on Care at the End of Life, and the Soros Foundation's Project on Death in America.
Attendees

Known funding:

\$60,000 tracked thus far
\$60,000 from Open Society Institute / Project on Death in America (Soros Foundation)
 to: Carolinas Center for Hospice and End of Life Care **\$60,000**

Robert M. Arnold, M.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

President (2005); former board member

American Board of Hospice and Palliative Medicine (ABHPM)

Trustee (2004)

Case Western Reserve Center for Bioethics

International Association of Bioethics

Journal of Palliative Medicine

Editorial Board

Last Acts

Members

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

Faculty Scholar

PC-Heart (Palliative Care Heart Failure Education and Research Trials)

Steering Committee

Physicians for a National Health Program

Signer

Physicians for Social Responsibility

1986-1991 (Treasurer, 1989-1990)

Society for Health and Human Values (SHHV) [see ASBH]

Founding member, 1985; President 1996-97

Society of General Internal Medicine

CoChair, 1994-1995

University of Pittsburgh

Faculty

University of Pittsburgh - Medical Center

Comprehensive Palliative Care Program

University of Pittsburgh School of Medicine

Known funding:

\$506,190 tracked thus far

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

to: University of Pittsburgh

\$228,190

\$278,000 from **Greenwall Foundation**

to: University of Pittsburgh

\$278,000

Conferences, research papers, task forces, ev

1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
Additional Contributors

1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement

2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

2003 **Physicians for a National Health Program issue call for universal health care, published in JAMA. Principals of PNHP include Christine Cassel and Marcia Angell. Endorsing the petition: Tulsky, Sulmasy, Meier, Yellig, Truog**
not sure this is the same arnold

Anthony L. Back, M.D.

Affiliations:

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

Faculty Scholar, 1998-2000

University of Washington

Division of Oncology

Known funding:

\$451,425 tracked thus far

\$149,447 from **Robert Wood Johnson Foundation**

to: University of Washington

\$149,447

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

to: University of Washington

\$70,000

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

to: University of Washington

\$231,978

Conferences, research papers, task forces, ev

2004 **Quill & Battin edit a book supporting PAS. Contributors include Christine Cassel**

David Barnard, Ph.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
1994, organized a Humanities Advisory Group; still heading it in 2001

Journal of Palliative Medicine
Editorial Board (2003)

Society for Health and Human Values (SHHV) [see ASBH]
President, 1991-92

University of Pittsburgh
Director of Palliative Care Education; Professor of Medicine

University of Pittsburgh - Medical Center

Known funding:

\$174,229 tracked thus far

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

to: University of Pittsburgh - Medical Center

\$174,229

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
2 Co-Chair

Ann M. Berger, RN, MSN, M.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
member and former chair of the Continuing Medical Education Committee

Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)
rep to National Consensus Project

National Institutes of Health - Department of Clinical Bioethics
Chief of Pain and Palliative Care (2000-)

University of Medicine and Dentistry of New Jersey, New Jersey Medical Scho
Assistant Professor in Medicine and Anesthesiology (1996-2000)

Yale School of Medicine
Assistant Professor in Medicine and Anesthesiology.(prior to 1996)

Known funding:

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

J. Andrew Billings, M.D.

Affiliations:

Harvard Medical School - Center for Palliative Care
Program in Palliative Care Education and Practice, Core Faculty

Harvard Medical School - Center for Palliative Medicine at Mass. General
Director, Palliative Care Services

Journal of Palliative Medicine
Senior Associate Editor

Last Acts

Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)
rep to National Consensus Project

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar 1995
(<http://www2.soros.org/death/prMay29-96.htm>)

Promoting Excellence in End-of-Life Care (see Missoula Demonstration Proj.)
Principal investigator,

Robert Wood Johnson Foundation

Conferences, research papers, task forces, ev

1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Palliative Care Task Force 1997

1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
Endorsed the statement

1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
Acknowledgments

1997 **Precepts of Palliative Care (Last Acts Palliative Care Committee)**
Members

1998 **RWJF awards grants to Stanford and Harvard for medical faculty programs.**
(Soros/PDIA)

2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

Known funding:

\$3,226,613 tracked thus far

\$2,783,893 from **Robert Wood Johnson Foundation**

to: Harvard Medical School - Center for Palliative Medicine at Mass. Gener **\$1,897,873**

to: Massachusetts General Hospital **\$886,020**

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

to: **\$50,000**

\$160,800 from **Mayday Fund**

to: Massachusetts General Hospital **\$160,800**

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

to: Massachusetts General Hospital **\$231,920**

Affiliations:

- American Board of Hospice and Palliative Medicine (ABHPM)
Trustee (2004)
- American College of Physicians - ACPS-ASIM
Consensus Panel
- Center For Applied Ethics and Professional Practice (see EDC)
Editorial Board, "Innovations"
- Harvard Medical School - Center for Palliative Care
Program in Palliative Care Education and Practice, Core Faculty
- Harvard Medical School - Center for Palliative Medicine at Mass. General
Co-Director
- Harvard Medical School - Dana Farber Cancer Insititute Inc.
Chief, Psychosocial Oncology
- Journal of Palliative Medicine
Editorial Board
- Last Acts
Members
- Open Society Institute / Project on Death in America (Soros Foundation)
Director, Faculty Scholars Program

Conferences, research papers, task forces, ev

- 1994 Soros launches "Project on Death in America"
- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees
- 1996 EPEC Project (Education for Physicians on End-of-Life Care)
Additional Contributors
- 1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Conference Attendees
- 1997 Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"
1 RWJF Project Director
- 1997 ACP-ASIM End-of-Life Care Consensus Panel is formed
- 1998 VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)
- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."
- 2003 Boston Globe article announces end of Soros/RWJF project

Known funding:

\$205,194	tracked thus far	
\$41,856	from Robert Wood Johnson Foundation	
	to: Harvard Pilgrim Health Care, Inc.	\$41,856
	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to:	
\$163,338	from National Institutes of Health - National Cancer Institute (NCI)	
	to: Harvard Medical School - Center for Palliative Medicine at Mass. Gener	\$62,354
	to: Harvard Medical School	
	to: Harvard Medical School - Center for Palliative Care	\$100,984

William S. Breitbart, M.D.

Affiliations:

American College of Physicians - ACPS-ASIM
Consensus Panel
Journal of Palliative Medicine
Editorial Board
Memorial Sloan-Kettering
Open Society Institute / Project on Death in America
(Soros Foundation)
Faculty Scholar 1995
<http://www2.soros.org/death/prMay29-96.htm>

Conferences, research papers, task forces, ev

- 1996 EPEC Project (Education for Physicians on End-of-Life Care)
EPEC Advisory Group
1997 ACP-ASIM End-of-Life Care Consensus Panel is formed
1998 APOS Standards of Care for the Management of Distress in
Patients with Cancer
2001 National Consensus Project -- national palliative care
guidelines.
Advisory Council

Known funding:

\$3,911,199 tracked thus far

\$140,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Cornell University - Weill Medical College **\$140,000**
\$718,225 from **National Institutes of Health - National Cancer Institute (NCI)**
to: Memorial Sloan Kettering **\$718,225**
\$3,052,974 from **National Institutes of Health - National Institute of Mental Health (NIMH)**
to: Memorial Sloan Kettering **\$3,052,974**

Howard Brody, M.D.

Affiliations:

American Society of Bioethics and Humanities (ASBH)
Board of Directors (03)
Clinton Health Care Task Force
1993
Hastings Center
Michigan State University
Family Medicine

Conferences, research papers, task forces, ev

- 1987 Appleton, Wisc: First of two conferences to establish
international guidelines for withdrawal of treatment. John
Stanley (later with Hastings/National Hospice
Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S.
Youngner, H. Brody represent US.
1988 Appleton Conference Project -- Second Meeting.
*DECISIONS INVOLVING NEONATES AND PATIENTS WHO
ARE NOT NOW AND NEVER HAVE BEEN COMPETENT*
1996 EPEC Project (Education for Physicians on End-of-Life Care)
Additional Contributors
2004 55 Bioethicists file brief in support of Michael Schiavo
Signers

Known funding:

Eduardo Bruera, M.D.

Affiliations:

American Board of Hospice and Palliative Medicine
(ABHPM)
Past Trustee
Center For Applied Ethics and Professional Practice (see
EDC)
Editorial Board, "Innovations"
International Association for Hospice and Palliative Care
(IAHPC)
Chair; Board of Directors
Journal of Palliative Medicine
Editorial Board (2004)
Last Acts Partnership
Board of Directors (2004)

Conferences, research papers, task forces, ev

- 2001 National Consensus Project -- national palliative care
guidelines.
Advisory Council

Known funding:

Thomas Edward Bryant, M.D., J.D.

Affiliations:

Carter Institute for Human Development (Rosalynn Carter Institute; RCI)
Board Co-Chair

Hospice Foundation of America
Board Vice Chairman (2004)

National Organization for the Reform of Marijuana Laws (NORML)
Advisory Board, 1976-78

Non-Profit Management Associates, Inc.
Chairman (1995)

Known funding:

Conferences, research papers, task forces, ev

- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**
Conference Attendees
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**
Conference Attendees

Robert A. Burt, J.D.

Affiliations:

Bazon Center for Mental Health Law -- Pain and Palliative Care Reporter
Board of Trustees; Chair, 1990-2000

Greenwall Foundation
Advisory Board 2003

Institute of Medicine
Committees on Care at the End of Life (1995-97); Ethical and Public Policy Issues in Xenograft Transplantation (1994-96)

Journal of Palliative Medicine
Editorial Board

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

Yale University
Alexander M. Bickel Professor of Law

Known funding:

Conferences, research papers, task forces, ev

- 1993 **IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines --"Approaching Death" -- and recommendations for Last Acts strategies.**
Workshop Participants
- 1994 **Soros launches "Project on Death in America"**
- 1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
- 2001 **Greenwall Foundation Faculty Scholars Program in Bioethics**
Advisory Board

Affiliations:

Academy of Hospice Physicians see **American Academy of Hospice & Pal. Care**
Ethics Chairman, 1994

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
Past President (1996 or 1997) (see Choice in Dying newsletter at <http://web.archive.org/web/19981207074351/www.echony.com/~choice/news98.htm>)

American College of Physicians - ACPS-ASIM
Consensus Panel

Center For Applied Ethics and Professional Practice (see EDC)
Editorial Board, "Innovations"

Chalice of Repose Project Corp.
Brought it to Missoula http://www.lifes-end.org/mediastories/missoula_experiment.phtml

Children's Hospice International
PACC National Advisory Council

Dartmouth College

Dartmouth Medical School

Dartmouth-Hitchcock Medical Center
Director of Palliative Medicine

Journal of Palliative Medicine
Editorial Board

Last Acts

Missoula Demonstration Project / Life's End Institute
Co-Founder

National Association of Attorneys General (NAAG)
2004 EOL Advisory Committee

National Health Council, Inc.
Board of Directors (2003)

Partnership for Caring
Chief medical consultant
(<http://www.findingourway.net/downloads/Byock.Op.Ed.pdf>)

Promoting Excellence in End-of-Life Care (see Missoula Demonstration Proj.)
Program Director; Promoting Excellence

University of Montana - Center for Ethics (dba Practical Ethics Center)

Conferences, research papers, task forces, ev

1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Palliative Care Task Force 1997

1996 **IOM's Committee on Care at the End of Life - Public Hearing #1 (led to "Approaching Death")**

1996 **RWJF awards grant to EDC to convene the National Task Force on End-of-Life Care for Patients in Managed Care. The Task Force would produce a widely publicized report, "Meeting the Challenge," in May, 1999.**
2) Committee Members

1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**

1997 **Promoting Excellence in End-of-Life Care (RWJF)**
1 Program Director

1997 **"Before I Die" on PBS with Tim Russert -- RWJF begins media campaign to build grass roots reaction to SUPPORT study**
Panelists

1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**

1997 **National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)**
Task Force Member

1997 **Finding Common Ground: Assisted Suicide Consensus Panel is convened**

1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**
Presenters

1997 **Precepts of Palliative Care (Last Acts Palliative Care Committee)**
Members

1997 **Choice in Dying, Alliance for Health Reform, and Hospice Organization of America co-sponsor congressional briefing to introduce the Advance Planning and Compassionate Care Act of 1997, designed to strengthen the Patient Self-Determination Act.**

1998 **Doctors, Death, and Dignity - Chautauqua**

1999 **From Contract to Covenant**

1999 **National Hospice Work Group Project: Planning for "Increasing Access to Hospice Care"**

- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2000 **Byock & Quill: "Responding to Intractable Terminal Suffering"**
- 2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
article
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)**
- 2003 **National Hospice Work Group publishes "Access to Hospice Care" findings (Hastings Center Report supplement)**
Authors
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**
- 2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care (Midwest Bioethics, PFC, RWJF)**
Speakers
- 2004 **2nd Annual Naropa University (Boulder, CO) Conference on A Contemplative and Holistic Approaches to End of Life and Elder Care: Integrating Spirit and Caregiving Conference 2004 in Garrison, NY (Byock, Halifax, Rohr, Maull)**
Keynote Speakers

Known funding:

\$6,587,037 tracked thus far

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

to: University of Montana - Center for Ethics (dba Practical Ethics Center)	\$4,148,665
to: University of Montana College of Arts and Sciences	\$1,247,260
to: Missoula Demonstration Project / Life's End Institute	\$611,112

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

to: Missoula Demonstration Project / Life's End Institute	\$50,000
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\$500,000 from **Nathan Cummings Foundation, Inc.**

to: Missoula Demonstration Project / Life's End Institute	\$500,000
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\$30,000 from **Engelhard Foundation (Charles)**

to: Missoula Demonstration Project / Life's End Institute	\$30,000
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Affiliations:

- American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
Ethics Committee
- Beeson Physician Faculty Scholars Program (see: AFAR)
Leaders in Research - U. Penn
- Commonwealth Fund
Grant recipient
- Greenwall Foundation
Grant recipient
- Journal of Palliative Medicine
Editorial Board (2004)
- National Hospice and Palliative Care Organization (NHPCO)
Board of Directors
- University of Pennsylvania School of Medicine
Fellow & Instructor of Geriatrics
- Veterans Administration - Hospice and Palliative Care (VAHPC)
- VistaCare Hospice Foundation
Grant recipient

Known funding:

\$124,794 tracked thus far
\$124,794 from **National Institutes of Health (General heading)**
to: University of Pennsylvania School of Medicine

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Ethical Considerations in End-of-Life Care and Research"

\$124,794

Affiliations:

American Board of Internal Medicine

President

American College of Physicians

Past president (first woman president)

American Federation for Aging Research (AFAR)

President

Beth Israel Medical Center - NYC

*former Professor & Chairwoman, Henry L. Schwartz
Department of Geriatrics and Adult Development*

Greenwall Foundation

Board of Directors 2001; Advisory Board 2003

Institute of Medicine

Last Acts

*Task Force on Institutional Innovation / Hospital
Committee*

Milbank Memorial Fund

*Cassel was Milbank's representative at the first
Grantmakers*

Mount Sinai School of Medicine

Oregon Health and Science University

Dean

Oregon Health and Sciences University

formerly a senior scholar (2002)

Physicians for a National Health Program

*Physicians' Working Group on Single-Payer National
Health Insurance*

Conferences, research papers, task forces, ev

- 1989 **As reported by Rita Marker: "PBS's MacNeil/Lehrer News Hour called it the "strongest public endorsement of doctorassisted suicide ever published."**
- 1992 **First published guidelines for assisted suicide: NEJM, "Case of the hopelessly ill: Proposed clinical criteria for physician-assisted suicide": D. Meier, T. Quill, C. Cassel**
- 1992 **Partners in Caregiving (PIC) -- Wake-Forest program leads to Faith in Action (and Respite Care Act?)**
National Advisory Committee
- 1993 **IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines --"Approaching Death" -- and recommendations for Last Acts strategies.**
Workshop Participants
- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**
Conference attendees
- 1996 **IOM's Committee on Care at the End of Life - Public Hearing #1 (led to "Approaching Death")**
Moderator
- 1996 **IOM's Committee on Care at the End of Life" - Public Hearing #2 (led to "Approaching Death")**
- 1997 **Clinton announces commission to create "Consumer Bill of Rights" to promote and assure patients have adequate appeals and grievance processes. "Commission will work to give Americans the tools they need to measure and compare health care quality."**
Commissioners
- 1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
- 1998 **D. Meier co-authors "Survey of PAS and Euthanasia" in NEJM. Next day, her "Change of Heart" on assisted suicide is published in the New York Times.**
- 1998 **VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)**
- 1998 **VA Faculty (Veterans Affairs Faculty): First Leadership Conference.**
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)**
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)**
Co-Director
- 2001 **Greenwall Foundation Faculty Scholars Program in Bioethics**
Advisory Board

- 2003 **Cassel & Quill "Position Paper" on Assisted Suicide: "studied neutrality"**
Authors
- 2003 **Physicians for a National Health Program issue call for universal health care, published in JAMA. Principals of PNHP include Christine Cassel and Marcia Angell. Endorsing the petition: Tulskey, Sulmasy, Meier, Yellig, Truog**
- 2004 **Quill & Battin edit a book supporting PAS. Contributors include Christine Cassel**

Known funding:

\$456,844	tracked thus far		
\$190,966	from Robert Wood Johnson Foundation		
	to: Mount Sinai School of Medicine		\$190,966
\$75,000	from Open Society Institute / Project on Death in America (Soros Foundation)		
	to: Mount Sinai School of Medicine		\$75,000
\$190,878	from Commonwealth Fund		
	to: Mount Sinai School of Medicine		\$190,878

Harvey Max Chochinov, MD, PhD, FRCPC

Affiliations:

Journal of Palliative Medicine
Editorial Board (2004)

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar 1996-97

University of Manitoba

Conferences, research papers, task forces, ev

- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
Endorsed the statement
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Interventions To Enhance the Spiritual Aspects of Dying"

Known funding:

\$460,083	tracked thus far		
\$70,000	from Open Society Institute / Project on Death in America (Soros Foundation)		
	to: University of Manitoba		\$70,000
\$390,083	from National Institutes of Health - National Cancer Institute (NCI)		
	to: University of Manitoba		\$390,083

Grace H. Christ, D.S.W.

Affiliations:

Columbia University School of Social Work
Associate Professor of Social Work

Journal of Palliative Medicine
Editorial Board

Last Acts
Members

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

Conferences, research papers, task forces, ev

- 2001 **PDIA/Last Acts joint planning for Social Work Leadership: Planning meeting held at Johns Hopkins**
Organizers
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **PDIA/Last Acts Social Work Summit at Duke University (North Carolina)**
- 2002 **Social Work Summit on End-of-Life and Palliative Care co-sponsored by the Last Acts Provider Education Committee, The Duke Institute on Care at the End of Life, and the Soros Foundation's Project on Death in America.**
Co-coordinators

Known funding:

\$151,351 tracked thus far

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

to: Columbia University School of Social Work

\$151,351

Nicholas A. Christakis, M.D., Ph.D., M.P.H.

Affiliations:

Conferences, research papers, task forces, ev

Harvard Medical School

Dept. of Health Care Policy

**Harvard Medical School - Center for Palliative Medicine
at Mass. General**

Journal of Palliative Medicine

Editorial Board

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

Faculty Scholar 1995

Robert Wood Johnson Foundation

Co-Director, Clinical Scholars Program (2004)

University of Chicago

University of Pennsylvania School of Medicine

RWJF Clinical Scholar, 1991-93

Known funding:

\$8,166,334 tracked thus far

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

to: Harvard Medical School - Center for Palliative Medicine at Mass. Gener **\$4,564,391**

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

to: University of Chicago **\$140,000**

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

to: Harvard Medical School **\$1,902,010**

to: University of Chicago **\$1,559,933**

Myra J. Christopher

Affiliations:

Center for Practical Bioethics (formerly Midwest Bioethics Center)

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

Consultant on patients' rights and organizational ethics education

Midwest Bioethics Center (aka Center for Practical Bioethics)

President & CEO, Midwest Bioethics Center (at MBC since 1985; Program Director 1998-2003; President 1994-1998)

National Association of Attorneys General (NAAG)

2004 EOL Advisory Committee

Veterans Administration - Hospice and Palliative Care (VAHPC)

Community Outreach Workgroup

Conferences, research papers, task forces, ev

1990 **Patient Self-Determination Act (PSDA)** requires institutions receiving federal funds to provide people they serve with written information about Advance Directives. Sponsored by Sen. John Danforth. Myra Christopher was Danforth's advisor.

Advisor to Danforth.

1990 **Case: Cruzan v. Director, Missouri Dep't of Health -- Supreme Court supported MO -- no clear evidence of patient's wishes. WNH ok. Later, state court pulled life support. (Colby lawyer for Cruzans; Myra Christopher involved.)**

was involved in the case

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**

Conference Attendees

1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**

1998 **RWJF and Midwest Bioethics announce planning for \$11.5 million Community-State Partnerships. "Community programs could reduce clamor for assisted suicide." Two rounds of funding; 33% additional matching funds required.**

1998 **State Initiatives on End-of-Life Care - Conference 2 (RWJF and National Council of State Legislatures)**

Panelists

1999 **Community-State Partnerships -- Second round of grants. To Minnesota, Florida, Oklahoma, New Hampshire, Michigan, North Dakota**

2001 **Compassionate Options**

2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**

article

2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care (Midwest Bioethics, PFC, RWJF)**

Speakers

Known funding:

\$2,509,199 tracked thus far

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

to: Midwest Bioethics Center (aka Center for Practical Bioethics) **\$2,409,199**

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

to: Midwest Bioethics Center (aka Center for Practical Bioethics) **\$75,000**

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

to: Midwest Bioethics Center (aka Center for Practical Bioethics) **\$25,000**

Larry Churchill, Ph.D.

Affiliations:

Duke University - Institute on Care at the End of Life
Associate Faculty Scholar
University of North Carolina - Chapel Hill
Professor, Department Of Social Medicine

Known funding:

Conferences, research papers, task forces, ev

Susan R. Clark

Affiliations:

Columbia Foundation
Executive Director (1995)

Known funding:

Conferences, research papers, task forces, ev

1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference Attendees

Stephen R. Connor, Ph.D.

Affiliations:

Hospice of Central Kentucky
(1998)
Last Acts
Task Force on Institutional Innovation / Hospice Committee
National Hospice and Palliative Care Organization (NHPCO)
V.P. for Research & Professional Development
National Hospice Organization - See National Hospice and Palliative Care Or
Member at Large (1st term ending 1/2000)

Known funding:

\$1,779,282 tracked thus far

\$1,519,282 from **Robert Wood Johnson Foundation**

to: National Hospice and Palliative Care Organization (NHPCO) **\$1,519,282**

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

to: National Hospice and Palliative Care Organization (NHPCO) **\$160,000**

\$100,000 from **AARP Andrus Foundation**

to: National Hospice and Palliative Care Organization (NHPCO) **\$100,000**

Conferences, research papers, task forces, ev

1998 National Hospice Outcomes Planning (RWJF)
Project Director
2000 National Hospice Work Group launches project: Increasing Access to Hospice
Task Force Members
2001 Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.
article
2002 Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)
2003 National Hospice Work Group publishes "Access to Hospice Care" findings (Hastings Center Report supplement)
Authors
2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

Anne Cordes, MHA

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
Executive Director

Known funding:

Conferences, research papers, task forces, ev

2001 National Consensus Project -- national palliative care guidelines.
NCP Steering Committee

Ronald Cranford, M.D.

Affiliations:

American Society of Law, Medicine, and Ethics
Editorial Board, Law, Medicine, & Health Care 1983 - ____

Choice in Dying -- see "Partnership for Caring"
Board of Directors 1992- [not on board in 1997]

Hastings Center

Hennepin County Medical Center (Minneapolis, MN)
Assistant Chief in Neurology

Physicians for Social Responsibility
Member 1985-present (as of 2003)

Society for Health and Human Values (SHHV) [see ASBH]

United Network for Organ Sharing (UNOS)
Ethics Committee 1987-1989, 1991-1993; Board of Directors, Virginia 1989-91

United Theological Seminary
Adjunct professor of Medical Ethics

University of Minnesota - Center for Bioethics
Professor of Neurology

Conferences, research papers, task forces, ev

- 1987 **Appleton, Wisc: First of two conferences to establish international guidelines for withdrawal of treatment.** John Stanley (later with Hastings/National Hospice Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S. Youngner, H. Brody represent US.
- 1988 **Appleton Conference Project -- Second Meeting.**
DECISIONS INVOLVING PATIENTS WHO WERE ONCE COMPETENT, BUT ARE NOT NOW COMPETENT, WHO HAVE NOT EXECUTED AN ADVANCED DIRECTIVE
- 1989 **As reported by Rita Marker: "PBS's MacNeil/Lehrer News Hour called it the "strongest public endorsement of doctorassisted suicide ever published."**
- 1994 **PVS: The Multi-Society Task Force Consensus**
Co-Chairmen
- 1995 **Aspen Neurobehavioral Conference Workgroup**
- 2001 **Death With Dignity - 2001 Annual Conference**
Clinical Perspectives
- 2002 **Minimally Conscious State (MCS): definitions and diagnostic criteria**
Authors
- 2002 **Terri Schindler-Schiavo:**
Called by Michael Schiavo
- 2004 **4th International Symposium on Coma and Death (Havana, Cuba)**
Speakers

Known funding:

LaVera M. Crawley, M.D.

Affiliations:

Americans for Better Care of the Dying (ABCD)
Board of Directors

Initiative to Improve Palliative Care for African-Americans (IIPCA)
Executive Director

Journal of Palliative Medicine
Editorial Board

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 1999-2001 (with Barbara Koenig)

Conferences, research papers, task forces, ev

- 2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
article
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Heritage, Health, and Hope (IIPCA)**
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Racial, Cultural, and Ethnic Factors"

Known funding:

\$50,000 tracked thus far
\$50,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to:

\$50,000

June L. Dahl, Ph.D.

Affiliations:

American Alliance of Cancer Pain Initiatives (AACPI)
Past President
Robert Wood Johnson Foundation
Project Director
University of Wisconsin - Madison Medical School

Conferences, research papers, task forces, ev

- 1992 **WCPI: RWJF funds Cancer Pain Initiative Resource Center; coalitions in 27 states; NIH collaboration**
Grantee contact
- 1995 **American Alliance of Cancer Pain Initiatives forms at the Univ. of Wisconsin Med School. It is an alliance of state pain initiatives (grassroots orgs) to reform state controlled substance regulations, as proposed by the World Health Organization.**
- 1998 **Pain as a Fifth Vital Sign: 30 leaders of national nursing organizations assembled at a symposium led by UNC-Chapel Hill School of Nursing; endorsed promotion of "Pain as the Fifth Vital Sign." ("Notes on a Peaceful Death" monograph distributed; RWJF)**
Director, Wisconsin Cancer Pain Initiative
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

Known funding:

\$3,983,327 tracked thus far

\$3,876,965 from **Robert Wood Johnson Foundation**

to: University of Wisconsin - Madison Medical School

\$3,876,965

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

to: University of Wisconsin - Madison Medical School

\$105,362

\$1,000 from **Mayday Fund**

to: Wisconsin Cancer Pain Initiative

\$1,000

Constance M. Dahlin, RNCS, MSN, OCN, CHPN

Affiliations:

Harvard Medical School - Center for Palliative Care
Center for Palliative Care; Program in Palliative Care Education and Practice, Core Faculty
Hospice and Palliative Nurses Association (HPNA)
Massachusetts General Hospital

Conferences, research papers, task forces, ev

- 2001 **RWJF convenes a group of Advanced Practice Nurses in Philadelphia, to forge a consensus statement on the role of APNs in palliative care. Produced "Pioneering Practices in Palliative Care."**
Writing Team
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

Known funding:

Jo Ann Dalton, R.N., M.S.N., Ed.D.

Affiliations:

American Alliance of Cancer Pain Initiatives (AACPI)
Advisory Council 2002-3
Journal of Palliative Medicine
Editorial Board
North Carolina Board of Nursing
North Carolina Cancer Pain Initiative
founder and co-chair
North Carolina Nurses' Association
Board of Directors (emerita)
North Carolina Pain Initiative
Contact (2004)
University of North Carolina - Chapel Hill

Conferences, research papers, task forces, ev

Known funding:

Karen Davis

Affiliations:

Commonwealth Fund
President (1995)

Known funding:

Conferences, research papers, task forces, ev

- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees

Kathleen (Kathy) Egan, MA, BSN, CHPN

Affiliations:

Hospice of the Florida Suncoast: Hospice Institute of the Florida Suncoast
Vice President
University of South Florida
Community Director

Known funding:

\$288,603 tracked thus far
\$288,603 from National Institutes of Health - National Cancer Institute (NCI)
to: Hospice of the Florida Suncoast: Hospice Institute of the Florida Sunco **\$288,603**

Conferences, research papers, task forces, ev

- 1994 Florida: Hospice Institute is founded at Hospice of the Florida Suncoast, underwritten by NIH.
- 1998 National Hospice Outcomes Planning (RWJF)
Representing her hospice
- 2000 ELNEC (End-of-Life Nursing Education Consortium) -- RWJF funds nursing education reform. Started with a grant to City of Hope to study nurses' text books; then major grant 37617 to AACN in 2000. Partnership of AACN and City of Hope in Los Angeles.
Curriculum consultants
- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 2002 Florida: Center for Hospice, Palliative Care and End-of-Life Studies. USF collaborative with Hospice of FL Suncoast, LifePath Hospice in Tampa, and Moffitt Cancer Center
Executive Committee: Community Partners
- 2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."
- 2003 ELNEC "Train the Trainer" - Carolinas Center for Hospice & EOL Care
Presenter

Linda L. Emanuel, M.D., Ph.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
Educational Planning Task Force (2001)

Harvard Medical School
Faculty Fellow, 1989-1990; Faculty Associate, 1990-1998; Assistant Director, Division of Medical Ethics until 1996; Professor of Medical Ethics until 1998

Hastings Center
Fellow

National Board of Medical Examiners
2002 EOL Committee

Northwestern University
Director of the Buehler Center on Aging

Known funding:

\$3,560,813 tracked thus far

\$3,502,698 from **Robert Wood Johnson Foundation**

to: Northwestern University

\$3,102,698

to: American Medical Association

\$400,000

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

to: Northwestern University

\$58,115

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
I Project Directors
- 1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **National Hospice Work Group publishes "Access to Hospice Care" findings (Hastings Center Report supplement)**
Authors
- 2004 **4th International Symposium on Coma and Death (Havana, Cuba)**
Speakers

John Feather

Affiliations:

AARP Andrus Foundation
Director (1995)

Conferences, research papers, task forces, ev

- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**
Conference Attendees
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**
Conference Attendees

Known funding:

Betty Rolling Ferrell, PhD, RN, FAAN

Affiliations:

- American Alliance of Cancer Pain Initiatives (AACPI)**
President, Board of Directors (2002)
- Center For Applied Ethics and Professional Practice (see EDC)**
Editorial Board, "Innovations"
- City of Hope National Medical Center**
Research Scientist
- Hospice and Palliative Nurses Association (HPNA)**
- Journal of Palliative Medicine**
Editorial Board
- Last Acts**
Members
- National Association of Attorneys General (NAAG)**
2004 EOL Advisory Committee
- Open Society Institute / Project on Death in America (Soros Foundation)**
Grant recipient
- Oregon Health and Sciences University**
External Advisory Committee, Center for Research on Symptom Management in Life-Threatening Illness
- Partnership for Caring**
According to Mayday, Ferrell was the contact for a small Mayday grant to Pfc, earmarked for National Consensus Project

Conferences, research papers, task forces, ev

- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Conference Attendees
- 1996 **Conference on Measuring Care at the End of Life** (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.
- 1996 **IOM's Committee on Care at the End of Life" - Public Hearing #2** (led to "Approaching Death")
- 1997 **Research Workshop "Symptoms in Terminal Illness"** (NIH responds to SUPPORT)
Participants
- 1999 **Textbook Revision: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.**
- 2000 **ELNEC (End-of-Life Nursing Education Consortium) -- RWJF funds nursing education reform. Started with a grant to City of Hope to study nurses' text books; then major grant 37617 to AACN in 2000. Partnership of AACN and City of Hope in Los Angeles.**
1 Investigators/Staff
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care** (Midwest Bioethics, Pfc, RWJF)
Speakers
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Overview of the Domains of Variables Relevant to End-of-Life Care"

Known funding:

\$1,569,910	tracked thus far	
\$825,714	from Robert Wood Johnson Foundation	
	to: City of Hope National Medical Center	\$825,714
\$76,650	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: City of Hope National Medical Center	\$76,650
\$5,000	from Mayday Fund	
	to: Partnership for Caring	\$5,000
\$662,546	from National Institutes of Health - National Cancer Institute (NCI)	
	to: City of Hope National Medical Center	\$662,546

Frank D. Ferris, M.D.

Affiliations:

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

Faculty Scholar, 1998-2000

San Diego Hospice

Medical Director, Palliative Care Standards

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
2 Co-Principal
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the
"National Consensus Conference on Medical Education for
Care Near the End of Life"**
Endorsed the statement
- 2000 **National Hospice Work Group launches project: Increasing
Access to Hospice**
Task Force Members
- 2000 **ELNEC (End-of-Life Nursing Education Consortium) --
RWJF funds nursing education reform. Started with a grant
to City of Hope to study nurses' text books; then major grant
37617 to AACN in 2000. Partnership of AACN and City of
Hope in Los Angeles.**
Organization Representatives
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine
Cassel to establish Center to Advance Palliative Care (CAPC)**
CAPC Manual
- 2001 **CAPC Manual is launched**
- 2001 **National Consensus Project -- national palliative care
guidelines.**
Advisory Council

Known funding:

\$86,400 tracked thus far

\$86,400 from **Robert Wood Johnson Foundation**

to: San Diego Hospice

\$86,400

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

to: San Diego Hospice

Marilyn J. Field, Ph.D.

Affiliations:

Institute of Medicine

deputy director of the Division of Health Care Services

Conferences, research papers, task forces, ev

- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Palliative Care Task Force 1997
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Conference Attendees
- 1996 **Conference on Measuring Care at the End of Life** (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
Endorsed the statement
- 1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**
Participants
- 1997 **Precepts of Palliative Care (Last Acts Palliative Care Committee)**
Members
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

Known funding:

\$350,000 tracked thus far

\$125,000 from **Robert Wood Johnson Foundation**

to: Institute of Medicine

\$125,000

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

to: Institute of Medicine

\$200,000

\$25,000 from **Commonwealth Fund**

to: Institute of Medicine

\$25,000

Perry G. Fine, M.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

a founding member

Americans for Better Care of the Dying (ABCD)

former board member

National Hospice and Palliative Care Organization (NHPCO)

V.P., Medical Affairs (2005)

Partnership for Caring

Board of Directors

University of Utah

University of Utah Health Sciences Center

Professor of Anesthesiology

VistaCare

National Medical Director, Director

Known funding:

Conferences, research papers, task forces, ev

- 2002 **2002 Annual Conference of Carolinas Hospice**
Relief of Intractable Suffering at Life's End
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

John Finn, M.D.

Affiliations:

Academy of Hospice Physicians see American Academy of Hospice & Pal. Care

Founding member

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

distinguished Fellow and Immediate Past President

Hospice of Michigan

Chief Medical Director

Robert Wood Johnson Foundation

Promoting Excellence

Known funding:

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Joseph Jack Fins, M.D.

Affiliations:

Cornell University - Weill Medical College
*Chief, Division of Medical Ethics; Associate Professor of
Medicine and Associate Professor of Medicine in
Psychiatry*

Hastings Center
Associate for Medicine (2004)

HealthCare Chaplaincy
Physician-Ethicist-in-Residence

Last Acts
*Convener, Task Force on Institutional Innovation /
Hospital Committee*

New York Presbyterian Hospital - Cornell Campus
Director of Medical Ethics

**Open Society Institute / Project on Death in America
(Soros Foundation)**
Faculty Scholar; 1997

Partnership for Caring
Board of Directors

Princeton University
Trustee Advisor

Conferences, research papers, task forces, ev

- 1994 **Congress on Clinical Societies: Futility in Clinical Practice.
By J. Fins, MD**
- 1996 **IOM's Committee on Care at the End of Life - Public
Hearing #1 (led to "Approaching Death")**
- 1996 **Congress of Clinical Societies: Conference on the Ethics of
Managed Care (RWJF, Hastings; sustainable health care)
Conference organizer; Project Director**
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the
"National Consensus Conference on Medical Education for
Care Near the End of Life"
endorsed the statement**
- 1999 **From Contract to Covenant**
- 1999 **Pain Relief Promotion Act of 1999 (HR 2260; S 1272)
opposed the bill**
- 2000 **Partnership for Caring is named National Program Office for
Last Acts
on Pfc board**
- 2001 **Alliance for Health Reform hosts "A Briefing on Gaps and
Potential Solutions in Financing Care for Those Who Are
Dying" featuring Karen Orloff Kaplan, Joseph Fins, Donald
Schumacher**
- 2002 **AAHSA Expo
taught Session: 100-H. Precepts to Practice: Seamless
Integration of Palliative Care Across the Continuum**
- 2003 **Last Acts Palliative Care Committee produces "On the Road
from Theory to Practice"**
- 2004 **4th International Symposium on Coma and Death (Havana,
Cuba)
Speakers**

Known funding:

\$754,245 tracked thus far

\$49,016	from Robert Wood Johnson Foundation	
	to: American Geriatrics Society, Inc.	\$49,016
\$70,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Cornell University - Weill Medical College	\$70,000
\$635,229	from Fan Fox and Leslie R. Samuels Foundation	
	to: Cornell University - Weill Medical College	\$635,229

Affiliations:

American Board of Hospice and Palliative Medicine
(ABHPM)

Trustee (2004)

Memorial Sloan-Kettering

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

Founding director and PDIA Advisory Board (as of 11-2003)

Conferences, research papers, task forces, ev

- 1993 IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines -- "Approaching Death" -- and recommendations for Last Acts strategies.
Workshop Participants
- 1994 Soros launches "Project on Death in America"
Director, PDIA
- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees
- 1996 EPEC Project (Education for Physicians on End-of-Life Care)
EPEC Advisory Group
- 1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
1 Speakers
- 1996 RWJF awards grant to EDC to convene the National Task Force on End-of-Life Care for Patients in Managed Care. The Task Force would produce a widely publicized report, "Meeting the Challenge," in May, 1999.
2) Committee Members
- 1997 Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"
endorsed the statement
- 1997 National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)
Task Force Member
- 1997 Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)
Participants
- 1998 Doctors, Death, and Dignity - Chautauqua
- 1999 Pain Relief Promotion Act of 1999 (HR 2260; S 1272)
opposed the bill
- 1999 Textbook Revision: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.
- 1999 Textbook Revision: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.
Speakers
- 2000 National Hospice Work Group launches project: Increasing Access to Hospice
Task Force Members

- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**
- 2003 **Boston Globe article announces end of Soros/RWJF project**

Known funding:

\$15,000,000 tracked thus far
\$15,000,000 from **Soros Foundation**
to: Open Society Institute / Project on Death in America (Soros Foundation) **\$15,000,000**

Lachlan Forrow, M.D.

Affiliations:

Albert Schweitzer Fellowship
President (project director for RWJF grant)

Beth Israel Deaconess Medical Center
Director of the Ethics Support Service; Chairs Ethics Advisory Committee

Harvard Medical School
Associate Professor of Medicine

International Physicians for Prevention of Nuclear War (IPPNW)
1994-1995 Chief Executive Officer; Acting Executive Director IPPNW (June - July 1992; May - August 1993)

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 1999-2001

Conferences, research papers, task forces, ev

- 1989 **SUPPORT study initiated: Program on the Care of Critically Ill Hospitalized Adults (GW Univ.; SUPPORT launched the RWJF/Soros end of life initiatives)**
SUPPORT investigators
- 1995 **SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)**
SUPPORT investigators

Known funding:

\$170,000 tracked thus far
\$100,000 from **Robert Wood Johnson Foundation**
to: Albert Schweitzer Fellowship **\$100,000**

\$70,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Beth Israel Deaconess Medical Center **\$70,000**

Anthony N. Galanos, M.D.

Affiliations:

Duke University - Institute on Care at the End of Life
Associate Faculty Scholar

Duke University - Medical School
Associate Professor, Medicine (Geriatrics)

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 2000-2002

Project Compassion
Board of Directors (2005)

Conferences, research papers, task forces, ev

- 1989 **SUPPORT study initiated: Program on the Care of Critically Ill Hospitalized Adults (GW Univ.; SUPPORT launched the RWJF/Soros end of life initiatives)**
Support Investigators
- 1995 **SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)**
Support Investigators

Known funding:

\$220,000 tracked thus far
\$70,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Duke University - Medical Center **\$70,000**

\$150,000 from **Kornfeld / PDIA (Soros) collaborative**
to: Duke University - Medical Center **\$150,000**

Rosemary Gibson, MA

Affiliations:

American Enterprise Institute
Senior Research Associate (former)

Economic and Social Research Institute
Vice President (former)

Georgetown University
Alumna (undergrad)

London School of Economics
Alumna (master's degree in public policy and finance)

Robert Wood Johnson Foundation
Program Officer

Virginia Commonwealth University
Consultant

Known funding:

Conferences, research papers, task forces, ev

- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees
- 1996 Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.

Debra B. Gordon, R.N., M.S.

Affiliations:

Journal of Palliative Medicine
Editorial Board

University of Wisconsin Hospitals & Clinics

Known funding:

Conferences, research papers, task forces, ev

David A. Gould, Ph.D.

Affiliations:

United Hospital Fund
V.P. for Programs (1995)

Known funding:

\$775,000 tracked thus far

\$600,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: United Hospital Fund **\$600,000**

\$175,000 from **Fan Fox and Leslie R. Samuels Foundation**
to: United Hospital Fund **\$175,000**

Conferences, research papers, task forces, ev

- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference Attendees
- 1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Conference Attendees

Patricia A. Grady, M.D.

Affiliations:

National Institutes of Health - National Institute of Nursing Research
Director (1997)

Known funding:

Conferences, research papers, task forces, ev

- 1997 Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)
Participants
- 2004 NIH State-of-the-Science Conference on Improving End-of-Life Care
1 Opening Remarks

Lisa P. Gwyther, MSW

Affiliations:

Duke University - Institute on Care at the End of Life

Core Faculty member

Duke University - Medical Center

ssociate clinical professor in the Department of Psychiatry and Behavioral Sciences

Known funding:

Conferences, research papers, task forces, ev

James L. Hallenbeck, M.D.

Affiliations:

Journal of Palliative Medicine

Editorial Board (2004)

Last Acts

Members

Palo Alto Healthcare System

Medical Director, Hospice

Stanford University

Faculty, Stanford Faculty Development Center facilitator-training course in End-of-Life Care (ELC), held from 2000 to 2002,

Veterans Administration - Hospice and Palliative Care (VAHPC)

Known funding:

Conferences, research papers, task forces, ev

1998 **VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)**

1998 **VA Faculty (Veterans Affairs Faculty): First Leadership Conference.**

2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

Charles Halpern

Affiliations:

Nathan Cummings Foundation, Inc.

President (1995) left in 2000 (see

<http://www.philanthropyroundtable.org/magazines/2000-03/staffingup.html>)

Known funding:

Conferences, research papers, task forces, ev

1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**

Conference Attendees

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**

Conference Attendees

Laura C. Hanson, M.D.

Affiliations:

Duke University - Institute on Care at the End of Life

Associate Faculty Scholar

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

Faculty Scholar, 1997

University of North Carolina - Chapel Hill

Known funding:

\$35,000 tracked thus far

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

to: University of North Carolina - Chapel Hill

\$35,000

Herbert Hendin

Affiliations:

American Suicide Foundation
Executive Director

Conferences, research papers, task forces, ev

- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference Attendees

Known funding:

Irene Higginson, Ph.D.

Affiliations:

Center For Applied Ethics and Professional Practice (see EDC)
Editorial Board, "Innovations"

Conferences, research papers, task forces, ev

- 2004 NIH State-of-the-Science Conference on Improving End-of-Life Care
"Lessons From Other Nations"

Known funding:

Joanne M. Hilden, M.D.

Affiliations:

Cleveland Clinic Foundation
Chair of the Department of Pediatric /Oncology
Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 2001

Conferences, research papers, task forces, ev

- 2001 Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.
article
- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

Known funding:

\$150,000 tracked thus far
\$150,000 from Open Society Institute / Project on Death in America (Soros Foundation)
to: Cleveland Clinic **\$150,000**

Pamela S. Hinds, Ph.D., R.N.

Affiliations:

Conferences, research papers, task forces, ev

- 2004 NIH State-of-the-Science Conference on Improving End-of-Life Care
"Key Factors Affecting Dying Children and Their Families"

Known funding:

Bryan Jennett, M.D.

Affiliations:

University of Glasgow

Conferences, research papers, task forces, ev

- 1972 PVS: Defined
- 1988 Appleton Conference Project -- Second Meeting.
Non-Writer Supporter
- 2002 Minimally Conscious State (MCS): definitions and diagnostic criteria
Authors

Known funding:

David E. Joranson, M.S.S.W.

Affiliations:

- National Association of Attorneys General (NAAG)
2004 EOL Advisory Committee
- National Association of State Controlled Substances and Authorities
Founder
- University of Wisconsin - Madison Medical School
Senior Scientist; Director of Pain & Policy Studies Group
- Wisconsin Cancer Pain Initiative
Founder (1986)
- World Health Organization
Director of Pain & Policy Studies Group, which is a WHO Collaborating Center for Policy and Communications

Conferences, research papers, task forces, ev

- 1997 Pain & Policy Studies Group (a World Health Organization Collaborating Center) conducted study of state regulatory policies from 1997-1999, to bring regulations more in line with medically appropriate prescribing of opioid analgesics for pain management.
- 1997 Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life offered much guidance in understanding the legislative and policy barriers to good pain treatment
- 1997 State Initiatives on End-of-Life Care - Conference 1 (RWJF and National Conference Of State Legislatures, with GWU, produced state legislative guidebook and two conferences)
Panelists
- 1998 American Alliance of Cancer Pain Initiatives established as non-profit.
- 1999 Pain Relief Promotion Act of 1999 (HR 2260; S 1272)
opposed the bill (see documents)
- 1999 Community-State Partnerships -- First round of grants: CA \$110,000; CT \$75,000; HI \$450,000; IA \$74,999; KS \$74,830; KY \$73,880; ME \$450,000; NV \$450,000; NY \$446,499; NC \$75,000; OK \$74,796; RI \$69,839; TX \$74,709; UT \$74,963; WV \$75,000
National Advisory Committee
- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 2002 Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)

Known funding:

\$2,357,720 tracked thus far

\$2,057,720 from **Robert Wood Johnson Foundation**

- to: University of Wisconsin - Madison Medical School **\$1,285,483**
- to: University of Wisconsin - Madison Medical School **\$693,407**
- to: Federation of State Medical Boards **\$78,830**

\$300,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**

- to: University of Wisconsin - Madison Medical School **\$225,000**
- to: University of Wisconsin - Madison Medical School **\$75,000**

Affiliations:

Children's Hospice International
PACC National Advisory Council

Choice in Dying -- see "Partnership for Caring"

Last Acts

Mount Sinai School of Medicine
Faculty (2005 -)

National Association of Attorneys General (NAAG)
2004 EOL Advisory Committee

National Association of Social Workers
before PFC she was Director of the National Center for Social Policy and Practice

National Association of Social Workers -Center for Social Policy & Practice
Founder, 1987 (she was still there in 1993)

Partnership for Caring
President & CEO

Rallying Points
Program Director

Wye River Group on Healthcare
Director of Special Initiatives (2004-)

Conferences, research papers, task forces, ev

1994 **Medical Education: Greenwall commits \$350,000 over 5 years to Choice in Dying for "Integrating Education about Care of the Dying into Existing Medical School Programs"**
Was Kaplan at Choice in 1994?

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**
Conference Attendees

1997 **Choice in Dying, Alliance for Health Reform, and Hospice Organization of America co-sponsor congressional briefing to introduce the Advance Planning and Compassionate Care Act of 1997, designed to strengthen the Patient Self-Determination Act.**

2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members

2000 **Partnership for Caring is named National Program Office for Last Acts**
Director

2000 **On Our Own Terms -- Bill Moyers**

2001 **Rallying Points [a Last Acts initiative] is launched (California)**

2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
article

2001 **Alliance for Health Reform hosts "A Briefing on Gaps and Potential Solutions in Financing Care for Those Who Are Dying" featuring Karen Orloff Kaplan, Joseph Fins, Donald Schumacher**

2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

2002 **NAACP, at regional meeting of Last Acts in Tampa, Florida, announces it will join Last Acts.**

2002 **Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)**

2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care (Midwest Bioethics, PFC, RWJF)**
Speakers

Known funding:

\$19,291,127 tracked thus far

\$17,260,202	from Robert Wood Johnson Foundation	
	to: Partnership for Caring	\$17,260,202
\$94,977	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Partnership for Caring	\$59,977
	to: Choice in Dying -- see "Partnership for Caring"	\$35,000
\$260,000	from Nathan Cummings Foundation, Inc.	
	to: Partnership for Caring	\$150,000
	to: Choice in Dying -- see "Partnership for Caring"	\$110,000
\$1,201,000	from Fan Fox and Leslie R. Samuels Foundation	
	to: Partnership for Caring	\$1,191,000
	to: Choice in Dying -- see "Partnership for Caring"	\$10,000
\$474,948	from Greenwall Foundation	
	to: Choice in Dying -- see "Partnership for Caring"	\$474,948

Timothy J. Keay, M.D., M.A.-Th., CAQGM, FAAFP

Affiliations:

Journal of Palliative Medicine

Editorial Board (2004)

Medical College of Wisconsin, Inc.

Alumnus (MD)

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

Faculty Scholar, 1996-97

University of Maryland

Adjunct Associate Professor, Department of Family Medicine

Conferences, research papers, task forces, ev

Known funding:

\$50,000 tracked thus far

\$50,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: University of Maryland	\$50,000

Rabbi Barry M. Kinzbrunner, MD, F.A.C.P.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

Director-at-Large

National Hospice Organization - See National Hospice and Palliative Care Or

has served on a sub-committee of the Standards Committee

VITAS Healthcare Corp.

Vice President of Clinical Research Analysis and Audit and Senior Vice President and Chief Medical Officer for VITAS Healthcare

Conferences, research papers, task forces, ev

2001 **National Consensus Project -- national palliative care guidelines.**

Advisory Council

2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

Barbara Ann Koenig, Ph.D.

Affiliations:

Hastings Center

former West Coast Research Coordinator; 1995 Elected Fellow

Last Acts

Convener and Co-Chair, Diversity Resource Committee 1997-99 (per her c.v.)

Mayo Clinic College of Medicine

Consultant and Professor of Bioethics in the Departments of Medicine and Psychiatry

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

Faculty Scholar, 1999-2001 (with LaVera Crawley)

Robert Wood Johnson Foundation

Last Acts conference facilitator

Stanford University

Principal Investigator

Stanford University School of Medicine

Associate Professor

University of California - San Francisco

formerly

Known funding:

\$4,141,726 tracked thus far

\$69,727 from **Robert Wood Johnson Foundation**

to: Stanford University

\$69,727

\$209,987 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Stanford University

\$209,987

\$1,325,446 from **National Institutes of Health - Department of Clinical Bioethics**

to: Stanford University

\$877,899

to: University of California - San Francisco

\$447,547

\$508,064 from **Greenwall Foundation**

to: Stanford University

\$33,064

to: Stanford University

\$475,000

\$33,970 from **Kaiser Family Foundation**

to: Stanford University

\$33,970

\$234,527 from **US DHHS - Agency for Healthcare Research and Quality (AHRQ)**

to: Stanford University

\$234,527

\$100,005 from **State of California**

to: Stanford University

\$100,005

\$950,000 from **SmithKline Beecham Corporation**

to: Stanford University

\$950,000

\$70,000 from **Beckman Foundation**

to: Stanford University

\$70,000

\$500,000 from **Haas Fund**

to: Stanford University

\$500,000

\$140,000 from **United States Department of Energy**

to: Stanford University

\$140,000

Conferences, research papers, task forces, ev

1993 IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines -- "Approaching Death" -- and recommendations for Last Acts strategies.

Workshop Participants

1996 EPEC Project (Education for Physicians on End-of-Life Care)

EPEC Advisory Group

1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)

2 Facilitators

1997 Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"

Endorsed the statement

Shashidhar H. Kori, MD

Affiliations:

Duke University - Institute on Care at the End of Life
Associate Faculty Scholar
Duke University - Medical Center

Conferences, research papers, task forces, ev

Known funding:

Jerome E. Kurent, M.D., MPH

Affiliations:

Medical University of South Carolina
Associate Professor of Medicine, Neurology and
Psychiatry
Open Society Institute / Project on Death in America
(Soros Foundation)
Faculty Scholar, 2000-2002
Promoting Excellence in End-of-Life Care (see Missoula
Demonstration Proj.)
South Carolina Center for Gerontology
Vice Chair (2004)

Conferences, research papers, task forces, ev

2004 **Mayday Fund announces six winners for the first year of The
Mayday Pain & Society Fellowship
Fellows**

Known funding:

\$283,474 tracked thus far

\$163,474 from **Robert Wood Johnson Foundation**
to: Medical University of South Carolina

\$163,474

\$120,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Medical University of South Carolina

\$120,000

Jean S. Kutner, M.D.

Affiliations:

Beeson Physician Faculty Scholars Program (see: AFAR)
National Hospice Work Group
Member, 2004
Robert Wood Johnson Foundation
Generalist Physician Faculty Scholars Program
University of Colorado Health Sciences Center
Director, Population Based Palliative Care Resource
Network

Conferences, research papers, task forces, ev

2001 **National Consensus Project -- national palliative care
guidelines.**
Advisory Council

2003 **NHPCO Research Conclave: "One of the primary purposes
of the conclave was to identify priorities for research funding
that NHPCO can support. NHPCO intends to advocate with
Congress, the National Institutes of Health, the Veterans
Administration..."**

Known funding:

\$1,401,395 tracked thus far

\$154,000 from **National Institutes of Health - National Cancer Institute (NCI)**
to: University of Colorado Health Sciences Center

\$154,000

\$1,247,395 from **National Institutes of Health - National Institute on Aging (NIA)**
to: University of Colorado Health Sciences Center

\$1,247,395

Andrea V. Kydd

Affiliations:

Nathan Cummings Foundation, Inc.
Director, health program (1995)

Conferences, research papers, task forces, ev

1995 **Meeting at PDIA headquarters, co-sponsored by Cummings
and Commonwealth fund. "Grantmakers Concerned with
Care at the End of Life." Over 20 organizations were
represented, including RWJF, AARP, CCMD, Joanne Lynn,
et al.**
Conference Attendees

1996 **Last Acts' first national leadership conference: "Care and
Caring at the End of Life." Brought together 140 leaders;
produced "challenges" (objectives) and "opportunities"
(tactics)**

Conference Attendees

Known funding:

Mary J. Labyak, MSSW, LCSW

Affiliations:

Hospice of the Florida Suncoast

President & Executive Director, 1983 - present

Last Acts

Task Force on Institutional Innovation / Hospice Committee

National Hospice and Palliative Care Organization (NHPCO)

Board (on of several National Directors; Treasurer, 2005; serves on "insurance board")

National Hospice Work Group

Partnership for Caring

Sec/Treas of PFC; rep to National Consensus Proj.

Project GRACE

Board Member

Known funding:

Conferences, research papers, task forces, ev

- 1999 **Florida Panel for the Study of End of Life Care produces its report, leading to change in advance directive laws and reg Panel**
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2003 **Rallying Points National convention; Boston**

Thomas C. Layton

Affiliations:

Gerbode Foundation (Wallace Alexander)

Executive Director (1995); President (1998)

Known funding:

Conferences, research papers, task forces, ev

- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**
Conference attendees

Judy Lentz, RN, MSN, OCN, NHA

Affiliations:

Hospice and Palliative Nurses Association (HPNA)

Ex Officio (prior to 2004: Executive Director)

Known funding:

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

Gwendolyn London, D.Min.

Affiliations:

District of Columbia Partnership to Improve End-of-Life Care

Duke University - Institute on Care at the End of Life

Interim Director

National Resource Center on Diversity in EOLC (RWJF)

Advisory Committee Member

Partnership for Caring

Board of Directors

Washington Home (a division of RAND Health)

volunteer in 1982 at what was then "Hospice of Washington"

Known funding:

\$1,375,000 tracked thus far

\$75,000 from **Robert Wood Johnson Foundation**

to: DC Hospital Association (DCHA) Program Services Company Inc.

\$75,000

\$1,300,000 from **Foundation for End of Life Care, Inc. (Vitas Healthcare)**

to: Duke University - Institute on Care at the End of Life

\$1,300,000

Elizabeth Lorant

Affiliations:

Open Society Institute / Project on Death in America
(Soros Foundation)
Director, Medical & Health Programs in Eastern Europe
(1995)

Conferences, research papers, task forces, ev

1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.

Conference attendees

Known funding:

Karl Lorenz, MD, MSHS

Affiliations:

Veterans Administration Greater Los Angeles Healthcare System

Conferences, research papers, task forces, ev

2004 NIH State-of-the-Science Conference on Improving End-of-Life Care

Known funding:

Dale Ellen Lupu, Ph.D.

Affiliations:

American Board of Hospice and Palliative Medicine (ABHPM)
CEO

American Hospice Foundation
Board

Conferences, research papers, task forces, ev

Known funding:

\$599,750 tracked thus far

\$380,370 from **Robert Wood Johnson Foundation**

to: American Board of Hospice and Palliative Medicine (ABHPM) **\$380,370**

\$219,380 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: American Board of Hospice and Palliative Medicine (ABHPM) **\$219,380**

Affiliations:

American Bar Association
Commission on Legal Problems of the Elderly

American College of Physicians - ACPS-ASIM
Consensus Panel

Americans for Better Care of the Dying (ABCD)
President

Center for Palliative Care Studies (CPCS)
Director

Concern for Dying
Board of Directors

Dartmouth College
SUPPORT, 1989

George Washington University

Hastings Center
Task Force which wrote Guidelines for the Termination of Treatment and the Care of the Dying

Institute of Medicine
1996

Kornfeld Foundation (a right-to-die organization)
Kornfeld Scholar (per RWJF Anthology)

National Board of Medical Examiners
2002 EOL Care Committee

Open Society Institute / Project on Death in America (Soros Foundation)
Board member in 1996 (see <http://www2.soros.org/death/news1.htm>)

RAND

Washington Home Center for Palliative Care Studies
Director

Conferences, research papers, task forces, ev

- 1985 "Fueled by a series of personal experiences that affected the leadership of the RWJF," RWJF calls meeting to discuss dying in America. (date within 1985 is not known)
- 1987 Appleton, Wisc: First of two conferences to establish international guidelines for withdrawal of treatment. John Stanley (later with Hastings/National Hospice Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S. Youngner, H. Brody represent US.
- 1988 Appleton Conference Project -- Second Meeting.
DECISIONS INVOLVING PATIENTS WHO WERE ONCE COMPETENT, BUT ARE NOT NOW COMPETENT, WHO HAVE NOT EXECUTED AN ADVANCED DIRECTIVE
- 1989 SUPPORT study initiated: Program on the Care of Critically Ill Hospitalized Adults (GW Univ.; SUPPORT launched the RWJF/Soros end of life initiatives)
Project Directors/Designers
- 1993 IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines -- "Approaching Death" -- and recommendations for Last Acts strategies.
Workshop Participants
- 1994 Soros launches "Project on Death in America"
- 1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees
- 1995 SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)
Co-Director (at Dartmouth)
- 1996 EPEC Project (Education for Physicians on End-of-Life Care)
EPEC Advisory Group
- 1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
1 Speakers
- 1996 RWJF awards grant to EDC to convene the National Task Force on End-of-Life Care for Patients in Managed Care. The Task Force would produce a widely publicized report, "Meeting the Challenge," in May, 1999.
2) Committee Members
- 1996 Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.
Presentation: What domains should be measured at EOL
- 1996 Congress of Clinical Societies: Conference on the Ethics of Managed Care (RWJF, Hastings; sustainable health care)
Speakers

- 1997 **"Before I Die" on PBS with Tim Russert -- RWJF begins media campaign to build grass roots reaction to SUPPORT study**
Panelists
- 1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**
- 1997 **National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)**
Task Force Member
- 1997 **Finding Common Ground: Assisted Suicide Consensus Panel is convened**
- 1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**
Presenters
- 1997 **State Initiatives on End-of-Life Care - Conference 1 (RWJF and National Conference Of State Legislatures, with GWU, produced state legislative guidebook and two conferences)**
Panelists
- 1998 **Manual published: "State Initiatives in End-of-Life Care Policy Guide for State Legislators" (RWJF)**
Co-Authors
- 1999 **Textbook Revision: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.**
Speakers
- 2000 **Joanne Lynn, Hal R. Arkes, et al. "rethinking SUPPORT," recommend that instead of trying to improve Dr/Patient communications (via AD, for example), the entire medical system and popular culture should be reformed, creating "a default glide path."**
- 2000 **On Our Own Terms -- Bill Moyers**
Attended 9/7/00 Capitol Hill reception
- 2001 **Washington Home**
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Heritage, Health, and Hope (IIPCA)**
Speaker
- 2002 **Washington Home Center for Palliative Care Studies (CPCS) (formerly CICD)**
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

\$6,528,954 tracked thus far

\$6,391,254 from **Robert Wood Johnson Foundation**

to:	Dartmouth-Hitchcock Medical Center	\$171,511
to:	Americans for Better Care of the Dying (ABCD)	\$140,000
to:	George Washington University	\$6,079,743

\$10,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Americans for Better Care of the Dying (ABCD) **\$10,000**

\$127,700 from **Fan Fox and Leslie R. Samuels Foundation**

to: RAND **\$127,700**

Neil MacDonald, CM, MD, FRCP(C), FRCP(Edin), LLD(HC)

Affiliations:

Center For Applied Ethics and Professional Practice (see EDC)

Editorial Board, "Innovations"

International Association for Hospice and Palliative Care (IAHPC)

McGill University (Montreal, Canada)

Alumnus (MD); Associate Dean of Faculty of Medicine in mid-1960s

Conferences, research papers, task forces, ev

1993 **IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines --"Approaching Death" -- and recommendations for Last Acts strategies.**

Workshop Participants

1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**

1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**

1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**

Presenters

2001 **National Consensus Project -- national palliative care guidelines.**

Advisory Council

2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

Susan C. McMillan, Ph.D., R.N.

Affiliations:

University of Louisville (KY)

Adjunct Professor of Nursing 1999-2001

University of South Florida

USF Professor of Nursing 1991 -

Conferences, research papers, task forces, ev

2002 **Florida: Center for Hospice, Palliative Care and End-of-Life Studies. USF collaborative with Hospice of FL Suncoast, LifePath Hospice in Tampa, and Moffitt Cancer Center**
USF

2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**

"Interventions To Facilitate Family Caregiving"

Known funding:

\$1,265,202 tracked thus far

\$1,265,202 from **National Institutes of Health - National Cancer Institute (NCI)**

to: University of South Florida **\$1,265,202**

Len McNally

Affiliations:

New York Community Trust
Senior Program Officer (1995)

Conferences, research papers, task forces, ev

1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.

Conference Attendees

Known funding:

Keith G. Meador, M.D., ThM., MPH

Affiliations:

Duke University - Divinity School
Professor of the Practice of Pastoral Theology and Medicine

Duke University - Institute on Care at the End of Life
Past Director

Duke University - Medical School
Clinical Professor of Psychiatry

Conferences, research papers, task forces, ev

2000 VITAS founder Hugh Westbrook (prominent progressive and Democratic funder) gives Duke \$13 million to found Duke Institute on Care at the End of Life

2001 National Consensus Project -- national palliative care guidelines.

Advisory Council

Known funding:

\$13,500,000 tracked thus far

\$13,500,000 from **Foundation for End of Life Care, Inc. (Vitas Healthcare)**

to: Duke University - Institute on Care at the End of Life

\$13,500,000

Diane Eve Meier, M.D.

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

Hospital Palliative Care Special Interest Group (2001)

American College of Physicians - ACPS-ASIM

Consensus Panel

Journal of Palliative Medicine

Editorial Board

Mount Sinai School of Medicine

Director

Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)

Director

National Board of Medical Examiners

2002 EOL Care Committee

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

Faculty scholar, circa 1995

(<http://www2.soros.org/death/prMay29-96.htm>)

Robert Wood Johnson Foundation

Project Director

Conferences, research papers, task forces, ev

- 1992 **First published guidelines for assisted suicide:** NEJM, "Case of the hopelessly ill: Proposed clinical criteria for physician-assisted suicide": D. Meier, T. Quill, C. Cassel
- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**
- 1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
Acknowledgments
- 1998 **D. Meier co-authors "Survey of PAS and Euthanasia" in NEJM. Next day, her "Change of Heart" on assisted suicide is published in the New York Times.**
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)**
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)**
Co-Director
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2002 **Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)**
- 2002 **Palliative Care Leadership Centers (RWJF)**
Director
- 2003 **Physicians for a National Health Program issue call for universal health care, published in JAMA. Principals of PNHP include Christine Cassel and Marcia Angell. Endorsing the petition: Tulsky, Sulmasy, Meier, Yellig, Truog**

Known funding:

\$14,861,893 tracked thus far

\$13,429,596 from **Robert Wood Johnson Foundation**

to: Mount Sinai School of Medicine - Center to Advance Palliative Care (CA) **\$12,979,938**

to: Mount Sinai School of Medicine **\$449,658**

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

to: Mount Sinai School of Medicine **\$140,000**

\$648,000 from **National Institutes of Health - National Cancer Institute (NCI)**

to: Mount Sinai School of Medicine - Center to Advance Palliative Care (CA) **\$648,000**

\$644,297 from **National Institutes of Health - National Institute on Aging (NIA)**

to: Mount Sinai School of Medicine - Center to Advance Palliative Care (CA) **\$536,297**

to: Mount Sinai School of Medicine **\$108,000**

Melanie Pratt Merriman, Ph.D., M.B.A.

Affiliations:

Brandeis University

Alumna, Biology

Harvard Medical School

Alumna

Touchstone Consulting

Principal

VITAS Healthcare Corp.

Director of Outcomes Measurement (1996)

Conferences, research papers, task forces, ev

1996 IOM's Committee on Care at the End of Life - Public Hearing #1 (led to "Approaching Death")

1996 Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.

1998 National Hospice Outcomes Planning (RWJF)

Evaluation Advisory Panel Member

2001 National Consensus Project -- national palliative care guidelines.

Advisory Council

2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

2004 Carolinas Center hosts conference with Melanie Merriman that "will teach the coalition and other stakeholders how to develop an organizational plan that will create sustainable changes that have already begun"

Known funding:

\$734,960 tracked thus far

\$734,960 from **Robert Wood Johnson Foundation**

to: Touchstone Consulting

\$734,960

Frederick J. Meyers, M.D

Affiliations:

University of California - Davis

Professor and Chair, Dept. of Internal Medicine (2004)

Conferences, research papers, task forces, ev

2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

Known funding:

\$313,545 tracked thus far

\$313,545 from **National Institutes of Health - National Cancer Institute (NCI)**

to: University of California - Davis

\$313,545

Robert A. Milch, M.D.

Affiliations:

Center for Hospice and Palliative Care (CHPC)
Last Acts
*Task Force on Institutional Innovation / Hospice
Committee*

Conferences, research papers, task forces, ev

- 2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
article
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

Susan C. Miller, Ph.D., MBA

Affiliations:

Brown University Center for Gerontology & Health Care Research
Assistant Professor of Community Health (Research)

Conferences, research papers, task forces, ev

- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

[Rolfe] Sean Morrison, M.D.

Affiliations:

Journal of Palliative Medicine
Editorial Board
Mount Sinai School of Medicine
Hermann Merkin professor of palliative
Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)
Advisor
Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar (c. 1995)
University of Florida
Steering Committee

Conferences, research papers, task forces, ev

- 1994 **Beeson Physician Faculty Scholars**
- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
Additional Contributors
- 1998 **D. Meier co-authors "Survey of PAS and Euthanasia" in NEJM. Next day, her "Change of Heart" on assisted suicide is published in the New York Times.**
- 2000 **On Our Own Terms -- Bill Moyers**
Participants
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Health Care System Factors"

Known funding:

\$1,550,000 tracked thus far

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

to: Mount Sinai School of Medicine

\$50,000

\$1,500,000 from **Agency for Health Care Policy and Research (see AHRQ)**

to: Mount Sinai School of Medicine

\$1,500,000

J. Cameron Muir, M.D., FAAHPM

Affiliations:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)

Director-At-Large

Hospices of the National Capital Region

Northwestern University

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

Faculty Scholar, 2000-2002

Conferences, research papers, task forces, ev

2001 **National Consensus Project -- national palliative care guidelines.**

Advisory Council

2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

\$70,000 tracked thus far

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

to: Northwestern University

\$70,000

Donald J. Murphy, M.D.

Affiliations:

Colorado Collective for Medical Decisions (CCMD)

Conferences, research papers, task forces, ev

1989 **SUPPORT study initiated: Program on the Care of Critically Ill Hospitalized Adults (GW Univ.; SUPPORT launched the RWJF/Soros end of life initiatives)**

SUPPORT investigators

1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**

Conference attendees

1995 **SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)**

SUPPORT investigators

Known funding:

Aryeh Neier

Affiliations:

Doctors of the World

a moving force behind Doctors of the World

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

President (1993-)

Conferences, research papers, task forces, ev

1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**

Conference attendees

Known funding:

Joseph F. O'Donnell, M.D.

Affiliations:

Dartmouth College

Journal of Palliative Medicine

Editorial Board

Conferences, research papers, task forces, ev

Known funding:

Karen S. Ogle, M.D.

Affiliations:

Journal of Palliative Medicine

Editorial Board (2004)

Michigan Commission on End of Life Care

Chair

Michigan Partnership for the Advancement of End-of-Life Care

Director

Michigan State University

Dept. of Family Medicine

Known funding:

Conferences, research papers, task forces, ev

Steven Z. Pantilat, M.D.

Affiliations:

Last Acts

Members

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

Faculty Scholar, 1998-2000

Society of Hospital Medicine

President 2005

University of California - San Francisco

Associate Professor of Clinical Medicine in the Department of Medicine; founding Director of the Palliative Care Service

Known funding:

\$1,629,640 tracked thus far

\$750,000 from **Robert Wood Johnson Foundation**

to: University of California - San Francisco

\$750,000

\$153,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: University of California - San Francisco

\$153,000

\$726,640 from **National Institutes of Health - National Institute on Aging (NIA)**

to: University of California - San Francisco

\$726,640

Conferences, research papers, task forces, ev

1999 **Textbook Revision: Last Acts, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.**

Steven D. Passik, Ph.D.

Affiliations:

Indiana Community Cancer Care Foundation

Indiana University

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

Faculty Scholar, 1999-2001

Known funding:

\$50,000 tracked thus far

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

to: Indiana Community Cancer Care Foundation

\$50,000

Conferences, research papers, task forces, ev

2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Richard Payne, M.D.

Affiliations:

American Pain Society (APS)
Immediate past president (as of 2005)

Carolinas Center for Hospice and End of Life Care
Speaker at Pre-Conference presentation, 2003 Annual Conference

Duke University - Institute on Care at the End of Life
Director (as of 2/2004)

Harlem Palliative Care Network
Founder

Initiative to Improve Palliative Care for African-Americans (IIPCA)
Founder

National Association of Attorneys General (NAAG)
2004 EOL Advisory Committee

National Institutes of Health - Behavioral Medicine Study Section
Former member

North General Hospital

Robert Wood Johnson Foundation
National Advisory Committee Promoting Excellence in End-of-Life Care

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group
- 1996 **Conference on Measuring Care at the End of Life** (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: **Promoting Excellence in End of Life Care.**
- 1997 **"Before I Die" on PBS with Tim Russert -- RWJF begins media campaign to build grass roots reaction to SUPPORT study**
Panelists
- 1997 **Publication of "Approaching Death: Improving care at the end of life"** by IOM's Committee on Care at the End of Life
Author of National Academy Press publication
- 1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**
Presenters
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Heritage, Health, and Hope (IIPCA)**
Soros grant director
- 2002 **NAACP, at regional meeting of Last Acts in Tampa, Florida, announces it will join Last Acts.**
- 2002 **EPEC2 -- RWJF awards grant for \$446,900 to Richard Payne, MD, and North General Hospital in NYC, to create "End-of-life care education for African-American health care professionals"**
Project Director
- 2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care (Midwest Bioethics, PFC, RWJF)**
Speakers

Known funding:

\$838,214	tracked thus far	
\$446,990	from Robert Wood Johnson Foundation	
	to: North General Hospital	\$446,990
\$241,224	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: North General Hospital	\$241,224
\$150,000	from Kornfeld / PDIA (Soros) collaborative	
	to: Memorial Sloan Kettering	\$150,000

Judith R. Peres, L.C.S.W.-C

Affiliations:

- Last Acts
- Partnership for Caring
Deputy Director (beginning 2002 -- per Form 990)
- Rallying Points
Deputy Director

Conferences, research papers, task forces, ev

- 2001 National Consensus Project -- national palliative care guidelines.
NCP Steering Committee
- 2002 Social Work Summit on End-of-Life and Palliative Care co-sponsored by the Last Acts Provider Education Committee, The Duke Institute on Care at the End of Life, and the Soros Foundation's Project on Death in America.
Attendees
- 2002 AAHSA Expo
taught Session: 100-H. Precepts to Practice: Seamless Integration of Palliative Care Across the Continuum
- 2002 Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)
- 2003 Last Acts Palliative Care Committee produces "On the Road from Theory to Practice"

Known funding:

Susan Foley Pierce, Ph.D., R.N.

Affiliations:

- American Nurses Association
NC representative; President of NC group
- Duke University - Institute on Care at the End of Life
Associate Faculty Scholar
- Georgetown University - Kennedy Institute of Ethics
Certificate in Bioethics from Kennedy Center for Ethics
- Hastings Center
member
- North Carolina Nurses' Association
President, 2002-5
- University of North Carolina - Chapel Hill
Nursing Ethics

Conferences, research papers, task forces, ev

- 1998 Pain as a Fifth Vital Sign: 30 leaders of national nursing organizations assembled at a symposium led by UNC-Chapel Hill School of Nursing; endorsed promotion of "Pain as the Fifth Vital Sign." ("Notes on a Peaceful Death" monograph distributed; RWJF)

Known funding:

\$129,694 tracked thus far
\$129,694 from Robert Wood Johnson Foundation
to: University of North Carolina - Chapel Hill

\$129,694

Elizabeth Ford Pitorak, MSN, RN, CHPN

Affiliations:

- Case Western Reserve University
- Hospice and Palliative Nurses Association (HPNA)
Board Member
- Hospice of the Western Reserve
Director, Hospice Institute
- Ireland Cancer Center
- Robert Wood Johnson Foundation
project director, Promoting Excellence in End-of-Life Care grant, partnership between the Ireland Cancer Center, a comprehensive cancer center and Hospice of the Western Reserve

Conferences, research papers, task forces, ev

- 2000 ELNEC (End-of-Life Nursing Education Consortium) -- RWJF funds nursing education reform. Started with a grant to City of Hope to study nurses' text books; then major grant 37617 to AACN in 2000. Partnership of AACN and City of Hope in Los Angeles.
Organization Representatives
- 2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

Known funding:

Russell K. Portenoy, M.D.

Affiliations:

Albert Einstein College of Medicine
Professor of Neurology

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
rep to National Consensus Project

American Board of Hospice and Palliative Medicine (ABHPM)
Vice-Chairman (2004)

American Pain Society (APS)
President

Beth Israel Medical Center - NYC
Chairman, Dept. of Pain Medicine & Palliative Care

Journal of Palliative Medicine
Editorial Board

Last Acts
Task Force on Institutional Innovation / Hospital Committee

Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)
co-author of CAPCManual

Open Society Institute / Project on Death in America (Soros Foundation)
Grant recipient 1998

Conferences, research papers, task forces, ev

1996 EPEC Project (Education for Physicians on End-of-Life Care)
Consultant

1996 Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Palliative Care Task Force 1997

1997 Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)
Presenters

1997 Precepts of Palliative Care (Last Acts Palliative Care Committee)
Members

2000 RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)
CAPCManual

2000 Soros's Project on Death in America announces second round of grants for their \$2 million Social Work Leaders Program -- \$419,400.

2001 CAPCManual is launched

2001 Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.
article

2001 National Consensus Project -- national palliative care guidelines.
NCP Steering Committee

Known funding:

\$519,000	tracked thus far	
\$50,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Beth Israel Medical Center - NYC	\$50,000
\$5,000	from Mayday Fund	
	to: Beth Israel Medical Center - NYC	\$5,000
\$414,000	from Fan Fox and Leslie R. Samuels Foundation	
	to: Beth Israel Medical Center - NYC	\$414,000
\$50,000	from Commonwealth Fund	
	to: Beth Israel Medical Center - NYC	\$50,000

Patricia Prem, M.S.W.

Affiliations:

Open Society Institute / Project on Death in America (Soros Foundation)
Advisory Board (as of 11-2003)

Conferences, research papers, task forces, ev

- 1994 **Soros launches "Project on Death in America"**
At George Soros' request, she brought together the people to create PDIA
- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life."** Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference Attendees
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
Endorsed the statement
- 2002 **Social Work Summit on End-of-Life and Palliative Care co-sponsored by the Last Acts Provider Education Committee, The Duke Institute on Care at the End of Life, and the Soros Foundation's Project on Death in America.**
2001 Leadership Committee

Known funding:

Thomas J. Prendergast, M.D.

Affiliations:

Dartmouth-Hitchcock Medical Center
Associate Professor of Medicine (Pulmonary Medicine) & of Anesthesiology

Last Acts
Members

Open Society Institute / Project on Death in America (Soros Foundation)
PDIA Faculty Scholar, 1999-2001

Robert Wood Johnson Foundation
VA Faculty Leader, 1998-2000

University of California - San Francisco
Alumnus, MD 1988

Conferences, research papers, task forces, ev

Known funding:

\$225,110 tracked thus far

\$85,110 from **Robert Wood Johnson Foundation**
to: Dartmouth-Hitchcock Medical Center

\$85,110

\$140,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Dartmouth-Hitchcock Medical Center

\$140,000

Christina M. Puchalski, M.D.

Affiliations:

George Washington University
Director

Last Acts

Co-Convenor, Spirituality & Bereavement Committee

Shalem Institute

"Dr. Puchalski completed a course in Spiritual Formation at the Shalem Institute" <http://www.faith-and-life.org/puchalski.html>

Templeton Foundation (John Templeton)

Board of advisors

Conferences, research papers, task forces, ev

- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)**
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

\$72,982 tracked thus far

\$72,982 from **Robert Wood Johnson Foundation**

to: George Washington University

\$72,982

Timothy E. Quill, M.D.

Affiliations:

American College of Physicians - ACPS-ASIM
Consensus Panel
Death With Dignity National Center
Board of Directors
Journal of Palliative Medicine
Editorial Board
University of Rochester
Professor of Medicine, Psychiatry, and Medical Humanities
ViaHealth - Greater Rochester Health Care System

Conferences, research papers, task forces, ev

- 1992 **First published guidelines for assisted suicide: NEJM, "Case of the hopelessly ill: Proposed clinical criteria for physician-assisted suicide": D. Meier, T. Quill, C. Cassel**
- 1994 **Physician Assisted Suicide: If it were legal, would it be workable?**
- 1997 **Case: Vacco v. Quill**
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**
- 1997 **Finding Common Ground: Assisted Suicide Consensus Panel is convened**
- 1998 **D. Meier co-authors "Survey of PAS and Euthanasia" in NEJM. Next day, her "Change of Heart" on assisted suicide is published in the New York Times.**
- 1998 **VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)**
- 1998 **Doctors, Death, and Dignity - Chautauqua**
- 1998 **VA Faculty (Veterans Affairs Faculty): First Leadership Conference.**
- 2000 **Byock & Quill: "Responding to Intractable Terminal Suffering"**
- 2001 **Death With Dignity - 2001 Annual Conference**
Clinical Perspectives
- 2002 **Death With Dignity: 2002 -- The Fifth Anniversary Forum: Results of the Oregon "Experiment"**
Clinical Perspectives from the Caregivers: Medical issues relating to end-of-life care and developments in Oregon since the passage of the Oregon Death with Dignity Act
- 2003 **Cassel & Quill "Position Paper" on Assisted Suicide: "studied neutrality"**
Authors
- 2004 **Quill & Battin edit a book supporting PAS. Contributors include Christine Cassel**
- 2004 **55 Bioethicists file brief in support of Michael Schiavo**
Signers

Known funding:

\$115,000 tracked thus far

\$115,000 from **Mayday Fund**

to: ViaHealth - Greater Rochester Health Care System

\$115,000

Michael W. Rabow, M.D.

Affiliations:

Center for Caregiver Training (CCT) at UCSF

Last Acts

Members

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

Faculty Scholar c. 2004

University of California - San Francisco

Associate Professor of Clinical Medicine; also, UCSF

Palliative Care Leadership Center

Conferences, research papers, task forces, ev

1998 USCF's Michael Rabow, MD, receives \$450,000 from RWJF; launches "Comprehensive Care Teams" project at Center for Caregiver Training.

1999 **Textbook Revision: Last Acts**, at PDIA/Soros headquarters, launches revision of medical textbooks. Presenting to publishers: Betty Ferrell who led nursing team; Stephen McPhee led medical text study; Joanne Lynn and Kathleen Foley addressed group.

Known funding:

\$450,000 tracked thus far

\$450,000 from **Robert Wood Johnson Foundation**

to: University of California - San Francisco

\$450,000

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

to: University of California - San Francisco

Kenneth E. Rosenfeld, M.D.

Affiliations:

Greater Los Angeles Health Care System

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

Faculty Scholar, 2000-2002

University of California - Los Angeles, School of Medicine

Veterans Administration Greater Los Angeles Healthcare
System

Conferences, research papers, task forces, ev

Known funding:

\$187,738 tracked thus far

\$137,738 from **Robert Wood Johnson Foundation**

to: Greater Los Angeles Health Care System

\$137,738

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

to: University of California - Los Angeles, School of Medicine

\$50,000

David Rothman

Affiliations:

Columbia University

*Director, Center for the Study of Society and Medicine
(1995)*

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

Board Member (1995)

Conferences, research papers, task forces, ev

1995 **Meeting at PDIA headquarters**, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.

Conference attendees

Known funding:

Fenella Rouse, J.D.

Affiliations:

- Kornfeld Foundation** (a right-to-die organization)
Executive Director (1998, 1999)
- Mayday Fund**
Executive Director
- Society for the Right to Die** -- see Partnership for Caring
c. 1984

Conferences, research papers, task forces, ev

- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life."** Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)
Palliative Care Task Force 1997
- 1997 **EDC and Mayday Fund collaborate to create "PainLink" online**
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
Endorsed the statement
- 1997 **Precepts of Palliative Care (Last Acts Palliative Care Committee)**
Members

Known funding:

True Ryndes, ANP, MPH

Affiliations:

- Last Acts**
Task Force on Institutional Innovation / Hospice Committee
- Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)**
Chair of the Hospital-Hospice Liaison Committee
- National Hospice and Palliative Care Organization (NHPCO)**
Public Policy Steering Committee 2005; former Chair, Standards and Accreditation Committee
- National Hospice Work Group**
President & CEO
- San Diego Hospice**
Vice President of Mission and Policy; Founding Director of the Center for Palliative Studie

Conferences, research papers, task forces, ev

- 1995 **National Hospice Work Group founded**
- 1996 **Conference on Measuring Care at the End of Life** (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: **Promoting Excellence in End of Life Care.**
- 1998 **National Hospice Outcomes Planning (RWJF)**
Evaluation Advisory Panel Member
- 1999 **National Hospice Work Group Project: Planning for "Increasing Access to Hospice Care"**
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2003 **National Hospice Work Group publishes "Access to Hospice Care" findings** (Hastings Center Report supplement)
Authors
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

Gregory A. Sachs, M.D.

Affiliations:

University of Chicago
Geriatrics Department; Co-Director, Center for
Comprehensive Care and Research on Memory Disorders

Known funding:

Conferences, research papers, task forces, ev

- 2004 NIH State-of-the-Science Conference on Improving End-of-Life Care
"Key Factors Affecting Those Dying With Dementia"

J. Donald Schumacher, Psy.D.

Affiliations:

Last Acts
Convener, Task Force on Institutional Innovation /
Hospice Committee

National Association of Attorneys General (NAAG)
2004 EOL Advisory Committee

National Hospice and Palliative Care Organization (NHPCO)
President & CEO

National Hospice Work Group
Founding member
(<http://itrs.scu.edu/fow/pages/coursesplash.html>)

Partnership for Caring
Board of Directors; Director of Public Policy (2003)

Known funding:

Conferences, research papers, task forces, ev

- 2000 National Hospice Work Group launches project: **Increasing Access to Hospice**
Task Force Members
- 2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
article
- 2001 Alliance for Health Reform hosts "A Briefing on Gaps and Potential Solutions in Financing Care for Those Who Are Dying" featuring Karen Orloff Kaplan, Joseph Fins, Donald Schumacher
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2002 **AAHSA Expo**
taught Session: 100-H. Precepts to Practice: Seamless Integration of Palliative Care Across the Continuum
- 2003 **Last Acts Palliative Care Committee produces "On the Road from Theory to Practice"**
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**
- 2003 **National Association of Attorneys General "Listening Conference" Improving End-of-Life Care (Midwest Bioethics, PFC, RWJF)**
Speakers
- 2003 **2003 Annual Conference of Carolinas Hospice**
Keynote Address: Hospice is changing at a very fast pace in this country.

Myles N. Sheehan, S.J., M.D.

Affiliations:

Dartmouth College

Alumnus

Journal of Palliative Medicine

Editorial Board (2004)

Last Acts

LAPartnership used his work for their Care of Spirit tip sheet

Loyola University (Chicago)

senior associate dean for educational affairs and associate professor, medicine and geriatrics

Neiswanger Institute for Bioethics and Health Policy (at Loyola/Stritch)

Advisory Board, Chair

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

Faculty Scholar, 1999-2001

Known funding:

\$120,000 tracked thus far

\$120,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Loyola University (Chicago)

\$120,000

Conferences, research papers, task forces, ev

2002 **Catholic EPEC: Recovering our Traditions**

Deborah Witt Sherman, PhD, APRN, ANP, BC, FAAN

Affiliations:

Bronx Veterans Administration Medical Center

Faculty

Journal of Palliative Medicine

Editorial Board (2004)

Mount Sinai School of Medicine

Her PDIA grant is for Mt. Sinai/NYU

New York University

Assoc. Professor

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

Faculty Scholar, 1998-2000

Known funding:

\$330,387 tracked thus far

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

to: Mount Sinai Medical Center

\$60,000

\$270,387 from **National Institutes of Health - National Cancer Institute (NCI)**

to: New York University

\$270,387

Conferences, research papers, task forces, ev

2001 **National Consensus Project -- national palliative care guidelines.**

NCP Steering Committee

Carole Shields

Affiliations:

Duke University - Institute on Care at the End of Life

Co-founded, with husband Hugh Westbrook

University of Miami

Board Member of Forum for Medical Ethics and Philosophy

VITAS Healthcare Corp.

While Vice President of Vitas Healthcare Corporation, she developed the nation's largest hospice program for persons living with AIDS.

Known funding:

Conferences, research papers, task forces, ev

2000 **VITAS founder Hugh Westbrook (prominent progressive and Democratic funder) gives Duke \$13 million to found Duke Institute on Care at the End of Life**

2003 **Hugh Westbrook and wife Carole Shields give an additional \$3 million to Duke University's Divinity School to enhance the Duke Institute on Care at the End of Life.**

David A. Simpson, MA, LSW

Affiliations:

Hospice of the Western Reserve

Executive Director, 1985-present

Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)

National Advisory Committee

National Hospice and Palliative Care Organization (NHPCO)

Board member, 1994 - 2000

National Hospice Work Group

Member, 2004

Ottawa University (Canada)

Alumnus

Known funding:

Conferences, research papers, task forces, ev

2001 **National Consensus Project -- national palliative care guidelines.**

NCP Steering Committee

Mildred Z. Solomon, Ed.D.

Affiliations:

Center For Applied Ethics and Professional Practice (see EDC)

Founder and Director

Education Development Center, Inc. (EDC)

Vice President

Harvard Medical School

Director, Harvard Medical School Fellowship in Medical Ethics

Journal of Palliative Medicine

Senior Associate Editor

Conferences, research papers, task forces, ev

- 1987 **Decisions Near the End of Life -- education program (founded by Bruce Jennings and Mildred Solomon)**
Co-founders
- 1996 **Adoption of Cancer Pain Guidelines in Managed Care**
- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**
2 Facilitators
- 1996 **RWJF awards grant to EDC to convene the National Task Force on End-of-Life Care for Patients in Managed Care. The Task Force would produce a widely publicized report, "Meeting the Challenge," in May, 1999.**
1) Steering Committee
- 1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**
- 1997 **EDC and Mayday Fund collaborate to create "PainLink" online**
Director
- 1997 **Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions**
Director
- 1997 **Innovations in End-of-Life Care: An International Journal and On-line Forum for Leaders in End-of-Life Care (EDC)**
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 1997 **National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)**
RWJF Contact for the project
- 1998 **Doctors, Death, and Dignity - Chautauqua**
- 1999 **Increasing Organ Donation by Enhancing End-of-Life Care: A Family-Centered, Quality Improvement Program (US DHSS, EDC)**
Director
- 1999 **SACGT: A Public Consultation on Oversight of Genetic Tests**
Director
- 1999 **Palliative Care in Germany and the United States: A Cross-National Comparison (EDC)**
Director
- 1999 **Meeting the Challenge: Twelve Recommendations for Improving End-of-Life Care in Managed Care (RWJF, EDC)**
- 2000 **Quality Improvement for End-of-Life Care in the Intensive Care Unit**
Director

- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2000 **Consumer Perspectives on the Promise of Cystic Fibrosis Gene Therapy**
Director

Known funding:

\$4,121,020	tracked thus far	
\$1,584,069	from Robert Wood Johnson Foundation	
	to: Education Development Center, Inc. (EDC)	\$1,238,437
	to: Education Development Center, Inc. (EDC)	\$345,632
\$449,951	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Education Development Center, Inc. (EDC)	\$149,951
	to: Education Development Center, Inc. (EDC)	\$300,000
\$937,000	from US DHHS (US Department of Health and Human Services)	
	to: Education Development Center, Inc. (EDC)	\$937,000
\$1,150,000	from Nathan Cummings Foundation, Inc.	
	to: Education Development Center, Inc. (EDC)	\$250,000
	to: Education Development Center, Inc. (EDC)	\$900,000

John M. Stanley, Ph.D.

Affiliations:

- American Health Decisions**
Wisconsin Health Decisions; past chairman AHD
- Hastings Center**
Hospice Access and Values Project
- Lawrence University (Wisconsin)**
1961-1999
- Pacific School of Religion (Berkeley, CA)**
Alumnus (B.D.)
- Wisconsin Health Decisions**

Conferences, research papers, task forces, ev

- 1987 **American Health Decisions is founded (part of a civic bioethics initiative of the Hastings Center)**
- 1987 **Appleton, Wis: First of two conferences to establish international guidelines for withdrawal of treatment. John Stanley (later with Hastings/National Hospice Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S. Youngner, H. Brody represent US.**
- 1988 **Appleton Conference Project -- Second Meeting.**
DECISIONS INVOLVING NEONATES AND PATIENTS WHO ARE NOT NOW AND NEVER HAVE BEEN COMPETENT
- 1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**
panelist
- 1997 **American Health Decisions (Atlanta, GA; Appleton, WI) releases report: Quest to Die With Dignity**
Co-project-director (Chairman, AHD)
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Task Force Members
- 2003 **National Hospice Work Group publishes "Access to Hospice Care" findings (Hastings Center Report supplement)**
Authors

Known funding:

\$254,440	tracked thus far	
\$254,440	from Robert Wood Johnson Foundation	
	to: American Health Decisions	\$254,440

Gary L. Stein, M.S.W., J.D.

Affiliations:

New Jersey Comfort Care Coalition (C-SP)

Project Director

New Jersey Health Decisions

Executive Director (joined NJHD in 1998)

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

End-of-Life Care Fellowship for Social Workers (SWLD)

Partnership for Caring

Mr. Stein was also a consultant to Partnership in Caring, through which he completed the Project on Health Care Attitudes in the Lesbian and Gay Community

Known funding:

\$982,219 tracked thus far

\$922,219 from **Robert Wood Johnson Foundation**

to: New Jersey Health Decisions

\$922,219

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

to: New Jersey Health Decisions

\$60,000

Conferences, research papers, task forces, ev

Karen E. Steinhauser, Ph.D.

Affiliations:

Duke University - Institute on Care at the End of Life

Associate Faculty Scholar

Duke University - Medical Center

Veterans Administration Medical Center

Research Scientist, Duke University Program on the Medical Encounter & Palliative Care, VAMC

Known funding:

Conferences, research papers, task forces, ev

2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

William C. Stubing

Affiliations:

Greenwall Foundation

President (2003)

Johns Hopkins

Board Member (2004)

Mount Sinai School of Medicine

Board of Advisors (2004)

Conferences, research papers, task forces, ev

1993 **IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments." This workshop began a process toward those guidelines --"Approaching Death" -- and recommendations for Last Acts strategies.**

Workshop Participants

1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**

Conference Attendees

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life." Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)**

Conference Attendees

1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**

2001 **Greenwall Foundation Faculty Scholars Program in Bioethics
Advisory Board**

Known funding:

Nigel Sykes, M.A., B.M., BCh, FRCGP

Affiliations:

Journal of Palliative Medicine

Editorial Board (2004)

St. Christopher's (Anglican) Hospice (London, England)

Director of Medicine (2004)

Known funding:

Conferences, research papers, task forces, ev

Joan M. Teno, M.D.

Affiliations:

Brown University Center for Gerontology & Health Care Research

Director

Center for Palliative Care Studies (CPCS)

When it was known as Center to Improve Care of the Dying

Dartmouth College

SUPPORT, 1989

Journal of Palliative Medicine

Editorial Board

Last Acts

Co-convener, Evaluation and Outcomes Committee

Conferences, research papers, task forces, ev

1993 **IOM's workshop to discuss whether it would be feasible to "develop guidelines for identifying and limiting futile treatments."** This workshop began a process toward those guidelines -- "Approaching Death" -- and recommendations for Last Acts strategies.

Workshop Participants

1995 **SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)**

Led the study (at George Washington)

1996 **Last Acts' first national leadership conference: "Care and Caring at the End of Life."** Brought together 140 leaders; produced "challenges" (objectives) and "opportunities" (tactics)

Conference Attendees

1996 **Conference on Measuring Care at the End of Life (developed a "toolkit" to rate quality of life -- not to improve quality of life). The draft toolkit will be used in the RWJF project directed by Ira Byock: Promoting Excellence in End of Life Care.**

Directed the Workshop

1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**

1998 **National Hospice Outcomes Planning (RWJF)**

Evaluation Advisory Panel Member

2001 **National Consensus Project -- national palliative care guidelines.**

Advisory Council

2002 **Means to a Better End: A Report on Dying in America Today (RWJF; Midwest Bioethics Center)**

2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**

"Measuring Outcomes Retrospectively"

Known funding:

\$4,333,737 tracked thus far

\$4,014,649 from **Robert Wood Johnson Foundation**

to: Brown University Center for Gerontology & Health Care Research **\$3,970,879**
to: George Washington University **\$43,770**

\$119,944 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Center for Palliative Care Studies (CPCS) **\$119,944**

\$50,000 from **Nathan Cummings Foundation, Inc.**

to: George Washington University **\$50,000**

\$124,166 from **Mayday Fund**

to: Brown University Center for Gerontology & Health Care Research **\$124,166**

\$24,978 from **Commonwealth Fund**

to: Brown University Center for Gerontology & Health Care Research **\$24,978**

Charles Terry

Affiliations:

Rockefeller Family Office
Director of Philanthropy (1995)

Conferences, research papers, task forces, ev

1995 Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.
Conference attendees

Known funding:

Patti (Patricia) Thielemann, PhD

Affiliations:

Hospice of the North Shore -- see Palliative Care Center of the North Shore
Lifepath Hospice and Palliative Care
Palliative Care Center and Hospice of the North Shore

Conferences, research papers, task forces, ev

2003 NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."

Known funding:

Daniel Tobin, M.D.

Affiliations:

Center for Advanced Illness Coordinated Care (CAICC)
Children's Hospice International
PACC National Advisory Council
Dartmouth Medical School
Adjunct Assistant Professor of Psychiatry
Dartmouth-Hitchcock Medical Center
Last Acts
Task Force on Institutional Innovation / Hospice Committee
Life Institute
Director
National Advanced Illness Coordinated Care (NAICC)
National Association of Social Workers
Board Member
Partnership for Caring
Board of Directors
Rallying Points
Research Foundation of State University of New York
Robert Wood Johnson Foundation
Chief investigator for RWJF funded NAICC
Stratton Veterans Administration Medical Center
Director
Supportive Care of the Dying
Consultant (per his bio at Life Institute)
Veterans Administration - Hospice and Palliative Care (VAHPC)
founder
Veterans Administration Healthcare Network, Upstate NY

Known funding:

\$750,000 tracked thus far
\$400,000 from **Robert Wood Johnson Foundation**
to: Life Institute *\$400,000*
\$350,000 from **Fan Fox and Leslie R. Samuels Foundation**
to: Partnership for Caring *\$150,000*
to: Research Foundation of State University of New York *\$200,000*

Conferences, research papers, task forces, ev

2000 **On Our Own Terms -- Bill Moyers**
attended 9/7/00 Capitol Hill reception
2001 **Finding Our Way: Living With Dying in America (Last Acts, RWJF) -- 15-part newspaper series via Knight-Ridder.**
Project Director and "chief architect"
2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
2002 **Last Acts releases "Precepts of Palliative Care for Children, Adolescents, and Their Families"**

Susan Tolle, M.D.

Affiliations:

Midwest Bioethics Center (aka Center for Practical Bioethics)
Chair, National Advisory Committee: Community-State Partners Program (2003)
Oregon Health and Sciences University
Director (1997) still director in 2004
Robert Wood Johnson Foundation
Community-State Partners Program (see Midwest Bioethics)

Conferences, research papers, task forces, ev

1995 **Task Force to Improve the Care of Terminally-Ill Oregonians**
1996 **IOM's Committee on Care at the End of Life" - Public Hearing #2 (led to "Approaching Death")**
1997 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
Consultants from Oregon
1998 **Oregon Death With Dignity Act: A Guidebook for Health Care Providers**
1999 **Community-State Partnerships -- First round of grants: CA \$110,000; CT \$75,000; HI \$450,000; IA \$74,999; KS \$74,830; KY \$73,880; ME \$450,000; NV \$450,000; NY \$446,499; NC \$75,000; OK \$74,796; RI \$69,839; TX \$74,709; UT \$74,963; WV \$75,000**
National Advisory Committee

Known funding:

\$848,351 tracked thus far

\$598,351 from **Robert Wood Johnson Foundation**

to: Oregon Health and Science University **\$598,351**

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

to: Oregon Health and Sciences University **\$150,000**

\$100,000 from **Nathan Cummings Foundation, Inc.**

to: Oregon Health and Science University **\$100,000**

James A. Tulsky, M.D.

Affiliations:

American College of Physicians - ACPS-ASIM

Consensus Panel

Duke University - Center for the Study of Aging and Human Development

Senior Fellow

Duke University - Medical Center

Greenwall Foundation

Board of Directors (2004)

Journal of Palliative Medicine

Editorial Board

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

Faculty Scholar, 1995-96

Veterans Administration - Hospice and Palliative Care (VAHPC)

Veterans Administration Medical Center

Director, Program on the Medical Encounter and Palliative Care

Conferences, research papers, task forces, ev

1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group

1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**

1997 **Finding Common Ground: Assisted Suicide Consensus Panel is convened**

1998 **VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)**

1998 **VA Faculty (Veterans Affairs Faculty): First Leadership Conference.**

2003 **Physicians for a National Health Program issue call for universal health care, published in JAMA. Principals of PNHP include Christine Cassel and Marcia Angell. Endorsing the petition: Tulsky, Sulmasy, Meier, Yellig, Truog**

2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**

"Interventions To Enhance Communication Among Patients, Providers, and Families"

Known funding:

\$778,531 tracked thus far

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

to: Duke University - Medical Center **\$140,000**

\$638,531 from **National Institutes of Health - National Cancer Institute (NCI)**

to: Duke University - Medical Center **\$638,531**

from **National Institutes of Health - Nursing Research (NINR)**

to: Duke University - Medical Center

Martha L. Twaddle, M.D., FACP, FAAHPM

Affiliations:

- American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)**
Past President
- Hospice of the North Shore -- see Palliative Care Center of the North Shore**
Medical Director
- Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)**
CAPC Advisor
- Northwestern University**
Assistant Professor of Palliative Medicine
- Rush Medical Center**
Program Director, Palliative Medicine Fellowship

Known funding:

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2003 **CBHD reviews Case Studies in AMA online journal**
wrote case commentary.

Charles F. von Gunten, M.D., PhD, FACP

Affiliations:

- American Board of Hospice and Palliative Medicine (ABHPM)**
Chairman
- Journal of Palliative Medicine**
Senior Associate Editor
- Last Acts**
Members
- Mount Sinai School of Medicine - Center to Advance Palliative Care (CAPC)**
rep to National Consensus Project
- National Board of Medical Examiners**
2002 EOL Care Committee
- Open Society Institute / Project on Death in America (Soros Foundation)**
Faculty Scholar, 1995-96
- San Diego Hospice**
Medical Director, Center for Palliative Studies
- University of California - San Diego, School of Medicine**
Associate Clinical Professor

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
1 Project Directors
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 1998 **APOS Standards of Care for the Management of Distress in Patients with Cancer**
- 2000 **National Hospice Work Group launches project: Increasing Access to Hospice**
Project Meetings and Other Assistance
- 2000 **ELNEC (End-of-Life Nursing Education Consortium) -- RWJF funds nursing education reform. Started with a grant to City of Hope to study nurses' text books; then major grant 37617 to AACN in 2000. Partnership of AACN and City of Hope in Los Angeles.**
Organization Representatives
- 2000 **RWJF awards nearly \$5 million to Diane Meier and Christine Cassel to establish Center to Advance Palliative Care (CAPC)**
CAPC Manual
- 2001 **CAPC Manual is launched**
- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee
- 2004 **NIH State-of-the-Science Conference on Improving End-of-Life Care**
"Interventions To Manage Symptoms at the End of Life"

Known funding:

\$1,119,822 tracked thus far

\$285,700	from Robert Wood Johnson Foundation	
	to: San Diego Hospice	\$285,700
\$140,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Northwestern University	\$140,000
\$544,122	from National Institutes of Health - National Cancer Institute (NCI)	
	to: Northwestern University	\$247,011
	to: San Diego Hospice	\$297,111
\$150,000	from Kornfeld / PDIA (Soros) collaborative	
	to: San Diego Hospice	\$150,000

David E. Weissman, M.D.

Affiliations:

- American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)**
Medical Education Task Force (2001)
- American Board of Hospice and Palliative Medicine (ABHPM)**
Past Trustee (prior to 2004)
- Education Development Center, Inc. (EDC)**
Associate Editor, "Innovations"
- Journal of Palliative Medicine**
Editor-in-Chief
- Last Acts**
Members
- Medical College of Wisconsin, Inc.**
Director of the Palliative Medicine Program
- National Board of Medical Examiners**
2002 EOL Care Committee
- Open Society Institute / Project on Death in America (Soros Foundation)**
Faculty Scholar, 1995-96
- Robert Wood Johnson Foundation**
Grant recipient

Conferences, research papers, task forces, ev

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
EPEC Advisory Group
- 1997 **Innovations in End-of-Life Care: An International Journal and On-line Forum for Leaders in End-of-Life Care (EDC)**
Associate Editor
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 1998 **National Residency End of Life Education Project established at Medical College of Wisconsin, funded by RWJF**
- 1998 **VA (Veterans Administration) Faculty Scholars Program (funded by RWJF)**
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

Known funding:

\$4,546,307 tracked thus far

\$3,745,214	from Robert Wood Johnson Foundation	
	to: Medical College of Wisconsin, Inc.	\$1,742,697
	to: Medical College of Wisconsin, Inc.	\$2,002,517
\$140,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Medical College of Wisconsin, Inc.	\$140,000
\$661,093	from National Institutes of Health - National Cancer Institute (NCI)	
	to: Medical College of Wisconsin, Inc.	\$661,093

Rev. Hugh A. Westbrook

Affiliations:

Democratic Senatorial Campaign Committee

National Finance Chairman during the 1993-1994 election cycle.

Duke University - Institute on Care at the End of Life

Founder (Arranged the funding to found the institute)

Project YES

Signed "Affirming Stand" Pledge

Rainbow/PUSH Coalition

Announced sponsorship of Philip Coleman at PUSH

VITAS Healthcare Corp.

CEO

Conferences, research papers, task forces, ev

- 2000 **VITAS founder Hugh Westbrook (prominent progressive and Democratic funder) gives Duke \$13 million to found Duke Institute on Care at the End of Life**
- 2003 **Hugh Westbrook of VITAS and Rev. Jesse Jackson announce the appointment of Philip Coleman, of VITAS, as Director of Hospice Education for Rainbow/PUSH. Coleman was also a member of IIPCA (EPEC2). Coleman works through One Thousand Churches Connected.**
- 2003 **Hugh Westbrook and wife Carole Shields give an additional \$3 million to Duke University's Divinity School to enhance the Duke Institute on Care at the End of Life.**

Known funding:

Jocelyn C. White, M.D., FACP

Affiliations:

Gay and Lesbian Medical Association

past president

Journal of Palliative Medicine

Editorial Board

Oregon Health and Science University

Adjunct Associate Research Scientist, Dept. of Sociomedical Sciences

Oregon Health and Sciences University

Known funding:

Conferences, research papers, task forces, ev

Diana Wilkie, Ph.D., R.N.

Affiliations:

University of Washington

Assoc. Professor, Cancer Pain Management

Conferences, research papers, task forces, ev

- 1998 **National Hospice Outcomes Planning (RWJF)**
Evaluation Advisory Panel Member
- 2003 **NHPCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCO can support. NHPCO intends to advocate with Congress, the National Institutes of Health, the Veterans Administration..."**

Known funding:

J. Richard Williams, Jr., M.D.

Affiliations:

Foundation for End of Life Care, Inc. (Vitas Healthcare)

Board of Directors

Last Acts

Task Force on Institutional Innovation / Hospice Committee

VITAS Healthcare Corp.

Executive Vice President

Known funding:

Conferences, research papers, task forces, ev

- 2001 **National Consensus Project -- national palliative care guidelines.**
NCP Steering Committee

Susan M. Wolf, J.D.

Affiliations:

Citizens Committee on Biomedical Ethics - see New Jersey Health Decisions

Advisory Committee

Harvard University

Fellow in the Program in Ethics and the Professions at Harvard University in 1992-93

Hastings Center

Fellow, 1993 -

University of Minnesota - Center for Bioethics

Faculty

Conferences, research papers, task forces, ev

1987 **Appleton, Wisc: First of two conferences to establish international guidelines for withdrawal of treatment. John Stanley (later with Hastings/National Hospice Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S. Youngner, H. Brody represent US.**

1988 **Appleton Conference Project -- Second Meeting. DECISIONS INVOLVING COMPETENT PATIENTS OR PATIENTS WHO EXECUTED AN ADVANCE DIRECTIVE BEFORE BECOMING INCOMPETENT**

2001 **Death With Dignity - 2001 Annual Conference**
Starting on the Same Page: An overview of national and state legislation about physician-aided dying

Known funding:

Joanne Wolfe, M.D., M.P.H.

Affiliations:

Harvard Medical School - Center for Palliative Care

Program in Palliative Care Education and Practice, Core Faculty

Journal of Palliative Medicine

Editorial Board (2004)

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

PDIA Faculty Scholar, 1999-2001

Conferences, research papers, task forces, ev

Known funding:

\$290,000 tracked thus far

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

to: Harvard Medical School - Dana Farber Cancer Insititute Inc. **\$140,000**

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

to: Harvard Medical School - Dana Farber Cancer Insititute Inc. **\$150,000**

Stuart J. Youngner, M.D.

Affiliations:

American Psychiatric Association

Fellow

American Society of Bioethics and Humanities (ASBH)

Founding Member, Board of Directors

Case Western Reserve Center for Bioethics

Case Western Reserve University

Chair, Dept. of Bioethics

Hastings Center

Fellow

Institute of Medicine

Consultant

Robert Wood Johnson Foundation

Consultant

Conferences, research papers, task forces, ev

- 1987 **Appleton, Wisc: First of two conferences to establish international guidelines for withdrawal of treatment. John Stanley (later with Hastings/National Hospice Workgroup/Last Acts), facilitates. J. Lynn, R. Cranford, S. Youngner, H. Brody represent US.**
- 1988 **Appleton Conference Project -- Second Meeting.**
DECISIONS INVOLVING COMPETENT PATIENTS OR PATIENTS WHO EXECUTED AN ADVANCE DIRECTIVE BEFORE BECOMING INCOMPETENT
- 1989 **SUPPORT study initiated: Program on the Care of Critically Ill Hospitalized Adults (GW Univ.; SUPPORT launched the RWJF/Soros end of life initiatives)**
SUPPORT investigators
- 1992 **First International Symposium on Coma and Death (held in Havana, Cuba)**
Keynote Speaker (per his cv)
- 1995 **SUPPORT published in JAMA (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) (RWJF)**
SUPPORT investigators
- 1997 **Medical Education Reform: Soros/RWJF co-sponsor the "National Consensus Conference on Medical Education for Care Near the End of Life"**
endorsed the statement
- 2000 **Third International Symposium on Coma and Death (Havana, Cuba)**
- 2004 **4th International Symposium on Coma and Death (Havana, Cuba)**
Speakers

Known funding:

Mary Ann Zehr

Affiliations:

Council on Foundations

Conferences, research papers, task forces, ev

- 1995 **Meeting at PDIA headquarters, co-sponsored by Cummings and Commonwealth fund. "Grantmakers Concerned with Care at the End of Life." Over 20 organizations were represented, including RWJF, AARP, CCMD, Joanne Lynn, et al.**
Conference attendees

Known funding: