

Here's a very brief thumbnail sketch of participants in this event:

Kimberly D. Acquaviva, Ph.D., MSW

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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

Carla S. Alexander, M.D.

professional background includes:

National Hospice and Palliative Care Organization (NHPCO)
President (2000); Medical Director (2003)
University of Maryland
University of North Carolina - Chapel Hill
Alumna
Veterans Administration - Hospice and Palliative Care (VAHPC)

Associated with the following events (most of which are on the timeline):

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

Theresa Altilio, ACSW

professional background includes:

American Alliance of Cancer Pain Initiatives (AACPI)
Advisory Council
Beth Israel Medical Center - NYC
Social Work Coordinator, Dept of Pain Management
Open Society Institute / Project on Death in America (Soros Foundation)
Social Work Leader of the Year
Smith College School of Social Work
Faculty

Associated with the following events (most of which are on the timeline):

- 2000 Soros's Project on Death in America announces second round of grants for their \$2 million Social Work Leaders Program -- \$419,400.
- 2001 National Consensus Project -- national palliative care guidelines.
Advisory Council
- 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

underwriting provided in part by:

\$60,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: Beth Israel Medical Center - NYC

\$60,000

Robert M. Arnold, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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

Director-at-Large
American Board of Hospice and Palliative Medicine
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

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

underwriting provided in part by:

\$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

Constantino Benedetti, M.D.

professional background includes:

American Cancer Society
Ohio Division, President Elect
Ohio State University
Director, Cancer Pain and Palliative Medicine

Associated with the following events (most of which are on the timeline):

1998 **APOS Standards of Care for the Management of Distress in Patients with Cancer**
2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

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

professional background includes:

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)

Associated with the following events (most of which are on the timeline):

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

J. Andrew Billings, M.D.

professional background includes:

- 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**

Associated with the following events (most of which are on the timeline):

- 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

underwriting provided in part by:

\$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

Susan Blacker, M.S.W., LCSW-C

professional background includes:

- Johns Hopkins, Department of Oncology Social Work**
- Last Acts**
Members
- Open Society Institute / Project on Death in America (Soros Foundation)**
Social Work Leadership Award

Associated with the following events (most of which are on the timeline):

- 2000 **Soros's Project on Death in America announces second round of grants for their \$2 million Social Work Leaders Program -- \$419,400.**
- 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 **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
- 2002 **PDIA/Last Acts Social Work Summit at Duke University (North Carolina)**

underwriting provided in part by:

\$60,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
 to: Johns Hopkins, Department of Oncology Social Work **\$60,000**

Susan Dale Block, M.D.

professional background includes:

- American Board of Hospice and Palliative Medicine**
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 Institute 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

Associated with the following events (most of which are on the timeline):

- 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**

underwriting provided in part by:

\$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**

Lynn Brallier

professional background includes:

Consciousness Connections Foundation

Associated with the following events (most of which are on the timeline):

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

Katherine (Kathy) Brandt, M.S.

professional background includes:

Florida Council on Aging

Representative, District V

Hospice of the Florida Suncoast

Director of Operations (in 2001)

Hospice of the Florida Suncoast: Hospice Institute of the Florida Suncoast

Director of Institute Outreach

(<http://www.mywhatever.com/cifwriter/content/18/dw57.html>)

National Hospice and Palliative Care Organization (NHPCO)

Professional Leadership, and Consumer and Caregiver Services (2004)

Rallying Points

Director, Rallying Points Resource Center

Veterans Administration - Hospice and Palliative Care (VAHPC)

Toolkit Review Committee

Associated with the following events (most of which are on the timeline):

- 2001 **Rallying Points [a Last Acts initiative] is launched (California)**
Florida representative
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2003 **2003 Annual Conference of Carolinas Hospice**
Moving Hospice Upstream

William S. Breitbart, M.D.

professional background includes:

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>

Associated with the following events (most of which are on the timeline):

- 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

underwriting provided in part by:

\$140,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
 to: Cornell University - Weill Medical College **\$140,000**

\$176,921 from **National Institutes of Health - National Cancer Institute (NCI)**
 to: Memorial Sloan Kettering **\$176,921**

\$984,846 from **National Institutes of Health - National Institute of Mental Health (NIMH)**
 to: Memorial Sloan Kettering **\$984,846**

Frank Brescia, M.D.

professional background includes:

Medical University of South Carolina
Professor of Medicine; Director, Palliative & Supportive Care Services

Associated with the following events (most of which are on the timeline):

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

Micke A. Brown, B.S.N., R.N.

professional background includes:

American Society of Pain Management Nurses
President

Associated with the following events (most of which are on the timeline):

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

Eduardo Bruera, M.D.

professional background includes:

American Board of Hospice and Palliative Medicine
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)

Associated with the following events (most of which are on the timeline):

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

Ira Robert Byock, M.D.

professional background includes:

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/newss98.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

Associated with the following events (most of which are on the timeline):

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

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)

- 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

underwriting provided in part by:

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

Margaret Campbell, R.N., M.S.N.

professional background includes:

Last Acts

Task Force on Institutional Innovation / Hospital Committee

Associated with the following events (most of which are on the timeline):

- 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 **Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life**
- 1997 **Precepts of Palliative Care (Last Acts Palliative Care Committee)**
Members
- 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.**
Advisory Council

David Jonathan Casarett, M.D., M.A.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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"

underwriting provided in part by:

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

to: University of Pennsylvania School of Medicine

\$124,794

Grace H. Christ, D.S.W.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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 **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

2002 **PDIA/Last Acts Social Work Summit at Duke University
(North Carolina)**

underwriting provided in part by:

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

to: Columbia University School of Social Work

\$151,351

Elizabeth J. Clark, Ph.D., ACSW

professional background includes:

National Association of Social Workers

National Coalition for Cancer Survivorship

Associated with the following events (most of which are on the timeline):

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

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

Advisory Council

underwriting provided in part by:

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

to: National Association of Social Workers

Anne Cordes, MHA

professional background includes:

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

Executive Director

Associated with the following events (most of which are on the timeline):

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

NCP Steering Committee

Patrick J. Coyne, R.N., M.S.N., O.C.N.

professional background includes:

American Alliance of Cancer Pain Initiatives (AACPI)

Advisory Council 2002-3

Last Acts

*Task Force on Institutional Innovation / Hospital
Committee*

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

Faculty Scholar, 2001

Virginia Cancer Pain Initiative

Associated with the following events (most of which are on the timeline):

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

Advisory Council

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

Fellows

underwriting provided in part by:

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

\$150,000

LaVera M. Crawley, M.D.

professional background includes:

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)

Associated with the following events (most of which are on the timeline):

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"

underwriting provided in part by:

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

\$50,000

June L. Dahl, Ph.D.

professional background includes:

American Alliance of Cancer Pain Initiatives (AACPI)

Past President

Robert Wood Johnson Foundation

Project Director

University of Wisconsin - Madison Medical School

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$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, OCNS, CHPN

professional background includes:

Harvard Medical School - Center for Palliative Care

Center for Palliative Care; Program in Palliative Care

Associated with the following events (most of which are on the timeline):

2001 **RWJF convenes a group of Advanced Practice Nurses in Philadelphia, to forge a consensus statement on the role of**

Education and Practice, Core Faculty
Hospice and Palliative Nurses Association (HPNA)
Massachusetts General Hospital

APNs in palliative care. Produced "Pioneering Practices in Palliative Care."

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

Deborah Danoff, M.D.

professional background includes:

Association of American Medical Colleges
Associate Vice President, Division of Medical Education
Last Acts
Members
McGill University (Montreal, Canada)
Associate Dean, Undergraduate Medical Education and Student Affairs and Professor of Medicine

Associated with the following events (most of which are on the timeline):

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

Mellar Davis, M.D.

professional background includes:

Cleveland Clinic Foundation
Medical Director, Harry Horvitz Center for Palliative Medicine

Associated with the following events (most of which are on the timeline):

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

Jeanne Dennis, LCSW

professional background includes:

VNS of New York Hospice Care (Visiting Nurse Service)
Director

Associated with the following events (most of which are on the timeline):

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

Derek Doyle, M.D., OBE, MD, FRCSE, FRCPE, FRCGP (Scotland)

professional background includes:

International Association for Hospice and Palliative Care (IAHPC)
Emeritus President
National Council for Hospice and Specialist Palliative Care Services
Vice President
Scottish Agency for Palliative Care; St. Columba's Hospice
Vice President

Associated with the following events (most of which are on the timeline):

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

Thomas Edes, M.D.

professional background includes:

United States Department of Veterans Affairs
Chief of Home and Community-Based Care
Veterans Administration - Hospice and Palliative Care (VAHPC)
Toolkit Review Committee

Associated with the following events (most of which are on the timeline):

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

Kathleen (Kathy) Egan, MA, BSN, CHPN

professional background includes:

Hospice of the Florida Suncoast: Hospice Institute of the Florida Suncoast
Vice President

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$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**

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
1 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

underwriting provided in part by:

\$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**

Betty Rolling Ferrell, PhD, RN, FAAN

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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"

underwriting provided in part by:

\$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.

professional background includes:

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 1998-2000

Associated with the following events (most of which are on the timeline):

- 1996 **EPEC Project (Education for Physicians on End-of-Life Care)**
2 Co-Principal

San Diego Hospice

Medical Director, Palliative Care Standards

- 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

underwriting provided in part by:

<p>\$86,400 from Robert Wood Johnson Foundation to: San Diego Hospice</p> <p>from Open Society Institute / Project on Death in America (Soros Foundation) to: San Diego Hospice</p>	\$86,400
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Marilyn J. Field, Ph.D.

professional background includes:

Institute of Medicine
deputy director of the Division of Health Care Services

Associated with the following events (most of which are on the timeline):

- 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

underwriting provided in part by:

\$125,000	from Robert Wood Johnson Foundation	
	to: Institute of Medicine	<i>\$125,000</i>
\$200,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: Institute of Medicine	<i>\$200,000</i>
\$25,000	from Commonwealth Fund	
	to: Institute of Medicine	<i>\$25,000</i>

John Finn, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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..."**

Kathleen M. Foley, M.D.

professional background includes:

American Board of Hospice and Palliative Medicine
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)

Associated with the following events (most of which are on the timeline):

- 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.**
Speakers
- 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 **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**

underwriting provided in part by:

\$15,000,000 from **Soros Foundation**

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

Muriel Gillick, M.D.

professional background includes:

Beth Israel Deaconess Medical Center

Physician in Chief

Harvard Medical School

Associate Professor

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Marcia Grant, DNSc, R.N., FAAN

professional background includes:

City of Hope National Medical Center

Research Scientist, Co-Investigator ELNEC

Associated with the following events (most of which are on the timeline):

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.

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

underwriting provided in part by:

\$300,619 from **National Institutes of Health - National Cancer Institute (NCI)**
to: City of Hope National Medical Center

\$300,619

Burton Grebin, M.D.

professional background includes:

St. Mary's Healthcare System for Children
President & CEO

Associated with the following events (most of which are on the timeline):

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

Terrence Gutsell, M.D.

professional background includes:

Hospice of the Bluegrass, Inc.
Medical Director
St. Joseph Hospital - Hospice Care Center

Associated with the following events (most of which are on the timeline):

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

James L. Hallenbeck, M.D.

professional background includes:

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)

Associated with the following events (most of which are on the timeline):

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

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

Joanne M. Hilden, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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..."**

underwriting provided in part by:

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

\$150,000

Bruce P. Himelstein, M.D.

professional background includes:

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

Director-At-Large

Children's Hospice International

PACC Clinical Review Committee

Children's Hospital of Wisconsin

Program Director

Harvard Medical School - Center for Palliative Care

"The Harvard Palliative Course was by far the best educational experience I have ever attended."

<http://www.hms.harvard.edu/cdi/pallcare/reviews.htm>

Medical College of Wisconsin, Inc.

Director, Palliative Care Program, Pediatric Hematology/Oncology

Associated with the following events (most of which are on the timeline):

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

Advisory Council

underwriting provided in part by:

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

to: **Medical College of Wisconsin, Inc.**

\$150,000

Gail Gibson Hunt

professional background includes:

National Alliance for Caregiving

Executive Director

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Nora A. Janjan, M.D.

professional background includes:

University of Texas

Professor of Radiation Oncology

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Bruce Jennings, M.A.

professional background includes:

American Health Decisions

Treasurer, 1999

Education Development Center, Inc. (EDC)

Hastings Center

1991-99, Executive Vice President

Robert Wood Johnson Foundation

Consultant

University of Michigan

Consultant to School of Public Health

Yale School of Medicine

Department of Epidemiology and Public Health

Associated with the following events (most of which are on the timeline):

1987 **American Health Decisions is founded (part of a civic bioethics initiative of the Hastings Center)**

1987 **Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. A report by the Hastings Center**

Associate Director

1987 **Decisions Near the End of Life -- education program (founded by Bruce Jennings and Mildred Solomon)**

Co-founders

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

Steering Committee

- 1997 **American Health Decisions (Atlanta, GA; Appleton, WI) releases report: Quest to Die With Dignity**
Director, American Health Decisions
- 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.**
Advisory Council
- 2003 **National Hospice Work Group publishes "Access to Hospice Care" findings (Hastings Center Report supplement)**
Authors

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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)
- 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)**

underwriting provided in part by:

\$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

Karen Orloff Kaplan, MPH, ScD

professional background includes:

- Children's Hospice International**
PACC National Advisory Council

Associated with the following events (most of which are on the timeline):

- 1994 **Medical Education: Greenwall commits \$350,000 over 5 years to Choice in Dying for "Integrating Education about**

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-)

Care of the Dying into Existing Medical School Programs"

- 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

underwriting provided in part by:

\$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 to: Choice in Dying -- see "Partnership for Caring"	\$59,977 \$35,000
\$260,000	from Nathan Cummings Foundation, Inc. to: Partnership for Caring to: Choice in Dying -- see "Partnership for Caring"	\$150,000 \$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

Barry M. Kinzbrunner, M.D., FAAHPM

professional background includes:

American Academy of Hospice and Palliative Medicine (AAHPM) (Illinois)
Director-at-Large
VITAS Healthcare Corp.
in Miami, FL

Associated with the following events (most of which are on the timeline):

- 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..."**

Kenneth W. Kizer, M.D., MPH

professional background includes:

National Quality Forum
President & CEO

Associated with the following events (most of which are on the timeline):

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

Mary Jane Koren, M.D., MPH

professional background includes:

Commonwealth Fund
Senior Program Officer
Partnership for Caring
Board of Directors (2002)

Associated with the following events (most of which are on the timeline):

- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2004 **Building Bridges**
Advisory Committee

Kim K. Kuebler, M.N., R.N., ANP-CS

professional background includes:

Adjuvant Therapies, Inc.
Palliative Care Nurse Practitioner

Associated with the following events (most of which are on the timeline):

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

Jean S. Kutner, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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..."**

underwriting provided in part by:

from **National Institutes of Health - National Institute on Aging (NIA)**
to:

Mary J. Labyak, MSSW, LCSW

professional background includes:

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

Associated with the following events (most of which are on the timeline):

1999 **Florida Panel for the Study of End of Life Care produces its report, leading to change in advance directive laws and reg**

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**

Deborah A. Lafond, M.S., RNCS, PNP

professional background includes:

Association of Pediatric Oncology Nurses

Children's National Medical Center

Advanced Practice Clinician, Hematology/Oncology

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Judy Lentz, RN, MSN, OCN, NHA

professional background includes:

Hospice and Palliative Nurses Association (HPNA)

Ex Officio (prior to 2004: Executive Director)

Associated with the following events (most of which are on the timeline):

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

NCP Steering Committee

Matthew Loscalzo, M.S.W.

professional background includes:

American Psychosocial Oncology Society (APOS)

Member at Large

Eastern Virginia Medical School

Associate Dean

Johns Hopkins

Research Associate

Johns Hopkins, Department of Oncology Social Work

Director of Patient and Family Services

Last Acts

Task Force on Institutional Innovation / Hospital Committee

Associated with the following events (most of which are on the timeline):

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

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

Advisory Council

underwriting provided in part by:

\$125,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Johns Hopkins

\$125,000

Gail Lovinger

professional background includes:

American Hospital Association

Vice President, Association Governance

American Hospital Association - HRET Washington DC

Associated with the following events (most of which are on the timeline):

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

Advisory Council

underwriting provided in part by:

\$848,295 from **Robert Wood Johnson Foundation**

to: American Hospital Association - HRET Washington DC

\$848,295

Joanne Lynn, M.D., MA, MS.

professional background includes:

American College of Physicians - ACPS-ASIM
Consensus Panel

Americans for Better Care of the Dying (ABCD)
President

Center for Palliative Care Studies (CPCS)

Dartmouth College
SUPPORT, 1989

George Washington University
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

Associated with the following events (most of which are on the timeline):

- 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 **National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)**
Task Force Member
- 1997 **ACP-ASIM End-of-Life Care Consensus Panel is formed**
- 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..."**

underwriting provided in part by:

\$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

\$127,700 from Fan Fox and Leslie R. Samuels Foundation
to: RAND

\$127,700

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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..."

Sylvia Ann McSkimming, Ph.D., R.N.

professional background includes:

Oregon Health and Sciences University

graduate, 1965

(www.ohsu.edu/son/giving/honorroll2002.pdf)

Providence Health Systems, Oregon Region -- Supportive Care of the Dying

Portland, OR

Rallying Points

Hosted Train the Trainer

Supportive Care of the Dying

Executive Director

Associated with the following events (most of which are on the timeline):

1994 Supportive Care of the Dying founded in Oregon in response to "public outcry for legalized PAS"

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

Attended taping (see Grant Results)

2001 National Consensus Project -- national palliative care guidelines.

Advisory Council

underwriting provided in part by:

\$195,000 from Robert Wood Johnson Foundation
to: Supportive Care of the Dying

\$195,000

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$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.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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**
Shortly after publication, Meier announced her "change of heart" on PAS.

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**

underwriting provided in part by:

\$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.

professional background includes:

Brandeis University
Alumna, Biology

Harvard Medical School
Alumna

Touchstone Consulting
Principal

VITAS Healthcare Corp.
Director of Outcomes Measurement (1996)

Associated with the following events (most of which are on the timeline):

- 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"**

underwriting provided in part by:

\$734,960	from Robert Wood Johnson Foundation	
	to: Touchstone Consulting	\$734,960

Mary L. Meyer

professional background includes:

Choice in Dying -- see "Partnership for Caring"

Last Acts Partnership

New York Citizens' Committee on Health Care Decisions
Secretary, Board of Directors (2004)

Partnership for Caring

Associated with the following events (most of which are on the timeline):

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

Robert A. Milch, M.D.

professional background includes:

Center for Hospice and Palliative Care (CHPC)

Associated with the following events (most of which are on the timeline):

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

Last Acts

Task Force on Institutional Innovation / Hospice Committee

- 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..."**

Steven H. Miles, M.D.

professional background includes:

- American Society of Bioethics and Humanities (ASBH)**
Task Force for Standards
- American Society of Law, Medicine, and Ethics**
past Board member
- Hennepin County Medical Center (Minneapolis, MN)**
Thanatology Committee (1975); With Ronald Cranford, developed model DNR policy
- Open Society Institute / Project on Death in America (Soros Foundation)**
Faculty Scholar, 1995-96
- Robert Wood Johnson Foundation**
National Task Force on End of Life Care in Managed Care, 1998
- University of Chicago**
taught ethics at the Center for Clinical Medical Ethics (1986)
- University of Minnesota - Center for Bioethics**

Associated with the following events (most of which are on the timeline):

- 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 **IOM's Committee on Care at the End of Life" - Public Hearing #2 (led to "Approaching Death")**
- 1997 **National Task Force for End-of-Life Care in Managed Care (CAEPP at EDC)**
Steering Committee
- 2001 **Death With Dignity - 2001 Annual Conference**
Seeing Physician Aid in Dying in a Cultural Context: Two Views.
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2004 **4th International Symposium on Coma and Death (Havana, Cuba)**
Speakers
- 2004 **55 Bioethicists file brief in support of Michael Schiavo**
Signers

underwriting provided in part by:

\$140,000 from **Open Society Institute / Project on Death in America (Soros Foundation)**
to: University of Minnesota - Center for Bioethics

\$140,000

Galen Miller

professional background includes:

- Children's Hospice International**
PACC National Advisory Council
- National Hospice and Palliative Care Organization (NHPCO)**
Executive Vice President
- National Hospice Organization - See National Hospice and Palliative Care Or**
RWJF grant contact in 1997
- Robert Wood Johnson Foundation**
Grant recipient

Associated with the following events (most of which are on the timeline):

- 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 **First RWJF project to train residents in end-of-life care, via teleconference, using train-the-trainer approach. An educational kit, "Care Beyond Cure: Physician Education in End-of-Life Care," was provided to participants**
- 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 **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
Speakers at the opening conference
- 2002 **Last Acts releases "Precepts of Palliative Care for Children, Adolescents, and Their Families"**

underwriting provided in part by:

\$113,280 from **Robert Wood Johnson Foundation**

to: National Hospice Organization - See National Hospice and Palliative Ca **\$113,280**

Susan C. Miller, Ph.D., MBA

professional background includes:

Brown University Center for Gerontology & Health Care Research

Assistant Professor of Community Health (Research)

Associated with the following events (most of which are on the timeline):

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..."**

Charles A. Mowll, FACHE

professional background includes:

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

Executive V.P., Business Development, Government & External Relations

Associated with the following events (most of which are on the timeline):

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

Advisory Council

J. Cameron Muir, M.D., FAAHPM

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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..."**

underwriting provided in part by:

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

to: Northwestern University **\$70,000**

Evvie F. Munley

professional background includes:

American Association of Homes and Services for the Aging (AAHSA)

Sr. Health Policy Analyst

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Patricia A. Murphy, Ph.D., R.N., C.S., FAAN

professional background includes:

American Nurses Association

Wrote ANA position statement on PAS

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

Faculty Scholar, 2000-2002

**University of Medicine and Dentistry of New Jersey, New
Jersey Medical Scho**

Associated with the following events (most of which are on the timeline):

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

Advisory Council

underwriting provided in part by:

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

to: University of Medicine and Dentistry of New Jersey, New Jersey Medical **\$70,000**

Naomi Naierman, M.P.A.

professional background includes:

American Hospice Foundation

President & CEO

Partnership for Caring

Board of Directors (2002)

Associated with the following events (most of which are on the timeline):

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**

Attended taping (see Grant Results)

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

Project Meetings and Other Assistance

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

Advisory Council

underwriting provided in part by:

\$269,118 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: American Hospice Foundation **\$269,118**

Janet E. Neigh

professional background includes:

Hospice Association of America

Executive Director

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Judith Eve Nelson, M.D., J.D.

professional background includes:

Mount Sinai School of Medicine

Associate Professor of Medicine

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

Faculty Scholar, 1999-2001

Associated with the following events (most of which are on the timeline):

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

Advisory Council

underwriting provided in part by:

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

to: Mount Sinai School of Medicine **\$60,000**

\$105,845 from **National Institutes of Health - National Institute on Aging (NIA)**

to: Mount Sinai School of Medicine **\$105,845**

Karen Nichols

professional background includes:

Valley Hospice, Inc.
CEO

Associated with the following events (most of which are on the timeline):

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

Tony O'Brien, M.D.

professional background includes:

Council of Europe - Comm. of Experts on the Organizn. Of Palliative Care
Chairman
Marymount Hospice, Cork., Ireland
National Advisory Committee on Palliative Care Services (Ireland)
Chairman

Associated with the following events (most of which are on the timeline):

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

Joseph F. O'Neill, M.D., MPH

professional background includes:

Johns Hopkins
Part-time faculty (2004)
Promoting Excellence in End-of-Life Care (see Missoula Demonstration Proj.)
Board
White House Office of AIDS Policy
Director (2002)

Associated with the following events (most of which are on the timeline):

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

Judith A. Paice, PhD, RN, FAAN

professional background includes:

Northwestern University
Research Professor of Medicine, Oncology/Hematology (Chicago campus)

Associated with the following events (most of which are on the timeline):

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

Judy Passerini, CNHA

professional background includes:

Catholic Health Care Services, Archdiocese of Philadelphia
Deputy Secretary

Associated with the following events (most of which are on the timeline):

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

Richard Payne, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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.**

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

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

underwriting provided in part by:

\$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

professional background includes:

Last Acts

Partnership for Caring

Deputy Director (beginning 2002 -- per Form 990)

Rallying Points

Deputy Director

Associated with the following events (most of which are on the timeline):

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"**

Russell K. Portenoy, M.D.

professional background includes:

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

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

Associated with the following events (most of which are on the timeline):

- 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

underwriting provided in part by:

\$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

Christina M. Puchalski, M.D.

professional background includes:

George Washington University

Director

Last Acts

Co-Convener, Spirituality & Bereavement Committee

Associated with the following events (most of which are on the timeline):

- 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..."

underwriting provided in part by:

\$72,982 from **Robert Wood Johnson Foundation**
to: George Washington University

\$72,982

Gloria C. Ramsey, R.N., B.S.N., J.D.

professional background includes:

American Nurses Association
1996-2001 Code of Ethics Project Task Force
American Society of Bioethics and Humanities (ASBH)
Nurse Affinity Group
National Resource Center on Diversity in EOLC (RWJF)
Advisory Panel
New York University
Adjunct Assistant Professor
Director, Legal and Ethical Aspects of Practice, New York University
Robert Wood Johnson Foundation
Grantee

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$190,000 from **Fan Fox and Leslie R. Samuels Foundation**
to: New York University

\$190,000

professional background includes:

American Nurses Association
1996-2001 Code of Ethics Project Task Force
American Society of Bioethics and Humanities (ASBH)
Nurse Affinity Group
National Resource Center on Diversity in EOLC (RWJF)
Advisory Panel
New York University
Adjunct Assistant Professor
Director, Legal and Ethical Aspects of Practice, New York University
Robert Wood Johnson Foundation
Grantee

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$190,000 from **Fan Fox and Leslie R. Samuels Foundation**
to: New York University

\$190,000

Mary Raymer, M.S.W.

professional background includes:

National Association of Social Workers
NASW representative at NHPCO 2003 (with Donna Reese)
National Hospice and Palliative Care Organization (NHPCO)
Past Chair, Social Work Section
Open Society Institute / Project on Death in America (Soros Foundation)
PDIA Social Work Leader

Associated with the following events (most of which are on the timeline):

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**
Speaker

underwriting provided in part by:

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

Anne Rhome, M.P.H., R.N.

professional background includes:

American Association of Colleges of Nursing (AACN)
Deputy Executive Director
Last Acts
Co-Conveners

Associated with the following events (most of which are on the timeline):

- 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.**
Advisory Council

underwriting provided in part by:

\$1,049,824 from **Robert Wood Johnson Foundation**

to: American Association of Colleges of Nursing (AACN)

\$1,049,824

Paula Trahan Rieger, RN, MSN, AOCN, CS, FAAN

professional background includes:

American Society of Clinical Oncology
Director of International Affairs
Oncology Nursing Society
Past President

Associated with the following events (most of which are on the timeline):

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

Paul Rousseau, M.D.

professional background includes:

Arizona College of Osteopathic Medicine
Professor, Division of Clinical Education
Veterans Administration Medical Center - Phoenix, AZ
Assoc. Chief of Staff, Geriatrics & Extended Care;
Director, Palliative Care

Associated with the following events (most of which are on the timeline):

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

Cynda Hylton Rushton, D.N.Sc., R.N.

professional background includes:

Catholic University
Johns Hopkins
Kornfeld / PDIA (Soros) collaborative
Kornfeld Fellow in end-of-life, ethics and palliative care
Medical University of South Carolina
Alumna
Open Society Institute / Project on Death in America (Soros Foundation)
principle investigator of a "Nursing Leadership Consortium on End of Life Care" and "A National Nursing Academy on End-of-Life Care"

Associated with the following events (most of which are on the timeline):

- 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
- 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
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council
- 2002 **Last Acts releases "Precepts of Palliative Care for Children, Adolescents, and Their Families"**

underwriting provided in part by:

\$594,163 from **Open Society Institute / Project on Death in America (Soros Foundation)**

to: Johns Hopkins

\$594,163

from **Kornfeld / PDIA (Soros) collaborative**

to: Johns Hopkins

True Ryndes, ANP, MPH

professional background includes:

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)

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

Associated with the following events (most of which are on the timeline):

- 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..."**

M. Colleen Scanlon, J.D., R.N., MS

professional background includes:

American Nurses Association

Director for Ethics and Human Rights (circa 1996)

Catholic Health Initiatives

Vice President, Advocacy

Last Acts

Convener

Associated with the following events (most of which are on the timeline):

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

Sherry R. Schachter, Ph.D.

professional background includes:

Memorial Sloan Kettering

*Asst. Attending Grief Therapist
Pain & Palliative Care Service
Psychiatry Service*

Associated with the following events (most of which are on the timeline):

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

J. Donald Schumacher, Psy.D.

professional background includes:

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)

Associated with the following events (most of which are on the timeline):

- 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.

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$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

David A. Simpson, MA, LSW

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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

Julia A. M. Smith, MSN, ANP-BC, AOCN

professional background includes:

Yale University School of Nursing

Associated with the following events (most of which are on the timeline):

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

Thomas J. Smith, M.D., FACP

professional background includes:

Last Acts
Task Force on Institutional Innovation / Hospital Committee

Massey Cancer Center

Open Society Institute / Project on Death in America (Soros Foundation)
Faculty Scholar, 1995-96

Virginia Commonwealth University
Chair, Division of Hematology/Oncology

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

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

Rev. Walter J. Smith, S.J., Ph.D.

professional background includes:

HealthCare Chaplaincy
President

National Association of Catholic Chaplains (NACC)
Treasurer

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$150,000	from Open Society Institute / Project on Death in America (Soros Foundation)	
	to: HealthCare Chaplaincy	\$150,000

Lois Snyder, J.D.

professional background includes:

American College of Physicians - ACPS-ASIM
Counsel for Ethics and Legal Affairs for ACP

Associated with the following events (most of which are on the timeline):

1996 **Last Acts' first national leadership conference: "Care and**

Harvard Medical School - Center for Palliative Care
Faculty
University of Pennsylvania School of Medicine
Faculty

Caring at the End of Life." Brought together 140 leaders;
produced "challenges" (objectives) and "opportunities"
(tactics)

Conference Attendees

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

Co-Principal Investigator

2000 **Role of Guidelines in the Practice of Physician-Assisted Suicide - Annals of Int. Med; Assisted Suicide Consensus Panel**

Co-Authors

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

Advisory Council

underwriting provided in part by:

\$25,000 from **Greenwall Foundation**

to: American College of Physicians - ACPS-ASIM

\$25,000

Daniel P. Sulmasy, O.F.M., M.D., Ph.D.

professional background includes:

New York Medical College - Bioethics Institute

Director (2004)

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

1996-97 Faculty Scholar

Physicians for a National Health Program

Signer

St. John's University (Queens, NY)

2003-2004, Paul J. McKeever Chair of Moral Theology

St. Vincent's Hospital and Medical Center

Sisters of Charity Chair in Ethics

Associated with the following events (most of which are on the timeline):

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

Acknowledgments

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

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**

underwriting provided in part by:

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

to: Georgetown University

\$140,000

\$162,000 from **Fan Fox and Leslie R. Samuels Foundation**

to: St. Vincent's Hospital and Medical Center

\$162,000

Lizabeth H. Sumner, R.N., B.S.N.

professional background includes:

San Diego Hospice

Ex. Dir., Children's Program

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Lorraine Tarnove

professional background includes:

American Medical Directors Association

Executive Director

Associated with the following events (most of which are on the timeline):

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

Advisory Council

Joan M. Teno, M.D.

professional background includes:

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

Associated with the following events (most of which are on the timeline):

- 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"

underwriting provided in part by:

\$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

Virginia Tilden, R.N., D.N.Sc., FAAN

professional background includes:

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

Grant recipient with Susan Tolle, 1999

Associated with the following events (most of which are on the timeline):

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

Daniel Tobin, M.D.

professional background includes:

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
Veterans Administration - Hospice and Palliative Care (VAHPC)
founder
Veterans Administration Healthcare Network, Upstate NY

Associated with the following events (most of which are on the timeline):

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"**

underwriting provided in part by:

\$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

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

professional background includes:

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

Associated with the following events (most of which are on the timeline):

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

professional background includes:

Associated with the following events (most of which are on the timeline):

1996

American Board of Hospice and Palliative Medicine
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

- 1990 **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"

underwriting provided in part by:

\$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 to: San Diego Hospice	\$247,011 \$297,111
\$150,000	from Kornfeld / PDIA (Soros) collaborative to: San Diego Hospice	\$150,000

Jamie Von Roenn, M.D.

professional background includes:

Northwestern University
Professor; Division of Hematology/Oncology

Associated with the following events (most of which are on the timeline):

- 1997 **Research Workshop "Symptoms in Terminal Illness" (NIH responds to SUPPORT)**
Participants
- 2001 **National Consensus Project -- national palliative care guidelines.**
Advisory Council

underwriting provided in part by:

\$236,984	from National Institutes of Health - National Cancer Institute (NCI) to: Northwestern University	\$236,984
\$300,000	from Kornfeld / PDIA (Soros) collaborative to: Northwestern University	\$300,000

T. Declan Walsh, MSc, FACP, FRCP (Edin)

professional background includes:

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

Director at Large

Cleveland Clinic

Director and Chair, The Harry B. Horvitz Center for Palliative Medicine

Ohio State University

Professor of Internal Medicine

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

1979-1984

Associated with the following events (most of which are on the timeline):

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

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

Joan C. Warden-Saunders, RNC, BSN, CDONA

professional background includes:

NADONA/LTC

Founder & Executive Director

Associated with the following events (most of which are on the timeline):

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

David E. Weissman, M.D.

professional background includes:

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

Medical Education Task Force (2001)

American Board of Hospice and Palliative Medicine

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

Associated with the following events (most of which are on the timeline):

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

underwriting provided in part by:

\$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

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

professional background includes:

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

Board of Directors

Associated with the following events (most of which are on the timeline):

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

Last Acts

*Task Force on Institutional Innovation / Hospice
Committee*

VITAS Healthcare Corp.

Executive Vice President
