### 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.
- 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

### 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.

### 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.

**Underwriting provided in part by:**

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

**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)
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

$278,000 from Greenwall Foundation to University of Pittsburgh

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](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
  - to: Massachusetts General Hospital
  - $1,897,873
  - $886,020
- **$50,000** from Open Society Institute / Project on Death in America (Soros Foundation)
  - to: Massachusetts General Hospital
  - $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)

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:

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

$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:
**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](http://www.mywhatever.com/cifwriter/content/18/dw57.html)
- National Hospice and Palliative Care Organization (NHPCO)
- 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](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
- $176,921 from National Institutes of Health - National Cancer Institute (NCI) to Memorial Sloan Kettering
- $984,846 from National Institutes of Health - National Institute of Mental Health (NIMH) to Memorial Sloan Kettering
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

Mickey 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)
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.lifes­end.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
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"


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

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.

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"
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
  Co-coordinators
- 2002 PDIA/Last Acts Social Work Summit at Duke University (North Carolina)

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

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
Virginia Commonwealth University
Director of Nursing Services

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 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...
### 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 NHPCCO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPCCO can support. NHPCCO 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


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, PJC, 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"

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**Underwriting provided in part by:**

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

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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
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)

CAPCManual

2001 CAPCManual is launched

2001 National Consensus Project -- national palliative care guidelines.

Advisory Council

underwriting provided in part by:

$86,400 from Robert Wood Johnson Foundation
to: San Diego Hospice

$86,400 from Open Society Institute / Project on Death in America (Soros Foundation)
to: San Diego Hospice

Marilyn J. Field, Ph.D.

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:

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<td>$25,000</td>
<td>Commonwealth Fund</td>
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</tbody>
</table>

John Finn, M.D.

Professional background includes:

- Academy of Hospice Physicians
  - American Academy of Hospice & Palliative Medicine
    - 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 Speaker
- 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" endorced the statement

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

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

1998 Doctors, Death, and Dignity - Chautauqua

1999 Pain Relief Promotion Act of 1999 (HR 2260; S 1272) opposed the bill


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

2001 National Consensus Project -- national palliative care guidelines.

2001 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.

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

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 Gutgsell, 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-trainer 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

Tuesday, June 21, 2005
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](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

---

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

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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
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

$94,977 from Open Society Institute / Project on Death in America (Soros Foundation)
to: Choice in Dying -- see "Partnership for Caring"

$260,000 from Nathan Cummings Foundation, Inc.
to: Choice in Dying -- see "Partnership for Caring"
**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:**

- **National Institutes of Health - National Institute on Aging (NIA)**
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<tr>
<td>Mary J. Labyak, MSSW, LCSW</td>
<td>Hospice of the Florida Suncoast, President &amp; Executive Director, 1983 - present</td>
<td>1999 Florida Panel for the Study of End of Life Care produces its report, leading to change in advance directive laws and regulations</td>
<td>Open Society Institute / Project on Death in America (Soros Foundation) from $125,000 to Johns Hopkins $125,000</td>
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<td>Last Acts</td>
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<td>National Hospice and Palliative Care Organization (NHPCO)</td>
<td>2001 National Consensus Project -- national palliative care guidelines.</td>
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<td>Board (on of several National Directors; Treasurer, 2005; serves on “insurance board”)</td>
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<td>National Hospice Work Group</td>
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<td>Partnership for Caring</td>
<td>2003 Rallying Points National convention; Boston</td>
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<td>Project GRACE</td>
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<td>Board Member</td>
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<td>Deborah A. Lafond, M.S., RNCS, PNP</td>
<td>Association of Pediatric Oncology Nurses</td>
<td>2001 National Consensus Project -- national palliative care guidelines.</td>
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<td>Children's National Medical Center</td>
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<td>Advanced Practice Clinician, Hematology/Oncology</td>
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<tr>
<td>Judy Lentz, RN, MSN, OCN, NHA</td>
<td>Hospice and Palliative Nurses Association (HPNA)</td>
<td>2001 National Consensus Project -- national palliative care guidelines.</td>
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<td>Ex Officio (prior to 2004: Executive Director)</td>
<td>NCP Steering Committee</td>
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<td>Matthew Loscalzo, M.S.W.</td>
<td>American Psychosocial Oncology Society (APOS)</td>
<td>1997 Publication of &quot;Approaching Death: Improving care at the end of life&quot; by IOM’s Committee on Care at the End of Life</td>
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<td>Eastern Virginia Medical School</td>
<td>2001 National Consensus Project -- national palliative care guidelines.</td>
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<td>Research Associate</td>
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<td>Johns Hopkins, Department of Oncology Social Work</td>
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<td>Director of Patient and Family Services</td>
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<td>Task Force on Institutional Innovation / Hospital Committee</td>
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<td>Gail Lovinger</td>
<td>American Hospital Association</td>
<td>2001 National Consensus Project -- national palliative care guidelines.</td>
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<td>Vice President, Association Governance</td>
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<td>American Hospital Association - HRET Washington DC</td>
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</tbody>
</table>
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)


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
"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

Co-Authors

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."

2001 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..."
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.
  - Conference on Measuring Care at the End of Life
1997 Publication of "Approaching Death: Improving care at the end of life" by IOM's Committee on Care at the End of Life
  - National Consensus Project -- national palliative care guidelines.
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..."
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):

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"
  endorses 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


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
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</table>

**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 NHPPO Research Conclave: "One of the primary purposes of the conclave was to identify priorities for research funding that NHPPO can support. NHPPO 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

**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):**
  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..."

---

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

---

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 Scho | $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.
  - Attended taping (see Grant Results)
- 1997 "Before I Die" on PBS with Tim Russert -- RWJF begins media campaign to build grass roots reaction to SUPPORT study
- 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

| 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 |

**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 Organiz. 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.
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):

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
- $241,224 from Open Society Institute / Project on Death in America (Soros Foundation) to North General Hospital
- $150,000 from Kornfeld / PDIA (Soros) collaborative to Memorial Sloan Kettering

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"
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 CAPC Manual
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)
  CAPC Manual
2000 Soros's Project on Death in America announces second round of grants for their $2 million Social Work Leaders Program -- $419,400.
2001 CAPC Manual is launched
  Article
2001 National Consensus Project -- national palliative care guidelines.
  NCP Steering Committee

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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)
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…"

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"

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
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

$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 Studies

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)
  - Convener

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
- 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
  - Founding member
  - Partnership for Caring
    - Board of Directors; Director of Public Policy (2003)
  - National Consensus Project - national palliative care guidelines.
    - NCP Steering Committee
- National Hospice Work Group
  - Founding member
  - Open Society Institute / Project on Death in America
    - Faculty Scholar, 1998-2000

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

**professional background includes:**
- Bronx Veterans Administration Medical Center
  - Faculty
- Journal of Palliative Medicine
- 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):**
- 2000 National Hospice Work Group launches project: Increasing Access to Hospice
  - Task Force Members
  - 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, P&C, RWJF)
  - Speakers
- 2003 2003 Annual Conference of Carolinas Hospice
  - Keynote Address: Hospice is changing at a very fast pace in this country.
### 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

**Underwriting Provided in Part by:**
- $50,000 from Open Society Institute / Project on Death in America (Soros Foundation)
  - to: Virginia Commonwealth University

**Associated with the Following Events (Most of Which Are on the Timeline):**
- 2001 National Consensus Project -- National Palliative Care Guidelines.
  - Advisory Council

### 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

**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 Finding Common Ground: Assisted Suicide Consensus Panel is convened
Co-Principal Investigator

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

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: Tulsky, 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

$162,000 from Fan Fox and Leslie R. Samuels Foundation
to: St. Vincent's Hospital and Medical Center

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

1996 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:

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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
- 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
  - 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"

---

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.
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

1970
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)
CAPCManual

2001
CAPCManual 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:

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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:

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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
   - 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