

Project on Death In America Grants

Arts and Humanities

Continuing Support Services, Inc.

Two musical traveling puppet shows for children, addressing the grief associated with loss of a loved one and AIDS/HIV, titled "Good Grief, It's Sky Blue Pink" and "Birds of a Feather...Learn about HIV/AIDS Together." A workshop is given in conjunction with the shows that provides children the opportunity to discuss disease, death, and grief with their teachers, counselors, and fellow students.

\$25,000 | One Year |

Ellen Bromberg and Douglas Rosenberg

The video documentary *Singing Myself a Lullaby* will chronicle the creation and performance of a multimedia performance work by John Henry, a dancer with AIDS. An investigation of identity, *Lullaby* presents vignettes from John's life along with more universal movement rituals. The film is grounded in the belief that the creative process and metaphor can facilitate understanding and acceptance of the dying process.

Tucson, Arizona | \$47,401 |

Thomas Cole

Anatomy & Humanity: Conversations with Donors and Dissectors, a film that explores the relationship between willed body donors and medical student dissectors. In moving interviews, donors share their life stories, explain their decision to donate their bodies, and express their hopes for future learning. Medical students describe the emotional, moral, and spiritual struggles that accompany this sanctioned violation of the interior space of another's body.

Galveston, TX | \$50,000 |

Sandra Gilbert

To write *The Fate of the Elegy: History, Memory, and the Mythology of Modern Death*, which will examine the cultural forces that shape what Wallace Stevens called "the mythology of modern death" with particular emphasis on the ways in which poets have responded to "modern death" and modern modes of mourning.

Berkeley, CA | \$50,000 |

Richard Kamler

To create *The Waiting Room*, an interactive art installation, built to the exact specifications of the death row visiting room at San Quentin Prison in California. The aim is to initiate through the evocative power of art a wide-ranging conversation into the various ways that the death penalty contributes to our collective cultural perceptions of death and dying.

San Francisco, CA | \$49,700 |

Ed Kashi and Julie Winokur

To create *Aging in America*, a compilation of photographs and essays exploring the unprecedented strains that have followed in the aftermath of the longevity revolution. The book examines innovative solutions being pioneered to deal with the end stages of life.

San Francisco, CA | \$50,000 | <http://www.edkashi.com/>

Meryl Levin

To create *Anatomy of Anatomy*, a book and traveling exhibition, which combines photographs of a group of medical students during their dissection of cadavers in gross anatomy class with excerpts from journals they kept during the course.

New York, NY | \$37,350 | <http://www.thirdrailpress.org/>

Nancy Mairs

To write *Life's Worth: Rethinking How We Live and Die*, a book of essays, shaped and informed by theology, disability studies, and feminist theory. It includes writings about children and death; physician-assisted suicide; ministering to the dying; blessings; the iconography of death and dying; images of afterlife; and eschatological meditations.

Tucson, AZ | \$50,000 |

Meredith Monk

For a series of conversations on death and dying that will become part of the touring component of *Magic Frequencies*, an interdisciplinary performance work that examines the realms of life and death through visitations of beings from other realms. It also deals with the idea of several different realities existing simultaneously.

New York, NY | \$50,000 |

Eugene Richards

To help support two films now in production: *Long as I Remember* and *All That's Sacred*. *Long as I Remember* will take the viewer inside Good Samaritan, the same nursing home the aged farmer in Richards' earlier film ([but, the day came](#)) wished with all his heart to avoid. The film will document the lives of the residents there, touching at first on the events and decision-making that preceded their placement.

All That's Sacred was inspired by the death last year of Richards' father-in-law. It will be a study of the effect of one person's death on the fabric of a whole community.

Brooklyn, NY | \$50,000 |

Eugene Richards

To create the film *but, the day came*, which details the complex lives of the "oldest old" (people 80 to over 100) in the town of Auburn, Nebraska. Central to the story are an 84-year-old still-practicing physician, a 92-year-old farmer fighting to keep out of a nursing home, and the rolling, mythic eastern Nebraska landscape. Richards's hope is to elucidate and personalize "aging," a term often derided and spurned by our youth-focused society.

New York, NY | \$50,000 |

Deidre Scherer

To create a work entitled *Surrounded by Family and Friends*. Working in the unusual medium of fabric-and-thread panels, Scherer evokes how families and friends, in offering support to the dying, behold the most powerful of life's events. *Surrounded by Family and Friends* will consist of six life-sized, fabric-and-thread panels portraying the richness and complexity of our relationships at the end of life.

Williamsville, VT | \$50,000 |

Lisa Schnell

To write *Learning How to Tell*, a book that deals with the brief life and death of Lisa Schnell's youngest daughter, Claire Margaret. Claire, who suffered from a rare and devastating birth defect called lissencephaly, introduced Schnell to a world of tremendous suffering that initially produced in her a sense of exile from her own life story. This book is Schnell's story of her intellectual and spiritual journey back to a life of immeasurable loss and immeasurable love.

Burlington, VT | \$50,000 |

Alan Shapiro

To write *The Dead Alive and Busy*, a book of poems dealing with contemporary experiences of sickness, love, and loss, referring continually to the mythic and literary worlds of cultures in which death was once viewed as an intimate part of daily life. The poems explore the complicated feelings we experience—horror, relief, impatience, exhaustion, exhilaration, projection, fear, self-criticism, and a sense of fulfillment—in the presence of the dying.

Chapel Hill, NC | \$50,000 |

David Slavitt

To translate the *Book of Lamentations*. Loss and grief used to be acknowledged and institutionalized in our religious and cultural life as an inevitable part of human experience. One of the most important texts for the communication of these dark but vital truths is the *Book of Lamentations*. This new translation, which places the biblical text in a social and historical context, helps the general reader find useful connections to one's personal encounters with grief.

Philadelphia, PA | \$50,000 |

Bastienne Schmidt and Philippe Cheng

To explore and document through photography and video the evolving culture of death in America; how we emotionally, spiritually, and practically experience mourning, grief, and loss; and how our social and cultural environments impact and shape these responses. The project will not only explore the traditional rituals surrounding the process of dying, death, and mourning, but also the emerging cultural and social rituals in response to more recent trends in dying, for example how diverse segments of the population have to deal with many premature deaths due to AIDS or inner-city violence.

\$60,000 | Two Years |

Tony Howarth

To explore the dying process through a play about the experience of an elderly man whose living is complicated by the chaos of dementia.

\$10,000 | Two Years |

National Hospice Foundation

To support the art exhibit *Hospice: A Photographic Inquiry*, originating at the Corcoran Gallery of Art in Washington, DC, and touring venues throughout the United States during the year 2000. Five internationally recognized photographers were commissioned to create important new works on the physical, emotional, and spiritual experience of receiving and providing hospice care around the United States.

\$100,000 | Two Years |

Community Support for Grief & Bereavement

William Wendt Center for Loss and Healing

The William Wendt Center for Loss and Healing (formerly the St. Francis Center for Illness, Loss and Grief) will provide immediate and ongoing support for families who survive the sudden or traumatic death of a loved one by working collaboratively with the District of Columbia Office of the Chief Medical Examiner. This program will provide professional grief counseling services supplemented by practical and emotional support provided through a cadre of trained, supervised, faith-based volunteers.

Robert Washington, project coordinator

Washington, DC | \$75,000 |

American Hospice Foundation

To design and pilot test a model for a school-based grief program in 14 schools in Phoenix, Arizona, and to then replicate the model in Oklahoma City and Washington, D.C. The model will include training workshops for school personnel, after-school support programs for grieving students, and comprehensive curricula focusing on age-appropriate grief concepts.

Naomi Naierman, project coordinator

Washington, DC | \$52,876 |

Balm of Gilead, Cooper Green Hospital

The Balm of Gilead program, the palliative care initiative of the Cooper Green Hospital, will identify the needs of the bereaved in a low-income population, develop collaborations and/or new resources to address the identified needs, and evaluate the effectiveness of various bereavement response strategies.

F. Amos Bailey, project coordinator

Birmingham, AL | \$65,835 |

Baptist Health Systems of South Florida

The population of South Miami-Dade largely comprises new immigrants from multiracial and multicultural backgrounds, who have been culturally and socially uprooted. Consequently, the experience of death and grief can be very complicated, especially if an individual is isolated from the traditional cultural and social support systems of the homeland. The Congregational Health Alliance Ministry Program (CHAMP), a faith-health partnership between Baptist Health Systems of South Florida and area congregations of all faiths, will establish a network of bereavement support groups, led by volunteer facilitators and located in faith-based communities. The volunteer facilitators of the bereavement support groups will be trained in an interactive, culturally sensitive program, led by professional grief counselors and educators.

Dale Young, project coordinator

Miami, FL | \$74,870 |

Boston University School of Medicine

Located in Boston's South End, the Department of Pediatrics and its affiliated teaching hospital serve a predominantly minority constituency made up of primarily the city's underclass, working poor, and lower-middle class. The children living in this urban area are exposed to a disproportionately higher number of deaths than their peers in surrounding suburbs and are vulnerable to the pervasive stresses associated with poverty and their minority status. The CIRCLE will make available grief support for these children and their families, through peer support groups, trained volunteers, community outreach, and clinical counseling services within individual neighborhoods of the city.

Marie Trozzi, project coordinator

Boston, MA | \$75,000 |

Harbor Hospital Center, Psychiatry Services—Safe Harbor Counseling

Maryland is fortunate to have a group of 150 highly committed, primarily volunteer, parish nurses who provide screening, education, and direct delivery of health-care services to members of their church or faith community. The parish nurses' experience in addressing people's physical and spiritual needs make this group well suited to the task of providing bereavement support. This project will fund ongoing clinical support and a series of learning opportunities to allow them to expand their mission and skills to include grief counseling. The nurses' involvement at the grassroots level allows them to effectively organize other volunteers to reach out to their fellows in times of loss.

Howard Reznick, project coordinator

Baltimore, MD | \$57,000 |

Service Employees International Union, Local 434B

There are more than 74,000 ethnically diverse members of the union of homecare workers of Los Angeles County who are represented by Local 434B of the Service Employees International Union (SEIU). These workers assist tens of thousands of low-income elderly, disabled, and terminally ill persons who are able to live out their lives in their own homes thanks to this assistance. This project will help homecare workers address the grief and bereavement difficulties they regularly experience in their work and improve the quality of care provided to their dying clients.

Tyrone Freeman, project coordinator

Los Angeles, CA | \$75,000 |

St. Mary's/Duluth Clinic Health System's Grief Support Center

To establish a model utilizing a hospital-based community grief and bereavement program working collaboratively with local, regional, and state agencies and organizations to educate over 2,500 professionals on the topic of grief and bereavement. As a result of the program, these professionals will be instrumental in starting or improving end-of-life and bereavement support groups, or in developing and collaborating on educational programs within their own health-care settings, religious community, or organizational community.

Ben Wolfe, project coordinator

Duluth, MN | \$69,500 |

University of Hawaii

Sponsored collaboratively by the University of Hawaii Center on Aging at the School of Public Health and the Hawaiian Islands Hospice Organization, this project will offer a four-part curriculum to congregations and other volunteer caregiver groups to strengthen their ability to support bereaved parishioners and families. The curriculum will address the clinical, legal, spiritual, and interpersonal issues grieving individuals contend with and ensure that their quality of care will be culturally competent and spiritually sensitive.

Katheryn L. Braun, project coordinator

Honolulu, HI | \$75,000 |

University of South Carolina

The Center for Child and Family Studies of the University of South Carolina will partner with interfaith community-based groups such as the South Carolina Coalition of Black Church leaders, the Christian Action Council, and the Palmetto Faith and Health Consortium to develop and design an interfaith, interdisciplinary, culturally respectful information resource center and to train volunteers of various faith communities to enhance their ability to help others deal with death and bereavement issues.

Lois Wright, project coordinator

Columbia, SC | \$74,811 |

Virginia Mason Medical Center

Violence and violent deaths are all too common experiences for many of today's incarcerated youth. This project will focus on providing incarcerated adolescents with a short-term educational program to diminish the pervasive and dysfunctional effects violent death has had on these youngsters. Learning healthier responses to violent dying will allow these young people to return to their communities and serve as healthy and productive role models.

Edward K. Rynearson, project coordinator

Seattle, WA | \$75,000 |

Grants Program 1994 - 1997

City of Hope National Medical Center

Betty R. Ferrell, Ph. D., FAAN, Associate Research Scientist

A pilot demonstration to improve the quality of care for patients and families in non-hospice home care agencies through design, implementation, and evaluation of a model education program. This educational project will develop and evaluate a model education program which can be disseminated widely through home care agencies to improve care for terminally ill patients and families. Over two years, a curriculum will be developed and testing in 5 home care agencies representing various models of home care delivery and providing care to culturally diverse populations.

\$76,650 | One Year |

The Missoula Demonstration Project

Ira R. Byock, MD, project coordinator

A long-term, community-based organization which came together to study and transform the culture and experience of dying. Research will be done to define the attitudes, expectations, and experiences related to death and dying in Missoula County, Montana. The results will provide the platform for future interventions and research in the next 15 years focused on bringing quality

to life's end.

\$50,000 |

American Medical Association

Mark Wolfe, Public Information Officer

The Coalition for Quality End-of-Life Care is developing a national symposium to be held on April 17, 1997, for health and medical reporters and other interested media representatives. Without ignoring the fact that physician-assisted suicide has become the subject of considerable judicial, legislative, and media attention, the goal is to help focus the public debate on the appropriate balance sought by caregivers and patients in meeting the needs of patients at the end of life and the role of health care professionals.

\$80,000 | One Year |

Medicare Rights Center

Diane Archer, Executive Director

Lack of information about financing options for end-of-life care is a substantial barrier to quality care at the end of life. This initiative will educate consumers, their families, caregivers, professional counselors, and clinicians about Medicare hospice and home healthcare benefits for the terminally ill in both the fee-for-service and HMO settings. The initiative will include an aggressive public-relations campaign and consumer guide.

\$150,000 | One Year |

United States Cancer Pain Relief Committee, Inc.

Russell K. Portenoy, M.D., project coordinator

Co-sponsored by The National Institutes on Health (U.S.), and the United States Cancer Pain Relief Committee, this conference, to be presented March 12–14, 1998, will provide an open forum for exchange of new research findings and methods of investigation relevant to palliative care. Prior to the conference's commencement, current information pertaining to research methodologies relevant in symptom control and palliative care will be collated and critiqued; a monograph will be created that defines the current state of affairs; and an agenda for future research will be decided. The abstracts will be published in the *Journal of Pain and Symptom Management*.

\$50,000 | One Year |

KPFA Radio/Pacifica Foundation

Susan G. Stone, project coordinator

Public broadcaster KPFA Radio will produce, market, and distribute nationwide a five-part multicultural radio series on death and bereavement. The series will address the varied cultural traditions in the United States of experiencing, mourning, and commemorating death.

\$40,000 | One Year |

Hospice of Midcoast Maine: Coalition for Dialogue on Death and Dying

John A. Norton, project coordinator

To create a coalition of community organizations in the region to improve the culture of dying; to deliver services more effectively to dying persons and their families during the period of illness and bereavement; and to serve as a catalyst for systemic change by bringing to the table hospitals and other providers of medical care, insurance companies, and major employers in the region.

\$45,000 | One Year |

Hospice Foundation of America

Jack D. Gordon, project coordinator

The video teleconference series is a resource for the public, health-care professionals, and social workers. This year's teleconference will deal with the subject of the grief felt by both the dying and their caregivers when faced with a terminal, progressive illness such as cancer or AIDS. "Living with Grief: When Illness is Prolonged" will air on April 17, 1997. Over the years, HFA has developed tremendous resources on grief and bereavement. "Living with Grief: After Sudden Loss," the 1996 video teleconference, focused on the grief faced by survivors after losing a loved one, colleague or community member to sudden and traumatic death. A resource book has been developed in conjunction with each teleconference and videos of both are also available.

\$50,000 |

National Prison Hospice Association

Florence S. Wald, MN, MS, FAAN, project coordinator
Co-funded with the Center on Crime, Community and Culture (\$18,000)

The aim of this study is to assess the need for adapting hospice care services for terminally ill patients under prison custody in the Connecticut State Department of Correction. Six prison infirmaries serving the state's 23 correctional facilities will undergo an evaluation of the health management practices, support services, and ancillary programs that provide terminal care for dying inmates.

\$18,000 | One Year |

Royal Victoria Hospital

Balfour Mount, M.D., project coordinator

A one-day seminar entitled "Searching for the 'Soul' of Euthanasia." The seminar will be held on September 11, 1996, in conjunction with the 11th International Congress on Care of the Terminally Ill. The seminar will seek to identify some of the characteristics that lie at the heart of prohibiting or permitting euthanasia and to clarify the implications of the current debate for the future.

\$12,000 |

Institute for the Study of Health and Illness

Rachel Naomi Remen, MD, project coordinator

"The Curriculum on Detoxifying Death for Physicians" is a multi-modal, continuing medical education curriculum that integrates cognitive, behavioral, psychological, and valuational approaches. The curriculum is aimed at physicians who care for patients living with a terminal illness. Goals include providing physicians with a different approach to caring for their patients as well as strategies for themselves for preventing burnout and for maintaining personal growth.

\$80,000 |

American Society on Aging

Gloria Cavanaugh, project coordinator

A special "In Focus" pull-out section of the January/February 1996 issue of *Aging Today* devoted to death and dying. The articles examine prevailing myths and fears of death, the role of medical care and hospice, the economics of death, key public policy issues, spiritual concerns, and legal and ethical issues faced when making end-of-life decisions.

\$6,000 | One Year |

Harlem Interfaith Counseling Service, Inc.

Doris W. Dennard, A.C.S.W., D.C.S.W.

A planning grant for the development of a community-based bereavement support center to serve Central Harlem, where family members—frequently grandparents and children—mourn the loss of loved ones often due to higher than average rates of death from AIDS and violence. Harlem Interfaith Counseling Service, a family mental health clinic, will serve as the lead agency and provide consultation to the Consortium.

\$5,000 | One Year |

New York Citizens' Committee on Health Care Decisions, Inc.

Beatrice Greenbaum, project coordinator

A model Train-the-Trainer program will be developed for health-care educators to empower senior adults to advocate on their own behalf in the physician-patient relationship. American Health Decisions, the Older Women's League, and the Iderhostel Network are among the national organizations who have expressed an interest in assisting with this project.

\$100,000 | One Year |

Health Force: Women and Men Against AIDS

Chris Norwood, project coordinator

The "Dear Death Project" is a community-based effort designed to confront the meaning and consequences of the massive death rates in poor neighborhoods across the United States. As a step towards resolving chronic grief, project participants will write letters to express their own feelings or messages directly to death. An art exhibit will be created from the "Dear Death" letters and will travel to communities grappling with similar rates of death from AIDS, violence, drugs, and other causes.

\$100,000 | Two Years |

Rush University

Erich E. Brueschke, M.D., project coordinator

A two-day interdisciplinary forum/conference on end-of-life issues to contribute to the understanding of dying which will be a catalyst for national dialogue to improve the experiences of the dying. Representatives from the legal and health-care professions, religious and civic leaders, and professional ethicists will take part.

\$5,000 | One Year |

Hospice Foundation of America

Jack D. Gordon, project coordinator

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

\$75,000 | One Year |

Death with Dignity Education Center

Charlotte P. Ross, project coordinator

Consensus Development Conference to bring together key critics and proponents of physician-assisted suicide in order to identify areas of agreement and disagreement, and to reach a consensus a plan that would provide the most benefit and least harm to terminally ill patients.

Cancer Care, Inc.

Diane Blum, ACSW, project coordinator

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

\$63,675 |

Tibet House New York

Beata Tikos, Administrative Director

The Tibet House and the New York Open Center will hold a major conference entitled "The Art of Dying II" to be held in New York City on March 21–24, 1997. The conference will present a diverse group of speakers, health professionals, educators, and administrators to examine perspectives on death and dying and to share methods of care provision and preparation for death.

\$5,000 |

Barnard College

Lesley A. Sharp, Ph.D.

An anthropological investigation into the cross-cultural dimensions of death and mourning, and their specific relevance to professional versus lay attitudes in the context of organ donation and procurement in urban Manhattan.

\$16,300 | One Year |

Poynter Center for the Study of Ethics and American Institutions

David H. Smith, director

To produce "The Social Face of Death," an ethnographic study of residents of four diverse Indiana communities to better understand the meaning that ordinary people attach to death.

\$35,000 |

University of Oklahoma, Health Sciences Center

Betty Pfefferbaum, MD, JD

To examine the nature and course of traumatic bereavement in children who lost a family member in the April 19, 1995, bombing of the Alfred P. Murrah Federal Building in Oklahoma City.

\$120,000 | Two Years |

University of California, San Diego

Lawrence J. Schneiderman, MD

To measure the effects of managed care on the types and volume of care delivered to the terminally ill. The study focuses on Medicare beneficiaries for two reasons: because fee-for-service data are readily available on all Medicare decedents, and because large numbers of decedents are enrolled in Medicare. The study seeks to determine whether the medical care delivered to Medicare enrollees in HMOs is any different than the medical care delivered to their fee-for-service counterparts.

Center for Ethics in Health Care

Co-Principal Investigators: Susan Tolle, M.D. and Virginia Tilden, RN, DNSc

To compare end-of-life care in three major settings in Oregon: acute care hospitals, nursing homes, and home/hospice. Using death certificates of recently deceased adults, the investigators will access families and providers and collect data on the following key variables: 1) advance directives; 2) the extent to which deaths followed advance planning; 3) access to hospice; 4) preference for location of death vs. location of actual death; 5) degree of pain and suffering vs. effectiveness of comfort care efforts; 6) decision making about level of aggressiveness of treatment; 7) family satisfaction with care and identification of problems; 8) provider identification of barriers to compassionate care.

\$150,000 | Two Years |

Baystate Medical Center

Lewis M. Cohen, M.D.

To conduct a bioethical, psychiatric, and clinical study of the decision by patients to terminate life-sustaining kidney dialysis treatment. Approximately 100 patients with end-stage kidney disease will be observed, interviewed, and evaluated to explore their decision-making process and to examine the quality of death that ensues.

\$137,656 | Two Years |

Stanford University

Barbara A. Koenig, Ph.D.

To conduct a detailed ethnographic study of death and the dying process across the life cycle in one African-American community in California. Goals of the study are to learn why African-Americans tend not to use services such as hospice and home care, and to explain why the bioethics practices governing end-of-life care—such as the use of advance directives—have been shunned by African-Americans, who often voice preferences about terminal care that differ from whites.

\$149,986 | Two Years |

Indiana University

Gregory P. Gramelspacher, M.D.

To study the experiences of the dying poor served by a public hospital system, in order to develop recommendations for improving end-of-life care for this population. The study will consist of a series of in-depth interviews with community focus groups, dying patients, their families, and health care providers.

\$146,185 | One Year |

Upaya

Joan Halifax, Ph.D.

To create the Institute for Contemplative Work with Dying People, a center for spiritual inspiration, education, and continuing support for dying people, their families, and caregivers as well as health-care professionals, educators, and administrators.

\$50,000 |

The Universalist Meeting House of Provincetown

Reverend Jennifer Justice

To continue support for a series of community programs the church offers, including a support group for HIV+ people, HIV- people, and partners who are grieving the loss of their loved ones; an eight-week course "Living with Dying"; and a volunteer team to provide additional spiritual support to dying people.

\$25,000 |

Interfaith Neighbors, Inc.

Eileen Lyons, CSW

To support the Children's Bereavement Project (CBP), which provides school-based bereavement services including assessment, group intervention, and follow-up services to 210 early adolescents each year. CBP will conduct outreach to educate students and teachers at ten schools regarding issues of grief, and will conduct research to identify the essential design considerations and ameliorative factors of school-based bereavement services located in neighborhoods with high rates of mortality and violence. CBP will train 40 guidance and youth practitioners from other community-based organizations to conduct school-based bereavement groups.

\$150,000 | Two Years |

Mayo Clinic

Principal Investigator: Mary E. Bretscher, M.D.

A study to assess the individual components of a patient's quality of life (QOL) during the terminal phases of illness in hospice. The study will measure QOL longitudinally to gain an understanding of how QOL changes with time and the trajectory of the patient's illness. The QOL of the primary caregiver will be assessed simultaneously.

\$6,989 | One Year |

Bailey-Boushay House

Wayne C. McCormick, MD, project coordinator

A study on the management of pain, discomfort, nutrition, and the costs of care for persons with AIDS near the end of life residing at Bailey-Boushay House. It will evaluate the program in a continuous quality improvement mode, and to disseminate information about this service-delivery model through publication of results.

\$22,000 | One Year |

Wellesley College

Paul Wink, Ph.D., Assistant Professor

At a time when increasing numbers of Americans are living well into their 80s, relatively little is known about the psychological processes that influence the role of the diverse social contexts of social mobility, gender, and war participation on bereavement, resiliency, and healthy adaptation to the process of aging. Drawing upon archival data from two longitudinal studies of men and women (The Oakland Growth and Berkeley Guidance Studies)—which include an array of personality, cognitive, and health data gathered in childhood, adolescence, and at three points in adulthood—this project will investigate adaptation, influence of past and present religious beliefs and spirituality, long-term and interpersonal factors and integrity in health, old age, death and bereavement. Participants average 68–76 years of age.

\$150,000 | Two Years |

Strong Museum

G. Rollie Adams, project coordinator

Memory and Mourning: American Expressions of Grief, an exhibit originating at the Strong Museum, combines historical artifacts and documents, images, and interactive stations to examine the cultural history of grief and its expression in America since the middle of the nineteenth century. This exhibit will travel to approximately ten museums over a three-year period with support for public conferences, school lessons, and other educational programs at each of the host museums.

\$90,000 | One Year |

University of Pittsburgh Medical Center

Gary Fischer, M.D., project coordinator

Over the last ten years, medical educators have identified deficiencies in the care of the terminally ill and developed interventions to correct the problems, yet it is difficult to know if these interventions are improving physicians' interactions with dying patients. This physician-patient communication project will develop a tool for teaching and evaluation purposes. The tool will be used to assess the behavioral skills of health professionals who care for the terminally ill by using four standardized patient scenarios regarding both giving bad news and eliciting patient preferences.

\$50,000 | Two Years |

University of Washington

Paul G. Ramsey, M.D., project coordinator

Physicians have a key role in directing care and resources to dying patients. Physicians are in a position to provide support and information to patients and their families as well as facilitate a team approach. Despite increasing interest in improving end-of-life care no systematic method to assess a physician's performance in this area has been developed. The evaluation system being developed will be a reliable, valid, and comprehensive tool to evaluate physicians' care of dying patients. It will use ratings from peer physicians and nurses, as well as, ratings from patients and their primary surrogates (family or close friends) to assess the physician's skills at the end of life.

\$150,000 | Two Years |

Vermont Ethics Network

Arnold Golodetz, M.D., project coordinator

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

\$50,000 | One Year |

Alliance for Aging Research

Daniel Perry, project coordinator

To produce a study for release to the news media and policy makers which will provide reliable, up-to-date data on health-care costs during the last year of life in the very old. The study is not intended to be an original research study, but will be an analysis of the most current literature and scientific data available on the topic.

\$93,959 | One Year |

Association of Academic Health Centers

R. Knight Steel, M.D., project coordinator

To review requirements of the Residency Review Committee of internal medicine and family practice; examinations of the primary boards of internal medicine and family practice; and the subspecialties of geriatrics, oncology, and cardiology. The requirements will be reviewed to determine the extent to which these examinations and training programs are directed to care of the dying, control of pain, and advance directives.

\$35,000 | One Year |

St. Francis Center

Principal Investigator: Janice L. Krupnick, Ph.D.; Co-Principal Investigators: Bruce Sklarew, M.D. and Martha Blechar Gibbons, Ph.D.

To provide and evaluate therapy services for bereaved inner-city youth who have experienced the death of a parent, often under traumatic circumstances. The aim of this program is to further develop, evaluate, and disseminate a new service-delivery program for bereaved school-age children in low-income, inner-city public schools.

\$125,000 | Two Years |

The Park Ridge Center

Laurence J. O'Connell, Ph.D.

To develop an education program to foster the establishment of structured, supportive environments in which individuals and faith-based communities can draw upon, revitalize, and expand the spiritual and practical resources offered by their religious and cultural traditions for understanding and facing death and dying. The lay ministry program will give participants an opportunity to provide spiritual, emotional, and practical support to the dying and their families.

\$110,000 | Two Years |

The HealthCare Chaplaincy

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

To develop and offer a community education program on death, dying, and bereavement to local clergy, laypeople, volunteers in local agencies and bereaved people. Following a series of focus groups, the education programs will be designed, offered, and evaluated. The project will also promote the concept and necessity of pastoral education for clergy and laypeople on death, dying, and bereavement through planning and participating in a national forum on issues in death education and bereavement.

\$150,000 | Two Years |

The Foundation for Interfaith Research & Ministry

Ronald H. Sunderland, Ed.D., Associate Director

Using the innovative "Care Team" model, to develop community-based programs to provide coordinated grief support and grief education programs for terminally ill child, adolescent, and adult populations. The Foundation for Interfaith Research & Ministry is the recipient of the 1997 Rosalynn Carter Caregiving Award.

\$126,826 | Two Years |

In Loving Memory

Linda Nielsen, project coordinator

This all-volunteer organization hosts conferences for bereaved parents who have lost their only children or all of their children and are just beginning their journey of grief and recovery. The conferences provide a safe environment for parents (and professionals) to network and attend workshops on many subjects to help with a positive resolution of grief. Funding was provided for the August 1995 conference held, in part, in response to the Oklahoma City bombing.

\$8,800 | One Year |

St. Vincent's Services

Sister Elizabeth Mullane, project coordinator

A program to facilitate the spiritual and emotional journey of parents in the advanced stages of HIV infection. This integrated program provides group and individual counseling, pastoral and spiritual care, outings for parents and their children, and support for parents as they discuss their impending death with their children.

\$50,000 | One Year |

University of Pittsburgh Medical Center

Gary Fischer, M.D., project coordinator

This physician-patient communication project will develop a tool for teaching and evaluation purposes. The tool will be used to assess the behavioral skills of health-care professionals who care for the terminally ill by using four standardized patient scenarios regarding both giving bad news and eliciting patient preferences.

\$50,000 |

Zen Hospice Project

Frank Ostaseski, project coordinator

To initiate a broad-based experiential community, professional, and client education program. Written materials that bring a new perspective to the care of the dying and to ways of approaching death will be developed. In addition, six three-day "Cultivating Compassion" workshops will be offered. The aim of the workshop is to demystify the caregiving process, investigate our response to suffering, and clarify our intention in service.

College of Physicians & Surgeons of Columbia University

Nancy S. Wexler, Ph.D., project coordinator

The development of a protocol and curriculum for addressing the issues related to the predictive testing for Huntington's disease and other late onset disorders. Huntington's disease is the first disorder for which we have the capacity to tell individuals—when they are healthy—that they are destined to die in a particular way. Some of the questions to be addressed are: How do you help people choose whether or not to be tested? How do you help people live with the knowledge of how they will die?

\$100,000 |

Center to Improve Care of the Dying

Principal Investigator: Joan M. Teno, M.D., M.S.

Co-Principal Investigators: Bradley Owen Boekeloo, Ph.D., and Jacqueline J. Glover, Ph.D.

Advanced care planning for improved care at the end of life in managed care settings. Using focus groups, an expert panel with consumer input, and quality improvements, this project will: 1) obtain consumers' and health-care providers' preferences for content and design of advance care planning about care near the end of life; 2) assemble an expert panel to articulate practical and ethically justified guidelines for advance care planning in managed care; 3) collect benchmark data regarding advance care planning and care of dying patients in an HMO; and 4) design and pilot an intervention to facilitate communication and enhance the care of the dying.

\$119,944 | Two Years |

Education Development Center, Inc.

Mildred Z. Solomon, Ed.D., project coordinator

To educate health professionals in order to enhance the care that cancer patients receive near the end of their lives. The program will seek to improve health-care professionals' knowledge, attitudes, and practices in ethics, law, and pain management; help them to resolve conflicts between the goals and values of aggressive cancer treatment and those of palliative care; and address the impact of cultural diversity on treatment decision making.

\$149,951 | Two Years |

Mount Sinai Medical Center

Christine K. Cassel, M.D.

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

\$75,000 | One Year |

The Compassionate Friends

Karl Snepp, project coordinator

The Compassionate Friends is a mutual assistance, self-help organization aiding parents and siblings to reach positive resolution of their grief following the death of a child. Compassionate Friends will develop and implement a training program for its chapter leaders, all of whom are volunteers and bereaved parents, in the skills and knowledge essential to leading a healthy chapter and facilitating a supportive and healing environment for newly bereaved parents and siblings.

\$100,000 | One Year | <http://www.compassionatefriends.org/>

The Hospice Foundation

Claire Tehan, MA, project coordinator

One of the greatest challenges in hospice work is the importance of supporting patient and family beliefs and practices around death and dying, regardless of one's own values or the obstacles of language or cultural barriers posed in today's diverse societies. In an effort to meet this challenge in Los Angeles and Orange Counties, a hospice will be created for Japanese nationals and Japanese Americans. Accompanying the hospice development, will be an education program for hospice and health-care professionals caring for Japanese patients. Both approaches will enable health-care professionals to overcome the language and cultural barriers that too often stand between the patient and quality end-of-life care.

\$10,000 | One Year |

Johns Hopkins University

Matthew Loscalzo, MSW, project coordinator

People who die of cancer and other chronic diseases receive most of their care, during the period just prior to death, from family members who are often unprepared and unskilled in dealing with the complex and demanding tasks they face. This project will develop a program to better prepare family members for caregiving responsibilities. Family caregivers will receive problem-solving education, information on caregiving, and continuing support for their problem-solving efforts from health professionals and peers.

\$125,000 | Two Years |

St. Jude Children's Research Hospital

Principal Investigator: Pamela S. Hinds, Ph.D., R.N., C.S.; Co-Principal Investigator: Wayne L. Furman, M.D.

To identify and define the factors that children and adolescents with cancer, their parents, and their health-care providers consider when deciding to cease curative and/or life-sustaining care efforts, and to identify of health-care providers' actions that contribute to parents' coping with the death of their child. Guidelines will be developed from the research findings to help health-care professionals assist patients and parents in making individual end-of-life decisions, and to help ensure that patients' and parents' preferences are considered during the decision-making process.

\$125,000 | Two Years |

Malachi House

Daniel B. Cotter, project coordinator

Malachi House has been a pioneer in serving those who face death alone, without appropriate caregiving support, without financial means, who do not qualify for hospitalization, and cannot afford or are ineligible for nursing home care. The home has served over 375 residents to date, with over 165 active volunteers who assist a staff of sixteen.

\$25,000 | One Year |

Miriam's House - Joseph's House

Carol Marsh, project coordinator

Joseph's House extended their mission to create a new project, Miriam's House, which provides a permanent home and support for recovery of homeless women living with AIDS, some of whom have children. Miriam's House brings compassionate attention to the physical, emotional, social, and spiritual needs of each resident within the context of a loving and respectful community. Four years in the running, Miriam's House is now a home for six women and four children.

\$5,000 | One Year |

George Whitmore Foundation, Inc.

Ada Frummerman, CSW, and Suzan Anson, Ph.D., project coordinators

When hospitalized, the deaf frequently sustain long periods of social isolation. They cannot communicate with doctors and other hospital staff unless a qualified interpreter is present. Currently, there are no hospice programs actively serving the deaf community. The George Whitmore Foundation, in collaboration with the Jacob Perlow Hospice, will create a program of hospice care for the deaf at the end stage of life. In order to gain better understanding, a key component of this pilot program will be to gather data from the deaf community about their experiences with end-stage illness.

\$75,000 | One Year |

The Neurologic Institute

Principal Investigator: Lewis P. Rowland, M.D.

Co-Principal Investigators: Peregrine L. Murphy, M.Div., and Dale Lange, M.D.

A longitudinal investigation of the patterns of palliative care in patients with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, from diagnosis to death. ALS is an inexorably progressive and ultimately fatal disease. The investigation will uncover the relationship between physicians' preferences for and attitudes toward life-sustaining treatment, how patients respond to the options offered, and the medical outcome. Physicians' attitudes and practices regarding palliative treatment may determine whether or not these medical options are presented to the patient.

\$125,000 | Two Years |

The Pennsylvania State University College of Medicine

Co-Directors: David Barnard and Anna Towers, M.D.

To construct a set of case narratives in palliative care that describe the experiences of dying patients, their families, and health-care providers as they interact with each other over the course of the patient's illness and treatment by the palliative care team. The emphasis in each narrative will be the patient's "inner life" or subjective experience and the caregivers' experiences of giving care. The narratives will depict how patients, families, and providers find personal meaning in illness and how personal meanings influence the experience and outcome of care.

\$100,000 | Two Years |

Edmonton General Hospital

Eduardo Bruera, M.D.

To develop a simple, multi-dimensional kit designed for daily or weekly evaluation and follow-up of terminally ill cancer patients and their families. The kit will allow for the assessment of physical, psychosocial, and spiritual needs of patients and their families in order

to arrive at an integrated vision of the patient's experience.

\$94,765 |

Ellen Stephen Hospice

Bruce A. Williams, project coordinator

The development of a hospice for the isolated, Native American community living at the Pine Ridge Indian Reservation. Care and management will be provided by an interdisciplinary professional and volunteer team according to national hospice-quality standards and within the Native American belief system. The hospice will serve as a model for other Native American communities.

\$150,000 | Two Years |

United Hospital Fund

David A. Gould, Ph.D., project coordinator

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

\$300,000 | Two Years |

Institute of Medicine

Marilyn J. Field, Ph.D., project coordinator

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

\$200,000 | Two Years |

Choice In Dying

Karen Orloff Kaplan, M.P.H., Sc.D., project coordinator

Support is provided to the organization's ongoing efforts in public and professional education and counseling for the preparation and use of advance directives.

\$35,000 | One Year |

Center for Ethics in Health Care

Principal Investigator: Susan W. Tolle, M.D

Co-Principal Investigator: Virginia P. Tilden, D.N.Sc.

Prompted by Oregon's vote on assisted suicide, a one-day planning meeting for the development of a new program of research on end-of-life care was convened by the Center for Ethics in Health Care at the Oregon Health Sciences University.

\$8,000 | One Year |

Dartmouth College, Dartmouth-Hitchcock Medical Center, Norris Cotton Cancer Center

Marguerite M. Stevens, Ph.D., Associate Professor

To develop a multi-method, cross-disciplinary analysis to understand more about the dying experience of seriously ill adults through analyzing patient and family reports of severe pain, and developing descriptive models of "good" and "bad" dying experiences from the viewpoints of the patient and family. With this new level of understanding and descriptions of pain and dying, NCI hopes to change the quality of dying and the existing culture of the dying experience through public and professional education. The completed and integrated analyses will contribute to books published by The Center to Improve Care of the Dying.

\$100,000 | Two Years |

Staten Island University Hospital

Barbara Malach, MD, Associate Director

Studies have noted that doctor-patient communication patterns play an important role in the relationship of patients from different cultures to their physicians. Furthermore, the role the family takes in decision making varies from culture to culture. Elderly Russian immigrant populations face cultural and language barriers associated with residing in a new environment and also the issues of aging in a strange land. Approximately 2,000 Russian patients per month over the age of 65 visit this nonprofit, 633-bed, multi-site health-care delivery system. Information is scarce about this population's health care preferences and particularly the influence of their culture on health-care decisions. The purpose of this project is to assess attitudes, beliefs, and knowledge regarding end-of-life and bereavement issues among this population and to develop a culturally sensitive educational program regarding these issues that will have a patient and health-care professional component.

Social Work Leadership Development Awards

Mary Sormanti, M.S.W., Ph.D.

Columbia University School of Social Work

This project involves the development, implementation, and evaluation of telephone support groups for cancer patients and their families during the dying process. Evaluation of these groups will provide important information about their efficacy as innovative and cost-effective interventions and will serve as models for measurement of new technologies in social work programs.

New York, NY | \$60,000 | 2000 |

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

New Jersey Health Decisions

The Excellence in End-of-Life Care Fellowship for Social Workers will develop, pilot, evaluate, and disseminate a model palliative care curriculum for training social workers in working with the elderly and people with disabilities. This collaborative effort will create New Jersey's first comprehensive initiative to educate social work practitioners in end of life care.

Verona, NJ | \$60,000 | 2000 |

Terry Altilio, A.C.S.W.

**Department of Pain Medicine and Palliative Care
Beth Israel Health Care System**

This project is a collaboration between social work and the multidisciplinary staff of a major Palliative Care Center to create a six

month social work fellowship program. A list serve will be developed and maintained as well as specific teaching modules on topics such as pain and symptom management and principles of palliative and end-of-life care for social work that can be accessed through the internet.

New York, NY | \$60,000 | 2000 |

Margo Okazawa-Rey, M.S.S.S., Ed.D., and Norma del Rio, M.S.W.

**Institute for Multicultural Research and Social Work Practice
San Francisco State University**

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

San Francisco, CA | \$60,000 | 2000 |

W. June Simmons, M.S.W.

Partners in Care Foundation

A regional coalition of agencies and schools, developed by the Geriatric Social Work Education Consortium and the Partners in Care Foundation is creating a new model of integrated end-of-life care with older adults in social work field and academic training in California. This project will influence social work EOL care national graduate education programming through shaping optimal practice standards and developing a base for education of future social work leadership in EOL care.

Burbank, CA | \$60,000 | 2000 |

Susan Taylor-Brown, M.P.H., A.C.S.W., Ph.D.

**Greater Rochester Collaborative MSW Program
Nazareth College–SUNY College at Brockport**

The Greater Rochester Collaborative MSW Program, Community Health Network (a medical facility for HIV-infected adults) and the Double "H" Ranch (a camp funded by the Paul Newman Foundation for individuals with chronic illness) will form a consortium known as Family Unity. A rich series of learning opportunities delivered at the outpatient treatment facility, Community Health Network, and the Family Unity Camp will improve social work students', practitioners' and educators' ability to work with families experiencing death and loss related to HIV/AIDS. Learning will be enhanced through participation in an intensive camp experience with these families.

Pittsford, NY | \$60,000 | 2000 |

Katherine Walsh-Burke, M.S.W., Ph.D.

**Association of Oncology Social Work
Springfield College School of Social Work**

Dr. Katherine Walsh-Burke will develop an internet-based continuing education program for social workers affiliated with the 1000-member Association of Oncology Social Work, Hospice Social Workers and related social work organizations. The program will offer courses that include essential theories and skills for social workers, program administrators and supervisors engaged in providing end-of-life care.

Springfield, MA | \$60,000 | 2000 |

Joan Berzoff, Ed.D., M.S.W.

Smith College School for Social Work

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

Northampton, MA | \$60,000 | 2000 |

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

Johns Hopkins Oncology Center

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

Baltimore, MD | \$60,000 | 2000 |

Iris Cohen, M.S.W., A.C.S.W., L.I.C.S.W.

Beth Israel Deaconess Medical Center

The Multidisciplinary Care Tools Program trains social workers and medical staff together in multidisciplinary teamwork and family conferencing skills. The program, which has training components for graduate students and early postgraduates as well as advanced professionals, is designed to educate social workers to be role models and leaders within interdisciplinary teams and across treatment sites.

Boston, MA | \$60,000 | 2000 |

Barbara Dane, Ph.D.

Ehrenkranz School of Social Work at New York University

This project aims to improve postgraduate training for area social workers by convening 11 agency-based social work experts to work with faculty members at the NYU-Ehrenkranz School of Social Work on the design of a new palliative care curriculum. The curriculum will pay particular attention to pain management and ways of addressing spirituality and cross-cultural issues in various service settings.

New York, NY | \$59,947 | 2000 |

Jim Keresztury, L.C.S.W., M.S.W., M.B.A.

Center for Health Ethics and Law

This project will establish a statewide advisory network, comprised of social work educators and practitioners, to develop an extensive survey tool that will examine the educational needs of social workers about end of life issues. A new curriculum will be developed to address these gaps in knowledge and will be implemented in graduate and postgraduate social work education throughout the state.

Morgantown, WV | \$60,000 | 2000 |

Elizabeth Mayfield Arnold, M.S.W., Ph.D.

**School of Social Work
The University of North Carolina at Chapel Hill
Duke Institute on Care at the End of Life**

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

Chapel Hill and Durham, NC | \$60,000 | 2000 |

John F. Linder, L.C.S.W.

UC Davis Cancer Center

Through development of a statewide coalition of Schools of Social Work and Schools of Theology and related field training agencies, this project will develop a highly interactive graduate level "end-of-life care" course that will be offered to social work, divinity, and religious studies students at California State University, Sacramento, and at the Graduate Theological Union (GTU)/UC Berkeley, in academic year 2001/02.

Sacramento, CA | \$59,400 | 2000 |

Amanda Sutton CSW, BCD, and Yvette Colon, MSW, ACSW

Cancer Care, Inc.

The End-of-Life Internet Forum

This teaching model will use the Internet to provide focused training in end-of-life care to master's level graduate students and social work professionals. Participating students will be trained to provide informed and sensitive services to patients and their families during the end of life. This "virtual community" of students and professionals will be an ongoing forum for discussion, information sharing, and mutual support. Evaluation results will be used to improve the program in subsequent years, and to measure the efficacy of interactive online education as a training modality for social work students. Evaluation results will also be widely disseminated to other professionals and educators in the field, particularly those with a special interest in caring for the dying.

New York, NY | \$44,000 | 2001 |

Mercedes Bern-Klug, MSW, MA

Center on Aging

Psychosocial Concerns at the End of Life for Nursing Home Residents: The Role of Social Work

Little is known about the psychosocial needs of nursing home residents and their families at the end of life. Even less is known about the extent to which nursing home social workers are helping to meet these needs. This project will document psychosocial concerns of dying residents and their families to better understand the role of the nursing home social worker regarding end-of-life care. Findings will be used to call attention to the unmet psychosocial concerns of nursing home residents and families, and to help shape the on-going debate about the role of the nursing home social worker.

Kansas City, KS | \$64,997 | 2001 |

Sheila R. Enders, MSW**UC Davis Medical Center**

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

This handbook will be field tested with female inmate patients at the Central California Women's Facility and male inmate patients at the California Medical Facility, Vacaville within the California state prison system. Corrections staff at both institutions will be educated about the special concerns of these special needs populations in the corrections setting. The project will create a complimentary educational video to promote understanding of key end-of-life issues and will make the handbook and video available for social workers, nurses, hospice, and skilled nursing facility personnel.

Sacramento, CA | \$64,440.17 | 2001 |

Richard B. Francoeur, PhD**Columbia University**

Palliative Care in an Inner-City Minority Population: The Impacts of Chronic Disease, Material Deprivation, and Financial Burden on Control of Pain and Symptoms, Biopsychosocial Outcomes, and Service Needs

Material and economic deprivation, especially acute in minority and underserved populations, exacerbate patient and family barriers to full assessment and compliance with treatment for pain and symptoms, thus eroding well-being and quality-of-life. Data collected will permit comparisons across subgroups of patients receiving palliative care for various illnesses. The project will determine whether patients who experience material deprivation and/or financial burden are more likely to endure uncontrolled pain and experience unmet service needs. The project seeks to determine whether material deprivation and financial burden interact simultaneously with other important factors, or follow them in sequence.

New York, NY | \$65,000 | 2001 |

Barbara L. Jones, MSW, CSW**Albany Medical Center**

Psychosocial Protocol and Training Program for End-of-Life Care for Children with Cancer: A Social Work Curriculum

Most end-of-life care models are designed for adult cases and have little application to pediatrics. This project will identify the current practices and training of social workers with respect to end-of-life care for children with cancer. This study will also examine the end-of-life experiences of families who have suffered the death of a child to cancer, and define what support services families need most. The project will develop a curriculum and training program for pediatric end-of-life care that can be used by schools of social work as well as hospitals and hospices.

Albany, NY | \$65,000 | 2001 |

Jane Lindberg, LCSW**Hinds Hospice**

Social Worker Bereavement Training Program

To respond to an increasing need for bereavement services in three rural central California Counties (Fresno, Madera, and Merced) this program will provide bereavement services and support for the rural poor, especially migrant Hispanic families, living in the small towns dotting the landscape in this agricultural region. Social workers, clergy and health professionals already working with the target population will be trained and assisted in establishing a network of knowledgeable, compassionate support. This pilot project

will be a model that can be used nationwide in to improve the care of the dying and bereaved.

Fresno, CA | \$65,000 | 2001 |

David A. Cherin, M.S.W., Ph.D.

**School of Social Work
University of Washington**

University of Washington's School of Social Work End-of-Life Care Knowledge Institute

In this intensive summer research workshop program for social workers and other health professionals, participants will design research and demonstration projects to be carried out in their home institutions. Students will develop a strong conceptual and applied background in palliative care services, empowering them to assume a strong institutional role in the delivery of end-of-life care practice models.

Seattle, WA | \$66,837 | 2001 |

Ellen L Csikai, MSW, MPH PhD, and Mary Raymer, MSW, ACSW

**School of Social Work, Stephen F. Austin State University
National Hospice and Palliative Care Organization**

The Social Work End-of-Life Care Educational Program (SWEET): A National Initiative

This project will use a national survey of health care workers in various settings to assess current educational preparation in end-of-life care and identify barriers to effective social work intervention. Survey results will contribute to the development of an end-of-life care curriculum that will provide knowledge and skills necessary for social workers to be able to handle end-of-life care situations effectively, sensitively, and ethically. This curriculum will be widely available through a "train-the-trainers" program of continuing end-of-life care education for social workers in a variety of fields.

Nacogdoches, TX, and Williamsburg, MI | \$73,946 | 2001 |

Judith Dobrof, DSW

**Department of Social Work Services
The Mount Sinai School of Medicine**

Caregivers and Professionals Partnership: Assessing a Structured Support Program

This project will assess the impact of the Caregivers and Professionals Partnership (CAPP), a structured support program for family caregivers of chronically, seriously, and terminally-ill adults. CAPP is an interdisciplinary, replicable program to strengthen and sustain the Mount Sinai Hospital and affiliate institutions' responsiveness to the role and needs of family caregivers of adults. The study will use existing data on the CAPP Caregivers Resource Center and from CAPP's performance improvement initiative to explore CAPP's effect on family caregiver outcomes. The project will demonstrate CAPP's value as a model support program for family caregivers and enhance social work's leadership in contributing to a critically important area of research.

New York, NY | \$52,000 | 2001 |

Susan Murty, ACSW, MSW, PhD

University of Iowa

Developing Social Work Leadership in End-of-Life Services in Rural Communities

This project will train students, faculty, and community partners at the University of Iowa's School of Social Work to become leaders promoting effective rural social work practice in end-of-life care. Two cohorts of students will be trained as leaders in rural end-of-life care as they progress through the two year curriculum for the master's degree in social work. They will develop knowledge, skills and values for work with death, dying, and bereavement among individuals and families in rural communities with a focus on rural Latino populations. Community partners and social work faculty will collaborate to develop the curriculum. The project will disseminate models of effective service delivery for rural areas by means of a web site, conference presentations, publications, and workshop presentations.

Iowa City, IA | \$60,000 | 2001 |

Bruce A. Paradis, PhD

Salem State College

End-of-Life Care: Birth through Old Age

This project will develop a second year MSW advanced concentration in end-of-life care and strengthen the ties between the Salem State College School of Social Work and the professional social work community. Students will complete a specialized year-long field placement in end-of-life care settings. They will participate in seminars designed to consolidate direct practice skill and to explore innovative service delivery models. Principal faculty members will develop collaborative relationships with the field sites selected for the program and create an advisory committee of social work professionals involved in end-of-life care. An elective course in end-of-life care will be developed and offered via interactive video technology and simulcast to the schools of social work in New England that do not have curriculum in end-of-life care.

Salem, MA | \$65,000 | 2001 |

Sherri Weisenfluh, LCSW

Hospice of the Bluegrass

The Kentucky Project, Enhancing End-of-Life Care: A social work manual for students and practitioners

Kentucky has few exemplary models for social work education and intervention methods. This project will create a statewide partnership of committed educators and service providers that will cooperate on a strategy to address the scarcity of graduate social workers trained in end-of-life care, and will develop and disseminate a culturally sensitive training manual to students and social work practitioners throughout the state.

Lexington, KY | \$61,725 | 2001 |

Betty J. Kramer, PhD

School of Social Work University of Wisconsin–Madison

Strengthening Social Work Education to Improve End-of-Life Care

Although social workers have important practice roles supporting families and individuals coping with terminal illness, grief, loss, and bereavement in a variety of settings, educational gaps often leave them ill-prepared to competently fulfill these roles. This project will develop end-of-life content guidelines for the social work profession, building upon the current standards used by medicine and nursing; to use these guidelines to conduct a critical review of the most frequently used textbooks in social work education; and to write a text that addresses some of the gaps identified in this review in order to enhance educational resources available to educators, students, and practitioners.

Madison, WI | \$67,000 | 2001 |

Shirley Otis-Green, MSW, LCSW, ACSW

City of Hope National Medical Center

Proyecto de Transiciones: Enhancing End of Life and Bereavement Support Services for Latinos within a Cancer Center Setting

Despite the high percentage of Latinos who reside in Los Angeles County, there are presently no integrated, Spanish-speaking end-of-life and bereavement support services. This demonstration project will develop a community partnership model appropriate for use in cancer centers nationwide. Findings from focus groups made up of the dying, family caregivers and the bereaved will be used to develop and refine the structure of a bereavement support group (Reflexiones) and a general cancer group (Compartiendo Esperanza). This demonstration project will explore the use of a community partnership model to determine applicability to other cancer center sites. Findings will also be useful for the development of culturally relevant social work interventions with other underserved groups.

Duarte, CA | \$67,000 | 2001 |

Terry A. Wolfer, Ph.D. and Vicki Runnion, M.S.S.W.

University of South Carolina Research Foundation

Casebook on Death and Dying for Social Work Education

The project will develop 24 decision cases to be published in book form and disseminated via the Internet. The cases will portray the actual experiences of social workers in a wide range of practice settings as they serve clients facing death or bereavement. The cases will pose open-ended, ambiguous dilemmas that require students to use their analytic and critical thinking skills, their knowledge of social work theory and research, and their common sense and collective wisdom to formulate and analyze problems, evaluate possible solutions, and recommend a preferred intervention. The cases and detailed teaching notes will be augmented with a curriculum guide on death and bereavement for social work educators and general instructions for teaching with decision cases.

\$69,125 | 2002 |

Bonnie Shultz, M.S.W., L.I.C.S.W.

Children's Hospital Foundation

Pediatric Palliative Care Education for Social Workers

Children's Hospital will implement a program to educate and organize networks of providers to improve palliative care for children. Children's Hospital's Palliative Care Consulting Service will develop a curriculum to educate social workers and other professionals about palliative care, communication, ethics, organizational change, and leadership. Educational conferences will lead to increased competency of social workers in the delivery of palliative care, increased ability of social workers to initiate palliative care and coordinate care for children with life-limiting conditions, and as a result, an increased number of children benefiting from palliative care. The program dovetails with Children's Hospital's mission to provide education to healthcare professionals, to advocate for children, and to improve the health and well-being of children.

Seattle, WA | \$65,000 | 2002 |

Elizabeth Chaitin, M.S.W., M.A., D.H.C.E.

University of Pittsburgh Medical Center, Shady Side

Interdisciplinary Specialty Team Training in Palliative Care

This project seeks to improve palliative care at the non-university based programs of UPMC Health Systems. Elizabeth Chaitin will develop and implement an educational program providing palliative care training, and will build a highly functioning interdisciplinary care team. Teams will be composed of social workers, nurses and physicians from specialties with significant exposure to end of life care, such as intensive care, neurology, oncology and cardiology services.

Pittsburgh, PA | \$65,000 | 2002 |

Nancy Cincotta, MSW

Mount Sinai Medical Center

A National Initiative to Unite Social Workers and Families in the Interest of Dying Children

Nancy Cincotta will organize a national network of social work experts in pediatric end-of-life care. Professionals and parents will partner to identify developmentally sensitive interventions, unique challenges, and opportunities to improve pediatric end-of-life care. Cincotta will create a listserv to serve as a virtual community for discussion, problem solving, resource sharing, and consultation for pediatric end-of-life care professionals.

New York, NY | \$65,000 | 2003 |

Rita Ledesma, PhD

California State University–Los Angeles

Loss and Bereavement in an American Indian and Alaska Native Community

Rita Ledesma will examine the impact of loss and bereavement in the American Indian and Alaska Native communities of the greater Los Angeles region. She will use qualitative methods with two expert samples: 1) American Indians and Alaska Natives who reside in the community; 2) health and human services providers who work within the American Indian and Alaska Native community. She will establish a council of consultants to review the research protocol and data. Her findings will be used to develop training materials and curricula for social workers and allied health professionals who work with American Indians and Alaska Natives.

Los Angeles, CA | \$65,000 | 2003 |

Aloen Townsend, Ph.D.

Mandel School of Applied Social Sciences

Family Assessment Collaboration to Enhance End-of-Life Support

Families are an essential source of support for most adults facing death and, along with the terminally-ill individual, the focus of hospice and palliative care services. The family, especially family caregivers, can have a major impact on the patient's quality of life and interactions with service providers. The goal of Aloen Townsend's project is to improve end-of-life care for patients by improving the assessment of family caregivers' needs. The project is designed to address a critical gap: the lack of clinically relevant and scientifically sound measures for assessing family caregiver strain near the end of life.

Cleveland, OH | \$65,000 | 2003 |

Elizabeth J. Clark, Ph.D., A.C.S.W., N.A.S.W.

National Association of Social Workers

Building Social Work Practice and Policy Competencies in End-of-Life Care

The National Association of Social Workers (NASW) is the largest professional organization for social workers in the world, and brings important institutional resources to shape both the public policy and social work practice related to the care of the dying. NASW Executive Director Elizabeth Clark has the opportunity to guide program development and mobilization within the social work profession to help transform health care systems to a more humane approach to death. Dr. Clark will advance the role and competency of social workers in end-of-life care through the development of practice standards, communication, and continuing education.

Washington, DC | \$65,000 | 2003 |

Nancy Contro, L.C.S.W.

Lucile Packard Children's Hospital

Latino Families in Pediatric Palliative Care

Most practitioners acknowledge that the most effective way to care for children is one based upon a family centered approach; however, within the realm of pediatric palliative care, there is almost no literature to guide practitioners. Even more lacking is literature examining the experiences and needs of children and families from non-Anglo cultures. The goals of Latino Families in Pediatric Palliative Care at Lucile Packard Children's Hospital are to enhance understanding and provide meaningful guidance to improve care for Mexican Latino families whose children are seriously ill or dying.

Palo Alto, CA | \$65,000 | 2003 |

David Browning, M.S.W.

Center for Applied Ethics & Professional Practice

Developing a Pediatric End-of-Life Care Curriculum for Social Workers

David Browning will develop a curriculum on child and family-centered end-of-life care for master's level social workers. The curriculum will provide social workers with the theoretical foundation, clinical expertise, and resources to provide optimal pediatric palliative care. The program includes facilitator's guides for educating social workers in the following six areas: engaging with children and families; relieving pain and other symptoms; improving communication and strengthening relationships; responding to suffering and bereavement; sharing decision-making; and establishing continuity of care.

Newton, MA | \$65,000 | 2003 |

Karen Bullock, Ph.D.

University of Connecticut

Resource Enrichment Center

Karen Bullock will create an online Resource Enrichment Center Project at the University of Connecticut School of Social Work, enabling the school to provide continuing education for practitioners and graduate students. The online resource center will also facilitate collaboration between the School of Social Work and practice sites that might not otherwise have access to up-to-date research on care for the dying and bereaved.

West Hartford, CT | \$65,000 | 2003 |

Faculty Scholars Program

Steven H. Miles, M.D.

University of Minnesota

Study, assess, and change end-of-life care as a form of primary care within managed care, develop a curriculum on end-of-life care issues within a managed care framework for medical schools and residencies.

Minneapolis, MN | 1995 |

Thomas J. Smith, M.D., F.A.C.P.

Medical College of Virginia

Research on epidemiology of cancer death, evaluating efficacy and cost-effectiveness of end-of-life care, and developing clinical practice guidelines and randomized controlled trials of financing alternatives in palliative care.

Richmond, VA | 1995 |

James A. Tulsky, M.D.

Duke University VA Medical Center

Development, implementation, and evaluation of model for teaching students and residents how to communicate better with dying patients.

Durham, NC | 1995 |

Sarah J. Goodlin, M.D.

White River Junction VA Medical Center

Development of a quality improvement process for end-of-life care and a care pathway for regional palliative care.

White River Junction, VT | 1995 |

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

University of Chicago

Research to expand the understanding of how physicians make prognoses about death and their relation to patient referral to hospice, in order to develop practical guidelines for palliative medicine.

Chicago, IL | 1995 |

Stuart Farber, M.D.

University of Washington Medical School

Development of a curriculum in the care of the dying for the Family Practice Residency Network of the University of Washington School of Medicine.

Tacoma, WA | 1995 |

Gerri Frager, R.N., M.D.

Izaak Walton Killam Children's Hospital

Development of a pediatric supportive care program including consultation service, early and ongoing support to patient and family, and use of community resources.

Halifax, Nova Scotia | 1995 |

Carlos F. Gomez, M.D., Ph.D.

University of Virginia School of Medicine

Development of a model program in end-of-life care of residents in palliative medicine; evaluation of the narratives of dying patients and their families.

Charlottesville, VA | 1995 |

Charles F. von Gunten, M.D., Ph.D.

Northwestern University Medical School

Establishment of a multidisciplinary palliative medicine education program for health care professionals with a hands-on educational experience for visiting health care professionals who wish to have exposure to palliative medicine.

Chicago, IL | 1995 |

David E. Weissman, M.D.

Medical College of Wisconsin

Development of a death-education curriculum for primary care.

Milwaukee, WI | 1995 |

J. Andrew Billings, M.D.

Trinity Hospice, Massachusetts General Hospital, and Harvard Medical School

Development of a palliative care service at Massachusetts General Hospital with a strong home-hospice component, including nursing home care, an outpatient palliative care program, an inpatient consultation team, and planning for an inpatient palliative care unit.

Boston, MA | 1995 |

William Breitbart, M.D.

Memorial Sloan-Kettering Cancer Center

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

New York, NY | 1995 |

Diane E. Meier, M.D., Judith C. Ahronheim, M.D., Jane Morris, R.N., and R. Sean Morrison, M.D.

Mt. Sinai Medical Center

Development of faculty from all clinical departments to be palliative care consultants and role models.

New York, NY | 1995 |

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

St. Vincent's Hospital and Medical Center

Development of measurements of the quality of care rendered to medical inpatients at the end of life including attention to patient care needs and patient and family satisfaction.

New York, NY | 1996 |

Sharon M. Weinstein, M.D.

Pain Management Center

Development and implementation of clinical care pathways to improve the care of dying cancer patients.

Salt Lake City, UT | 1996 |

Harvey Max Chochinov, M.D., F.R.C.P.C.

**Manitoba Cancer Treatment and Research Foundation
University of Manitoba**

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

Awarded the 1996 Rh Award for his research on the role of brief screening instruments to identify clinical depression among dying patients; the extent to which psychological variables influence survival; and the temporal stability of "will to live" in terminal disease. His findings provide some of the most important empirical data available today to guide policy decisions with respect to "right to die" issues.

Winnipeg, Manitoba | 1996 |

Timothy J. Keay, M.D., M.A.-Th., C.A.Q.G.M., F.A.A.F.P.

University of Maryland School of Medicine

Development of a model quality-improvement plan with a learner-centered educational program for nursing home physicians that improves the quality of end-of-life nursing home care.

Baltimore, MD | 1996 |

David R. Kuhl, M.D.

**University of British Columbia, Palliative Care Program
St. Paul's Hospital**

Development of programs to enhance patient care and physician awareness, based on the results of a study of the emotional, psychological, and spiritual issues surrounding the suffering experienced by people with terminal illnesses.

Vancouver, BC | 1996 |

Marcia Levetown, M.D.

University of Texas Medical Branch at Galveston

Development of a multi-disciplinary curriculum that will focus on inter-disciplinary team-building, pain and symptom management, legal and ethical issues in end-of-life care, and the medical professional's own response to helping patients with terminal illnesses and their families.

Galveston, TX | 1996 |

Michael Lipson, Ph.D.

Columbia College of Physicians and Surgeons & Harlem Hospital

To develop a skills-based training for health professionals that addresses their personal reconciliation to death and loss.

New York, NY | 1996 |

Susan J. McGarrity, M.D.

**Pennsylvania State University Hospital
Milton S. Hershey Medical Center**

Establishment of a hospital-based palliative care program to serve Penn State/Hershey Medical Center and its affiliated hospitals.

Hershey, PA | 1996 |

Walter M. Robinson, M.D., M.P.H.

Harvard Medical School & Children's Hospital

An examination of the medical and ethical aspects of end-of-life care for chronically ill children and their families and development of a specialized team of physicians, nurses, and other caregivers to meet their particular needs.

Boston, MA | 1996 |

John Lee Shuster Jr., M.D.

**University of Alabama School of Medicine
University of Alabama at Birmingham**

Development of clinical and educational programs focusing on psychiatric issues in terminal care such as anxiety, confusion, and delirium.

Birmingham, AL | 1996 |

Janet L. Abrahm, M.D., F.A.C.P.

University of Pennsylvania

A Disease Management Program for the Care of the Dying in the University of Pennsylvania Health System

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

1997 |

Robert Mark Arnold, M.D.

University of Pittsburgh

Teaching Physician Change-Agents to Communicate with Terminally Ill Patients About Psychosocial and Ethical Aspect of Care

A cohort of oncologists, geriatricians and doctors caring for HIV-positive patients will learn skills necessary to more effectively communicate about the ethical, psychosocial, and existential issues surrounding terminal care. These physician change agents will in turn train other health care providers at their institution in an effort to improve the care of dying patients in Western Pennsylvania.

Pittsburgh, PA | 1997 |

J. Randall Curtis, M.D., MPH

Harborview Medical Center

Quality of Communication About End-of-Life Care

Effective patient-doctor communication about end-of-life medical care can improve the quality of the dying experience. The main goals of this study are to validate a measure of the quality of the dying experience among persons with AIDS and assess the relationship between quality of patient-doctor communication about end-of-life care and the quality of the dying experience.

1997 |

Joseph J. Fins, M.D., F.A.C.P.

The New York Hospital–Cornell Medical Center

Reconstructing the Care of the Dying through the Integration of Clinical Ethics and Palliative Care

Recognizing that the care of the dying can be improved through the enhanced integration of clinical ethics and palliative care, a model educational program and scholarly literature will be developed linking these two disciplines. This inter-disciplinary program will

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

1997 |

Laura C. Hanson, M.D., MPH, and Martha Henderson, MSN, D.Min.

University of North Carolina at Chapel Hill

Improving Nursing Home Care for the Dying

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

Chapel Hill, NC | 1997 |

Nancy Hutton, M.D.

The Johns Hopkins University School of Medicine

Completing the Circle: End-of-Life Care for Children with AIDS

The purpose of the project is to design, implement and evaluate a comprehensive model program for care at the end of life for children with HIV/AIDS. This program includes comprehensive medical and social services to children and families infected and affected by HIV/AIDS.

Baltimore, MD | 1997 |

Betsy MacGregor, M.D.

Beth Israel Medical Center

Project on Dying and the Inner Life

To gain a deeper understanding of the caregiving and dying process, this project will involve an investigation of the personal inner life experiences of those involved with dying – people with terminal illness, their family caregivers, and health care professionals. Through the use of relaxation and self-reflection techniques, together with in-depth interview and qualitative research analysis, the potential role of the inner life will be evaluated as a resource for support for those involved with dying.

1997 |

Marianne LaPorte Matzo, Ph.D., RN, CS

New Hampshire Technical College

Care for the Dying Patient: An Educational Program for the Associate Degree Nursing Student

An educational program will be developed for associate degree nursing students equipping them with the skills necessary to improve the quality of care to dying adult patients and their families and to provide appropriate care to accommodate their needs.

1997 |

Peter A. Selwyn, M.D., M.P.H.

Montefiore Medical Center*Care of Patients with Late-Stage AIDS in a Skilled Nursing Facility*

A model center will be developed for clinical, palliative and end-of-life care, teaching, and research at a dedicated, skilled nursing facility for people with HIV/AIDS. The goal of the model is to improve clinical outcomes for patients and their families and to create a greater understanding among care providers of the unique end-of-life issues faced by this population in our community and elsewhere.

1997 |

Wayne A. Ury, M.D.**Saint Vincent's Hospital and Medical Center of New York***A Palliative Medicine Curriculum for an Internal Medicine Residency Program*

In this project, an innovative palliative care curriculum will be developed, implemented, and evaluated. The curriculum will utilize case and problem-based learning techniques.

New York, NY | 1997 |

Neil S. Wenger, M.D., MPH**University of California—Los Angeles***Measuring the Quality of Care for Seriously Ill Inpatients and an Intervention to Improve Care Toward the End of Life*

This project will develop a set of objective criteria to evaluate the quality of care delivered to seriously ill and dying inpatients, and will use these criteria to evaluate an intervention to improve care at the end of life.

Los Angeles, CA | 1997 |

Deborah Witt Sherman, Ph.D., R.N., A.N.P., C.S.**New York University School of Education***Implementation, Evaluation, and Refinement of an Advanced Practice Palliative Care Nursing Program*

Despite a growing recognition for the universal need for competent and compassionate end-of-life care, educational preparation in this area has been relatively neglected in nursing curricula. Addressing the complex physical, emotional, social, and spiritual needs of patients and families experiencing incurable terminal illness requires nurses with advanced knowledge of palliative care. The project's goal is the implementation, evaluation, and refinement of an advanced practice palliative care masters program in nursing which is the first program in the nation to prepare palliative care nurse practitioners. The focus will be on the philosophy and principles of palliative care, death and grief education, pain and symptom management, and related legal and ethical issues.

New York, NY | 1998 |

Frank D. Ferris, M.D.**Mt. Sinai Hospital
Temmy Latner Center for Palliative Care***Consensus Building as a Process to Effect Change in Care of the Dying*

In 1993, the Canadian Palliative Care Association embarked on a consensus building process to develop national principles of

practice and standards that would reduce variability between the many hospice and palliative care programs that have been developed in the last twenty-five years. This project will assess the effectiveness and level of consensus that has resulted from the use of these proposed standards and will seek to further refine these principles in order to create an ideal standard against which all programs can be measured. It is expected that a new document outlining the nationally accepted principles of practice will result from this process.

1998 |

Linda Ganzini, M.D.

Oregon Health Sciences University

Legalized Physician-Assisted Suicide in Oregon

As the first state in the United States to allow physicians to help terminally ill patients end their lives, Oregon's experience will be closely watched by other states. This project will examine the practical aspects of assisted suicide. This includes understanding the conditions under which patients might request a lethal prescription and physicians' experiences with requests for lethal prescriptions. Physicians will be surveyed about their experiences with explicit requests for assisted suicide in order to compare current attitudes to those from a 1995 survey. The requests for lethal prescriptions, characteristics of patients who make these requests, the physicians' processes for assessing patients and the impact of the experience on the physician, family, and other health care professionals will also be studied.

1998 |

Jean A. Linzau, M.D., and Michelle Grant Ervin, M.D.

Howard University Hospital

End-of-Life Care Provider Education in an Ethnically and Spiritually Diverse Community

Howard University Hospital, located in the heart of Washington, D.C., serves a culturally diverse population and has a rich history of serving the poor and predominantly black community that surrounds its campus. The project's goal is to develop a center of excellence regarding end-of-life care. This team will survey the providers and members of the general patient population about their attitudes towards end-of-life care. This information will then be extrapolated to develop and implement a model curriculum that teaches medical students to respond appropriately to culturally diverse and spiritually oriented patient and provider populations.

Washington, DC | 1998 |

Steven Z. Pantilat, M.D.

University of California, San Francisco

A Palliative Care Curriculum for Medicine Residents and Hospitalist Trainees

Sixty-three percent of patients still die in hospitals and many die in pain. Traditionally, hospital residents, and more recently, hospitalists, provide much of the care for these patients, but are largely untrained in palliative care. The hospitalist, a new breed of physician, is an internist who spends at least 25% of his/her time caring for inpatients in place of a patient's primary care provider. This project is designed to develop, implement, and evaluate a palliative care curriculum for medicine residents and for fellows training to specialize as hospitalists at UCSF.

San Francisco, CA | 1998 |

Samuel K. Payne, M.D.

University of Iowa, College of Medicine

Rural health care in Iowa is provided by community-based delivery systems. A series of interactive telemedicine seminars in palliative care will be provided for physicians, nurses, and allied health providers throughout the state. Also, the role of telemedicine in palliative care will be evaluated for assisting patients as they transition from the acute hospital setting to the home with the goal of creating a seamless continuity of care.

1998 |

Anthony Back, M.D., and Robert Pearlman, M.D., M.P.H.

University of Washington

Evaluating and Ameliorating End-of-Life Suffering

At the end of life, suffering has special resonance for patients and physicians, and relief of suffering becomes the fundamental goal of medicine. Yet physicians rarely evaluate suffering or discuss it explicitly with patients. This two-part project aims to improve medical evaluation and amelioration of suffering for patients in the last year of life. The project team will conduct a qualitative study of patient experiences in the last year of life, involving longitudinal patient interviews, to characterize suffering and its evolution over time. These patient narratives will then be integrated in an education program for faculty physicians with inpatient medicine attending responsibilities to improve patient-physician communication and will add to the growing body of medical research of suffering and its treatment.

1998 |

Jeffrey H. Burack, M.D., M.P.P., BPhil

University of California

Exploring the Transition to Terminal Illness

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

1998 |

James F. Cleary, M.B., B.S., F.R.A.C.P.

University of Wisconsin Comprehensive Cancer Center and Medical School

Introducing Graduate, Postgraduate, and Continuing Medical Education in Palliative Medicine with Practice Changes in Inpatient, Clinic, and Remote Settings

The University of Wisconsin Medical School provides a central focus for the provision of health care and medical education throughout the state of Wisconsin. Through efforts at the University of Wisconsin Comprehensive Cancer Center, Palliative Medicine is obtaining a significant foothold within the UW Health System while continuing to collaborate with community hospices. The service now has the opportunity to develop and implement educational initiatives in palliative medicine for faculty, residents and medical students. This effort will occur both within the UW Health system as well as the UW Medical School's partners in clinical education throughout Wisconsin.

1998 |

Lewis M. Cohen, M.D.

Baystate Medical Center

The Renal Palliative Care Initiative

Death and dying are seldom discussed in dialysis treatment centers, perhaps because of fears that doing so would run counter to the prevailing sensibility about dialysis as life-saving treatment. Yet, while dialysis sustains life by substituting for kidneys, the underlying disease responsible for causing renal failure usually continues to progress and the mortality rate is higher than that associated with HIV or many types of cancer. The Renal Palliative Care Initiative will involve eight dialysis clinics in the Connecticut Valley Region of New England. This program is designed to address denial of death by dialysis patients and nephrology staff and widen the community and institutional role in end-of-life care for this population.

1998 |

LaVera M. Crawley, M.D., and Barbara Koenig, R.N., Ph.D.

Stanford University Center for Biomedical Ethics

Improving End-of-Life Care for the Underserved through Targeted Continuing Education for African American Physicians

Patients from culturally diverse backgrounds benefit from the provision of culturally competent and sensitive care. This project will increase the network of physicians capable of providing comprehensive end of life care to underserved communities and will develop and implement a series of continuing education programs on end of life care to educate African American physicians.

Palo Alto, CA | 1999 |

Lachlan Farrow, M.D.

**Division of General Medicine and Primary Care
Beth Israel Deaconess Medical Center
Harvard Medical School**

Expanding a Palliative Care Initiative at Beth Israel Deaconess Medical Center and Care Group

This project creates within Beth Israel Deaconess Medical Center and CareGroup an exemplary program of care that utilizes validated patient/family-centered outcomes as the principal basis for evaluation and quality improvements in end of life care. It will work with other initiatives within Harvard-affiliated institutions to maximize its generalizability to health care organizations in Massachusetts.

1999 |

Judith Eve Nelson, M.D., JD

Mount Sinai School of Medicine

Integrating Palliative Care in the Intensive Care Unit

Between 15 and 20 percent of adults patients admitted to Intensive Care Units (ICU) in the United States do not survive hospital discharge. This project aims to characterize and improve the experience and satisfaction of critically ill cancer patients, and their families in the ICU. This new model will impart that palliative care is not simply a sequel to intensive care but an essential component of comprehensive intensive care, provided in a concurrent and coordinated manner to all patients.

1999 |

Steven D. Passik, Ph.D.

**Oncology Symptom Control Research (OSCR)
Community Cancer Care, Inc.**

Creating a Palliative Care Clinical, Educational, and Research Initiative in a Community-Based, Rural, Oncology Setting

This initiative in a community-based clinical setting will improve pain and symptom management and the psychosocial care of patients at the end of life, through a series of initiatives. These include: improving the knowledge of oncologists in palliative care; upgrading the standard of care through screening and algorithm-based interventions; making available promising palliative care research treatments to rural patients in their own communities; and contributing to the evidence based supporting palliative care interventions by monitoring patients on protocols and throughout their care.

1999 |

Thomas J. Prendergast, M.D.

Dartmouth Medical School—VA Medical Center

Developing a Curriculum for End-of-Life Care within the Intensive Care Unit

Intensive Care Units (ICUs) exist to rescue desperately ill patients from imminent death. Physicians who specialize in critical care medicine require training in the philosophy and practice of palliative care. This project will develop a curriculum for teaching health care professionals who work in the ICU the principles of palliative care with particular emphasis on negotiation and conflict resolution.

1999 |

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

Loyola University Medical Center

Improving Care of the Dying in the American Catholic Community

Catholic hospitals are one of the major providers of healthcare in the United States. This project focuses on improving care of the dying through an educational program, at the community level, for parishes and physicians. The curriculum will discuss the Catholic tradition of death and dying, respect for human dignity, pain & symptom relief, and recognizing the inevitability of natural death.

1999 |

Joanne Wolfe, M.D., MPH

Dana-Farber Cancer Institute

Improving Care at the End-of-Life for Children with Cancer

Although most children with cancer survive, 40% eventually die of their disease. Recent survey data demonstrates that the dying child experiences substantial suffering. This multi-institutional study aims to critically evaluate the quality of care provided to children with advanced cancer. It will assess the impact of implementing a symptom assessment tool on the integration of a palliative care service in the management of medical problems.

1999 |

Victor T. Chang, M.D., and Shirley S. Hwang, R.N., AOCN, M.S.

VA New Jersey Health Care System

University of Medicine and Dentistry New Jersey Medical School

Study of Outcome Measurement in Terminal Cancer Patients

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

East Orange, NJ | 2000 |

Anthony N. Galanos, M.D.

**Duke University Medical Center
Center for Aging—Duke University Medical School**

Determining specific barriers to a good death at a tertiary care, academic medical center

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

Durham, NC | 2000 |

Jerome E. Kurent, M.D.

Center for the Study of Aging—Medical University of South Carolina

The Development of an Institute for Community and Professional Education in End-of-Life Care

There is an explicit need for education on end-of-life care within the culturally diverse state of South Carolina. This project seeks to develop and organize an easily accessible comprehensive educational resource in end-of-life care for members of the community and healthcare professionals. Key content areas will include pain management, utilization of advanced directives in DNR, spirituality in end-of-life care, and the role of the faith community in achieving a "good death."

Charleston, SC | 2000 |

Anne C. Mosenthal, M.D., F.A.C.S. and Patricia A. Murphy, Ph.D., R.N., CS, F.A.A.N.

**University of Medicine and Dentistry
New Jersey Medical School & University Hospital**

Palliative Care in an Inner-City Trauma Service

In an urban inner city environment it has become increasingly difficult to provide proper palliative care to trauma patients. By adapting a program of end-of-life care based on the pioneering efforts of Beth Israel Medical Center in New York City, this project will design and implement systemic and replicable improvements in end-of-life care within an urban trauma service at UMDNJ's University Hospital.

Newark, NJ | 2000 |

J. Cameron Muir, M.D.

Palliative Care and Home Hospice Program—Northwestern University Medical School

Development of Interdisciplinary Outpatient Palliative Care Services: Enhancing the Continuum of End-of-Life Care

Given the current economic environment in health care, there is increased emphasis on the delivery of efficient, cost-effective medicine. The goal of this project is to seek funding to develop an interdisciplinary outpatient clinic for the management of palliative care issues including pain and symptom management, advance care planning, and coping with advanced disease. The project seeks to evaluate and implement the development of an interdisciplinary outpatient palliative care clinic that will not only provide direct palliative care but will enhance the continuum of whole person care provided by the other well-established aspects of this program.

Chicago, IL | 2000 |

Kendra Peterson, M.D.

Stanford University Medical Center—Stanford University Medical School

Quality of Life / Quality of Death: Living and Dying with a Malignant Brain Tumor

Little is currently known about the experience and needs of patients dying with malignant brain tumors and their caregivers. The main goal of this project is to characterize the experience of patients dying with malignant brain tumors, and that of their caregivers, in order to facilitate the development of improved models of care for these patients. This study is expected to generate novel insights about the experience of patients dying with brain tumors and that of their caregivers and positively effect the future practices of numerous trainees and faculty at Stanford Medical Center and providers around the country.

Stanford, CA | 2000 |

Kathleen Puntillo, R.N., DNSc., F.A.A.N.

University of California, San Francisco, School of Nursing

Improving Symptom Assessment and Management during Palliative Care of Dying Patients in Intensive Care Units

People who die in Intensive Care Units (ICUs) suffer greatly from distressing symptoms such as pain, dyspnea, and agitation. The goal of this project is to describe symptom assessment and management practices for dying patients in ICUs and use this information to design, implement and evaluate an academic course in symptom assessment and management in the ICU.

San Francisco, CA | 2000 |

Kenneth E. Rosenfeld, M.D.

**Greater Los Angeles Healthcare System
University of California, Los Angeles, School of Medicine**

Pathways: An Institutional Quality Improvement Program in End-of-Life Care

Recent SUPPORT studies have demonstrated the quality of care that United States' hospitals provide to patients near the end of life has been slow to improve. The goal of this project is to implement and evaluate the implementation process and impact of an institution-wide quality improvement program to provide continuous coordinated and comprehensive palliative care to patients with poor-prognosis conditions at the Greater Los Angeles Healthcare System.

Los Angeles, CA | 2000 |

Richard Brumley, M.D., and Kris Hillary, R.N.P., M.S.N.

Kaiser Permanente TriCentral Service Area

Transferring End-of-Life Knowledge in Clinical Culture

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

2001 |

Christopher Daugherty, M.D.

University of Chicago School of Medicine

A Proposal to Better Understand Decision Making, Information Seeking, and Awareness of Prognosis among Dying, Advanced Cancer Patients, and Involved Physicians

For advanced cancer patients who, by definition, have a life-ending diagnosis, it remains highly unclear what factors influence their decisions to receive particular forms of care in the years, months, or weeks before death. Alternatives of care include hospice care and/or clinical trial participation involving experimental agents. This project aims to better understand decision making, information seeking and awareness of prognosis among dying patients with advanced cancer and involved physicians.

Chicago, IL | 2001 |

Joanne M. Hilden, M.D.

The Cleveland Clinic

Children's Oncology Group: Pediatric Advanced Illness Care Coordination

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

2001 |

Daniel C. Johnson, M.D.

University of Colorado Health Sciences Center

Decreasing Symptom Distress at the End-of-Life through Evidence-Based Education

Although good symptom control is an essential component of end-of-life care, many patients continue to suffer from treatable symptoms. This project will develop, implement, and evaluate evidence-based educational interventions for improving symptom management at the end of life.

2001 |

Judith A. Kitzes, M.D., M.P.H.

University of New Mexico Health Sciences Center

Native American End-of-Life Care

In 1996, there were an estimated 2.3 million Native Americans, including Alaska Natives in the United States. The end-of-life experiences for Native Americans mirror that of the general population in that they are commonly extended and take place away from family and community. This project aims to formalize the collaborative efforts between the national Federal/Tribal/Urban Indian Health Care system and the University of New Mexico Health Science Center through the establishment of a Native American Collaborative Center for the Promotion of Palliative Care. The program will support tribal sovereignty and self-determination in palliative care services, and evaluate collaborative palliative care training as it relates to the specific needs of Native American groups.

2001 |

Laurie Jean Lyckholm, M.D., and Patrick Coyne, R.N., M.S.N.

Virginia Commonwealth University School of Medicine

Improving End-of-Life Care for the Medically Underserved by Defining Barriers to Access and Developing an Educational Curriculum

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

2001 |

Mary E. Paulk, M.D.

University of Texas Southwestern Medical Center

Palliative Care for Indigent and Minority Patients, and Investigation into the Constitutionality of Current Government Funding Practices for End-of-Life Care

Provision of palliative care for indigent patients in the U.S. has not been well studied. Many U.S. hospitals are financially limited in their ability to provide palliative care, and without a system of universal coverage, a sizable portion of the population does not have easy access to healthcare. This project will evaluate a palliative care model for hospitals caring largely for indigent and minority patients, and investigate the constitutionality of current government funding practices for end-of-life care.

2001 |

Michael A. Weitzner, M.D.

**H. Lee Moffitt Cancer Center
University of South Florida College of Medicine**

Increasing Clinicians' Awareness and Screening for Clinical Depression in Home Hospice Cancer Patients

Although many health care professionals view clinical depression as an inevitable part of terminal illness, there are many other factors that play a role in the generation of clinical depression. This project will test the explanatory value of a social cognitive model of depression in home hospice cancer patients, and create improved screening assessments for clinical depression in hospice settings.

2001 |

F. Amos Bailey, M.D.

**Safe Harbor Project
Birmingham VA Medical Center
University of Alabama, Birmingham**

Integration of Palliative Care Training into the Curricula of Medical Oncology and Geriatric Medicine Fellowship Training at University of Alabama, Birmingham

Subspecialty training programs in medical oncology, geriatrics, pulmonary medicine, cardiology, nephrology, and neurology rarely include palliative medicine in the curriculum even though physicians trained by these programs will care for patients with serious and life threatening illnesses and will provide the bulk of care to our aging population. In this project, Dr. Bailey will develop a model palliative care curriculum, then test, evaluate, and disseminate the results.

Birmingham, AL | 2002 |

Bruce Himmelstein, M.D.

Children's Hospital of Wisconsin

Rapid-Cycle Quality Improvement in Pediatric Palliative Care Education

In order to improve care for children with life-threatening illnesses, educational deficits in pediatric palliative care must be addressed. Although relevant curricular materials are available, little is known about the best way to teach this material. In this project, Dr. Himmelstein will use rapid-cycle quality improvement methodology to improve the training and practice of interdisciplinary pediatric healthcare teams, and will create an educational model that can be adapted to other pediatric healthcare institutions.

Milwaukee, WI | 2002 |

Terri Maxwell, R.N., M.S.N.

**Center for Palliative Care
Thomas Jefferson University**

Health System-Wide Quality Improvement Initiative for Palliative Care

In response to the need to improve care of seriously ill patients and their families, the Center for Palliative Care was established in 1999 in the Department of Family Medicine at Thomas Jefferson University. Terri Maxwell will bring together the Quality Council of the Jefferson Health System and the Center for Palliative Care to collaborate on a system-wide palliative care quality improvement initiative. The project will provide a new model for improving care at the end of life by combining educational and curriculum initiatives with a system-wide performance improvement project.

Philadelphia, PA | 2002 |

Eric Krakauer, M.D., Ph.D.

**Massachusetts General Hospital
Harvard Medical School**

Clinical Policy Development for Optimum End-of-Life Care

This project aims to reduce barriers to optimum care by developing and advocating for institutional policies and clinical practice guidelines for end-of-life care. Based on evidence that such policies can improve clinical outcomes and patient satisfaction, the policies and guidelines will be designed to be adaptable by institutions nationwide.

Boston, MA | 2002 |

Susan C. Miller, Ph.D., M.B.A.

**Community Health Center for Gerontology and Health Care Research
Brown University School of Medicine**

Research has shown that a large proportion of nursing home and community-based hospice residents have lengths of stay of one week or less, and that this trend has increased significantly in recent years. Short lengths of stay in hospice represent a major challenge to the provision of high-quality end-of-life care. Dr. Miller, working with Home and Hospice Care of Rhode Island, will examine the circumstances of earlier and later hospice referral, and of non-referral to hospice. She will incorporate findings from this work into clinical and administrative case studies to be disseminated nationally.

Providence, RI | 2002 |

Holly G. Prigerson, Ph.D.

Yale University School of Medicine

Psychiatric Disorders in Dying Patients and the Family Caregivers Who Survive Them

Little is known about the prevalence and treatment of psychiatric disorders among terminally-ill patients and their caregivers, the ways that mental health affects the patient's comfort at death, and the impact this may have on the caregiver's experience of grief and bereavement. The goal of this project is to determine how the diagnosis and treatment of psychiatric disorders among dying cancer patients and their caregivers affects the quality of the patients' death and the surviving caregivers' adaptation to the death.

New Haven, CT | 2002 |

Tammie E. Quest, M.D.

Emory University School of Medicine

Emergency Medicine as a Partner in End-of-Life Care: A Palliative Care Curriculum for Emergency Medicine Residents

No training requirement currently exists for emergency medicine trainees in palliative or end-of-life care despite the fact that persons at the end of life have a high symptom burden and often use emergency services for medical, social, and/or psychological reasons. Dr. Quest will create a directed educational model to provide emergency physicians with the appropriate skills needed to care for dying patients in the emergency department setting.

Atlanta, GA | 2002 |

Michael W. Rabow, M.D.

University of California, San Francisco, Medical School

Between the Blackboard and the Bedside: An Examination of the Hidden Curriculum in End-of-Life Care

Medical education in end-of-life care involves not only the accumulation of knowledge and skills, but also a process of socialization and the creation of professional identity. To be effective, medical education reform to improve end-of-life care and training must include attention to the unofficial and informal influences on students. In this project, Dr. Rabow will assess the hidden end-of-life care curriculum at the University of California, San Francisco Medical School, and develop an intervention to address educational barriers to optimal training in end-of-life care. Findings will be shared nationally, focusing on how such an assessment might be applied to other training settings.

San Francisco, CA | 2002 |

Joseph S. Weiner, M.D., Ph.D.

Long Island Jewish Medical Center

Emotional Distress of Physicians Discussing Advance Care Planning: Impact of a New Training Program for Fellows, Interns, and

Medical Students

Many physicians are unwilling to discuss advance care planning with their patients. Without such discussions, physicians may incorrectly assume or ignore patients' treatment preferences. Dr. Weiner will develop structured communication training programs in advance care planning for physicians and medical students. These programs will address physicians' emotional, cognitive, and skills barriers, and will encourage greater willingness to engage in advance care planning with patients.

New Hyde Park, NY | 2002 |
