

## REFLECTIONS ON DEATH IN AMERICA

**GEORGE SOROS**

CHAIRMAN, OPEN SOCIETY INSTITUTE



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Y father died at home in 1963. He was terminally ill. Although he agreed to an operation, he didn't particularly want to survive it because he was afraid that the combination of the illness and the operation would invade and destroy his autonomy as a human being. Unfortunately, that in fact is what happened. After the operation he had very little time left. I'm afraid I wrote him off at that point. I was there when he died, yet I let him die alone. I could see him, but I wasn't at his bedside. The day after he died I went into the office. I didn't talk about my father's death. So I kind of denied his dying. I certainly didn't participate in it.

My mother's death was more recent. She had joined the Hemlock Society and had at hand the means of doing away with herself. I asked her if she needed my help; I offered it, although I wasn't particularly keen to do it. But I would have helped her because I felt that I owed it to her. At the point of decision, however, she did not want to take her own life, and I'm glad she didn't. Her decision gave the family a chance to rally around and be there as she

prepared to die. And this time we did maintain good contact right to the end.

She had this experience, which is described in the work of Elizabeth Kubler-Ross, of walking up to the gates of heaven, and I was accompanying her. She told me she was worried that she might drag me with her. So I reassured her that I was firmly ensconced on this earth and she should not worry. Her dying was really a very positive experience for all of us because of the way she handled herself and the way the family, not just me but particularly my children, could participate in it.

These personal experiences with the deaths of my parents are some of the reasons I established the Project on Death in America to promote a better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death.

Through its Faculty Scholars Program and Grants Program, the project supports initiatives in research, scholarship, the humanities, and the arts, as well as innovations in the provision of care, public education, professional education, and public policy.

What do we want to transform and why? An explanation begins with a small matter, the name of our project. It took a considerable amount of discussion to rid ourselves of clever euphemisms and settle on a name that

states our purpose directly, even starkly: the Project on Death in America.

In America, the land of the perpetually young, growing older is an embarrassment, and dying is a failure. Death has replaced sex as the taboo subject of our times. Only our preoccupation with violence breaks through this shroud of silence.

Even doctors, especially doctors, don't like to think

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**“As many as eighty percent of people die in hospitals, yet, for most people, hospitals are not a good place to die. Hospitals are set up to take care of acute illnesses, and dying is not an illness. It doesn't belong to an official medical category, it has no billing code that would permit reimbursement for the hospital and the physician. If you go to a hospital to die, the doctors have to find something wrong with you, something to treat, like pneumonia or dehydration, or they cannot admit you.”**

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about death. A federal pamphlet for physicians on HIV infection recommends making arrangements for the care of the children when the patient becomes sick, but says nothing about the need for long-term plans for when the patient dies. It is easier to find descriptions of the way people die and what can be done to ease their death in turn-of-the-century medical textbooks than in today's voluminous literature on the treatment and cure of diseases.

This emphasis on treating disease, instead of providing care, has altered the practice of medicine. People live longer, surviving four or five illnesses before dying. But

the health care bill grows with every illness. Our success has also brought other unintended consequences. We have created a medical culture that is so intent on curing disease and prolonging life that it fails to provide support during one of life's most emphatic phases — death. Advances in high-technology interventions have contributed to this weakness in our medical system, deluding doctors and patients alike into believing that the inevitable can be delayed almost indefinitely.

The reality of death and the perceptions of the participants — the dying person, the doctor, the family members — are separated by a wide gap. We need to bring the two into closer alignment. Doctors who are on a first-name basis with disease must reacquaint themselves with the patient. They must recognize that, by focusing exclusively on conquering disease and prolonging life,

they abandon the dying when, in their own words, there is nothing more to be done.

As many as eighty percent of people die in hospitals, yet, for most people, hospitals are not a good place to die. Hospitals are set up to take care of acute illnesses, and dying is not an illness. It doesn't belong to an official medical category, it has no billing code that would permit reimbursement for the hospital and the physician. If you go to a hospital to die, the doctors have to find something wrong with you, something to treat, like pneumonia or dehydration, or they cannot admit you. They hook you up to

tubes and machines and try to fix a condition that isn't fixable. The need to arrive at a reimbursable diagnosis changes the reality. The doctors and nurses are working to prolong life, instead of preparing a patient for death. The ideal of a peaceful death is impossible in such an alien setting, under such extreme conditions.

A peaceful death is more likely to be achieved at home in familiar surroundings that are more conducive to the comfort and ritual of leave taking from family and friends. Only 20 percent of people die in their own home, in a nursing home, or in a hospice. Hospices offer the kind of palliative care that should be routine procedure in every institution that cares for the dying. Proper care includes the control of pain and other symptoms as well as attention to the psychological and spiritual needs of the patient. To provide this care, hospices employ teams of doctors, nurses, social workers, and bereavement counselors.

The recommendations that follow from these observations are obvious. First and foremost, doctors, nurses, and other health professionals need better training in the care of the dying, especially in the relief of pain. Physical pain is what people fear most about dying. A dying person in pain cannot think about anything else, leaving no room for coming to terms with death, for reviewing one's life, putting one's affairs in order, for saying goodbye. Therefore, pain relief must come first.

Second, hospitals must be required to develop and adopt a comprehensive billing code for terminal care. This single change would go a long way towards removing the hypocrisy that now surrounds a hospital's treatment of the

dying and freeing doctors and nurses to provide the kind of care that doesn't rely on technology — such as the simple act of paying attention to a dying person, holding their hand, listening, and comforting them.

Third, we must increase the availability of hospice services for terminally ill patients, removing restrictions on admittance and enhancing reimbursement regulations. We should consider laws that permit next of kin to decide to forgo life-sustaining medical interventions even when a patient's wishes are not known. The government may have to help family members financially so that they can take care of the dying at home by the least expensive means. These are only a few of the approaches to transforming the culture of dying that our project is exploring.

How much will all this cost? Can we afford to care for the dying properly? The number of people dying in the United States currently stands at 2.2 million annually. Increases in cancer and AIDS deaths and the aging of the baby boomers will cause this figure to climb faster than the population. Today 1 in 8 Americans is 65 years or older. In 30 to 40 years, 1 in 5 will be in that age group. The average life expectancy for those reaching age 65 is already 81 for men and 85 for women. The fear is that the dying of the elderly will drain the national treasury. Like most fears, this one is based on a myth, the popular perception that elderly, terminally ill patients consume enormous amounts of resources shortly before they die.

It is true that nearly half of all medical expenses are incurred in the last six months of people's lives. But it is also true that medical expenditures in the last year of life are

lower for people 80 years and older than for those in younger age groups. Aggressive, life-prolonging interventions, which may at times go against the patient's wishes, are much more expensive than proper care for the dying.

This brings me to that hotly debated subject, physician-assisted suicide and euthanasia. This is the one aspect of dying that is talked about everywhere — on television, in public forums, in newspaper headlines and serious journal articles, and in the courts. I believe in personal autonomy; I believe people should be allowed to determine their own end. But I also recognize that legalizing euthanasia could have unintended consequences, leading to all kinds of abuses. The issues need to be carefully weighed. Very few terminally ill patients would avail themselves of the opportunity even if euthanasia were legalized. After all, my mother refused my help and I am glad she did. The Project on Death in America concerns itself with the vast majority of people who are not looking for physician-assisted suicide, and there is much work to be done.

As people come to terms with death, recognizing it as a fact of life, then the demand for physician-assisted suicide, as well as for unnecessary medical interventions, will drop. That is one way I hope our efforts will influence the culture of dying.

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*This essay was adapted from a speech given at the College of Physicians and Surgeons of Columbia University in November 1994, soon after the establishment of the Project on Death in America.*



Maxine Peters, 90, suffered from Alzheimer's and Parkinson's disease. With help from hospice workers in Gladesville, WV, she was able to take her last breath at home, surrounded by family and friends.

## PROJECT ON DEATH IN AMERICA: LEADERSHIP, DISCOURSE, PARTNERSHIP

### GARA LAMARCHE

DIRECTOR OF U.S. PROGRAMS, OPEN SOCIETY INSTITUTE



THE Project on Death in America was one of the first philanthropic initiatives of George Soros that focused on the United States. As the project concludes its first six years, now is a good moment to take stock of its impact, as a pioneer among OSI's U.S. Programs, on the strategies and approaches the foundation uses to address barriers to participation in open society.

### Leadership

From the beginning, PDIA recognized the critical role of leadership in strengthening the field of end-of-life care, and the Faculty Scholars Program has been at the center of the project's ambitious mission to change the culture of dying in the United States. Beginning with physicians and nurses but more recently broadening its focus to include social workers, PDIA's professional education projects aim to build a cadre of leaders, provide opportunities for networking and technical support, and foster innovation and risk-taking.

OSI has drawn on these lessons in creating and working with the Soros Justice Fellows, the New York and Baltimore Community Fellows, and the program on Medicine as a Profession Advocacy Fellows.

## Broadening Discussion

In just six years, PDIA and its scholars and grantees have increased the public discourse about death, which, while a universal event, remains a highly sensitive and personal one. Through the writings of its Faculty Scholars and of Dr. Kathleen Foley and PDIA's highly engaged staff and board, the plays, dances, and films of its Arts and Humanities grantees, and the voices of those supported through its varied grants program, PDIA has us all talking more about death — the way families, communities, and government deal with it and the choices we all make. Nothing demonstrated this changed landscape more dramatically than the huge public response to Bill Moyers' 2000 PBS series "On Our Own Terms," which featured many PDIA scholars and grantees.

Broadening public discussion and debate on sensitive and difficult topics has been a hallmark of virtually all OSI U.S. Programs that have followed PDIA, characterizing the Lindesmith Center's work on drug policy, the Center on Crime, Communities and Culture's focus on incarceration, and the Gideon Project's efforts around the death penalty and indigent defense.

## Partnerships

Although OSI has often stepped out ahead of others, and sometimes functions alone, all of the significant open society problems we deal with require broad partnerships to make a sustained difference. Again, PDIA pointed the way in joining with the Robert Wood Johnson Foundation, the Nathan Cummings Foundation, the Rockefeller Family Office, and the Commonwealth Fund to form Grantmakers Concerned with Care at the End of Life to collaborate and share information and strategies. Virtually

all subsequent U.S. Programs have followed this model. More recently, OSI has sought to develop partnerships or join at the genesis of an initiative. The Funders' Collaborative for Gun Violence Prevention is a partnership with the Irene Diamond Fund and others, and a recent effort to improve New York City public schools is being pursued with the Carnegie Corporation and the Bill & Melinda Gates Foundation.

The Project on Death in America itself has benefited from membership in the OSI family of initiatives. In the last few years, PDIA has increasingly dealt with death and dying issues faced by more vulnerable and traditionally marginalized groups: the maldistribution of access to palliative care for African Americans; the special needs of those who face death while incarcerated; and urban young people who must deal with more death than anyone should have to experience at such an early age. In response to these last two issues, PDIA has engaged in especially fruitful collaborations with three other OSI programs, the

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Lindesmith Center (now an independent organization), the Center on Crime, Communities and Culture, and Youth Initiatives.

Finally, PDIA is increasingly focusing on public policy goals and supporting an array of advocacy strategies to achieve them. Through its support for Americans for Better Care of the Dying, for example, PDIA is advancing efforts to reform Medicare reimbursement policies for continuous, long-term palliative care. Through its support of the Judge David L. Bazelon Center for Mental Health Law, PDIA is supporting litigation strategies to build a constitutional right to appropriate pain relief and palliative care.

The dynamism of the PDIA board and staff in identifying and supporting leaders, fostering discussion, and forging partnerships holds great promise that a better experience for dying people, their families, and loved ones will become a reality for more and more of us in the years to come.

## TRANSFORMING THE CULTURE OF DYING

### **KATHLEEN M. FOLEY, M.D.**

DIRECTOR, PROJECT ON DEATH IN AMERICA



#### **PDIA Advisory Board**

(top, l to r) Susan Block, M.D., Harvard Medical School, Dana Farber Cancer Institute; Robert Butler, M.D., International Longevity Center; Kathleen M. Foley, M.D., Memorial Sloan-Kettering Cancer Center; (bottom, l to r) Patricia Prem, M.S.W.; Robert Burt, J.D., Yale Law School; Anna O. Dumois, Ph.D., D.S.W.

**T**HIS second three-year report describes the Project on Death in America's continuing effort to foster change in the culture and experience of dying in America. Responding to the public's increasing concern with care at the end of life, our funding initiatives identify barriers to humane, compassionate end-of-life care and propose patient and family-centered solutions. A national discourse — "death talk" — has ensued, opening doors to a broad public conversation on the needs of dying patients, caregivers, families, and the institutions providing care.

PDIA's funding has placed emphasis on building a credible and sustainable field of palliative and hospice care. Palliative care — the care of patients with life-threatening illnesses — emphasizes symptom control, quality of life, and addresses the needs of patients and families for support and services to manage their social, cultural, and existential concerns.

Since the majority of Americans die in health care institutions, PDIA's major funding priority has been to create a cadre of role model health care professionals — nurses, physicians, and social workers — to serve as institutional leaders in palliative care. More than half of our funds

support professional education initiatives. But influencing the culture of medicine is just one part of our strategy. To change the way society thinks about dying has required us to support a broad series of initiatives. For example, PDIA board member David Rothman chaired our arts and humanities initiative. These grantees have produced video, photography, poetry, essays, dance, and art which capture individual and community experiences of illness, death, and grief in ways that encourage conversation and thoughtful reflection. The complexity of human experiences with illness and death resonate in these projects and provide an enduring form for insight and remembrance.

Support and understanding of the varied experiences and expressions of grief is rare in American culture. In 1998, PDIA board member Robert Burt led the development of a community grief and bereavement initiative to address individual and community experiences of grief. From interfaith community-based and school-based programs, to programs for special groups — incarcerated youth, family members and victims of violent death, union home health care workers — these grantees are creating model programs for replication and integration into existing social services.

Recognizing that disparities in access to palliative and hospice care for African Americans reflect historical, cultural, and medical experiences, PDIA helped create the Initiative to Improve End-of-Life Care in African American Communities by encouraging public and professional dialogue and identifying opportunities for improvement in care and policy.

Today, only 18 percent of Americans receive comprehensive end-of-life care. In order to make quality care widely available, PDIA supports projects that address

legal and economic barriers to institutionalizing palliative and hospice care. PDIA has awarded grants to the Bazelon Center for Mental Health Law to develop a legal resource center in palliative care, to the Medicare Rights Center for its hospice benefit consumer education project, and to a wide range of nongovernmental organizations that advocate for the needs of their targeted populations.

This report also reflects our broad collaborative efforts with other Open Society Institute U.S. Programs, including Youth Media, Crime, Communities & Culture, and the now independent Lindesmith Center — Drug Policy Foundation. By combining PDIA's interests and funds with other U.S. Programs, we have had the extraordinary opportunity to give voice to teenagers' perspectives on death and grief, to highlight the special concerns of caring for dying prisoners and to support a balanced drug policy so that all patients with pain have access to adequate analgesic drugs. PDIA is also working with the OSI Network Public Health Program to support palliative care initiatives in the countries of Central and Eastern Europe and the former Soviet Union. Each of these collaborations has helped to expand PDIA's role in improving end-of-life care.

There is no doubt that palliative care is a field whose time has come, and our grantees have benefitted from the timing of our initiative. PDIA has had the opportunity to work closely with numerous other foundations whose leadership, collegiality, and vision have enormously contributed to the development and sustainability of the field. The Robert Wood Johnson Foundation, the Nathan Cummings Foundation, the Fetzer Foundation, the Milbank Memorial Fund, the Commonwealth Fund, the Fan Fox and Leslie R. Samuels Foundation, and numerous family and community foundations have supported our scholars and

grantees, and emphasized philanthropic attention to end-of-life care. A group of these foundations have joined with PDIA to create GCCEL: Grantmakers Concerned with Care at the End of Life, an affinity group and resource center for foundations interested in funding end-of-life care. We have also been able to use relatively small grants to leverage major support for grantees such as the United Hospital Fund, which undertook a significant project to improve palliative care in New York City.

We place a high priority on communicating with and about our grantees. Our staff makes project information available through the PDIA website, newsletters, press briefings, and research briefs. The PDIA advisory board and staff provide energy, advice, and support in building the field of palliative care. David Rothman and William Zabel have retired from the board, and Anna Dumois, activist and expert in community health, joined the PDIA board in 1999.

## PROFESSIONAL EDUCATION



From *Anatomy of Anatomy* by Meryl Levin

**P**HYSICIANS, social workers, and nurses have a profound impact on the experiences of dying patients and their families. Inadequate training in pain and symptom control, psychological, social, and spiritual support for the patient and family, and communication with patients about palliative care options presents a major — and unnecessary — barrier to good end-of-life care.

In order to address the unique needs of individual professions, the Project on Death in America developed the Faculty Scholars Program, the Social Work Leadership Development Awards, and a nursing leaders program. These funding initiatives seek to foster the development of knowledge, attitudes, and skills in health care professionals that enable them to serve as compassionate and competent caretakers of patients at the end of life, develop innovative programs in clinical care, research, education and advocacy, take local and national leadership roles at their institutions, and develop an intellectually vibrant, mutually supportive network of colleagues involved in multiple facets of work with the dying and their families.

## Faculty Scholars Program

With six cohorts, the Faculty Scholars Program continues to foster activity in academic health centers to improve care for dying patients and their families. To date, the program has funded 68 faculty scholars in 42 medical schools in the United States and Canada. Awards of up to \$70,000 a year provide scholars with two years of support for 60 percent of their time on activities to improve professional practices and education related to end-of-life care. As a result of this program, faculty with an interest in end-of-life care are receiving long overdue recognition and support.

Faculty scholars have contributed leading articles in palliative care in the *New England Journal of Medicine*, the *Journal of the American Medical Association*, *Annals of Internal Medicine*, and international journals such as *The Lancet*, and the *British Medical Journal*. They serve on key state and national committees that focus on improving end-of-life care. Faculty scholars have taken leadership positions in such professional organizations as the Academy of Hospice and Palliative Medicine, the American Nursing Association, the American Geriatric Society, the American College of Physicians, the American Psychosomatic Association, and the American Society of Clinical Oncology.

Through their academic and clinical excellence, these scholars are institutionalizing change in their own hospitals, medical schools, hospices, nursing homes, and professional organizations. Their research, scholarly publications, and presentations provide the critical evidence to influence and facilitate broad social change in end-of-

life care. Interaction among the scholars has fostered new interdisciplinary approaches to the important issues related to dying in America.

Over the past several years, faculty scholars have worked to develop educational curricula in end-of-life care. For example, Dr. David Weissman spearheaded the development of the *Journal of Palliative Care*, and, with funding from the Robert Wood Johnson Foundation, the online End of Life Physician Education Resource Center ([www.eperc.org](http://www.eperc.org)). Drs. Marianne Matzo and Deborah Sherman collaborated as editors on the recently published nursing textbook *Palliative Care Nursing: Quality Care to the End of Life*. Another recent publication, *Managing Death in the Intensive Care Unit: The Transition from Cure to Comfort*, was co-edited by Dr. J. Randall Curtis. Drs. Harvey Chochinov and William Breitbart co-edited the *Handbook of Psychiatry in Palliative Medicine*. These are just a few of the many faculty scholar publications enriching the field.

The program has enhanced the visibility of the faculty scholars, enabling them to become more effective leaders and mentors within their fields. Institutional publications have profiled many of the scholars; several received broad local and national publicity for their end-of-life care activities. The scholars attest to the critical impact of their awards in moving them into more influential positions within their institutions, in confirming that work with the dying is important, and providing an opportunity for professional growth and recognition.

*Susan Block, M.D., Director, Faculty Scholars Program*

**MISSION**

**Faculty Scholars Program**

*The Faculty Scholars Program supports outstanding clinicians, educators, and researchers in disseminating existing models of good care, developing new models for improving care of the dying, and creating new approaches to the education of health professionals.*



Memorial service at Bailey-Boushay House, an AIDS hospice in Seattle.

1998–2000

**FACULTY SCHOLARS****Anthony Back, M.D.****Robert Pearlman, M.D., M.P.H.**Seattle Institute for Biomedical and  
Clinical ResearchUniversity of Washington School of Medicine  
Seattle, WA*Evaluating and Ameliorating End-of-Life  
Suffering*

For patients at the end of life, suffering is a subjective experience that can encompass not just physical pain, but social, psychological, existential, or spiritual disruptions that may outweigh physical discomfort. Physicians rarely evaluate suffering in this larger sense or discuss it explicitly with patients. This two-part project is designed 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, using patient interviews to characterize suffering and its evolution over time. These patient narratives will then be integrated into an education program for faculty physicians to improve patient-physician communication.

**Jeffrey H. Burack, M.D., M.P.P., B.Phil.**University of California at San Francisco  
Medical CenterUniversity of California, Berkeley  
Berkeley, CA*Exploring the Transition to Terminal Illness*

When curing a patient's illness is no longer possible, or is considered excessively burdensome, medical emphasis shifts to palliative care. 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 mark a life change of dramatic psychological, spiritual, and existential consequence. Dr. Burack will examine patient, physician, and caregiver perspectives on the transition into terminal illness, from primarily curative into exclusively palliative modes of medical care.

**James F. Cleary, M.B., B.S., F.R.A.C.P.**University of Wisconsin Comprehensive  
Cancer CenterUniversity of Wisconsin Medical School  
Madison, WI*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 focus for the provision of health care and medical education throughout the state. This project will establish a clinical program in palliative care for the UW Health System, piloting the program at the UW Comprehensive Cancer Center. Essential to this program is a strong relationship between the Cancer Center and the community hospice. Dr. Cleary is developing and implementing educational initiatives in palliative medicine for faculty, residents, and medical students both within the UW Health System and with UW Medical School partners in clinical education throughout Wisconsin.

**Lewis M. Cohen, M.D.****Baystate Medical Center**

Tufts University School of Medicine  
Springfield, MA

*The Renal Palliative Care Initiative*

Death and dying are seldom discussed in dialysis treatment centers, perhaps because of a prevailing sensibility about dialysis as a life-saving treatment. Dialysis does sustain life by substituting for kidneys, yet the underlying disease responsible for renal failure usually continues to progress, and the mortality rate is higher than that associated with HIV or many types of cancer. This initiative works with eight dialysis clinics in the Connecticut Valley region of New England. The goal of this research is to describe and evaluate the decision-making process of people with end-stage renal disease who have elected to terminate dialysis, to learn what constitutes a “good” death in this context, to develop a model of palliative care, and to create a comprehensive bereavement program. Additionally, Dr. Cohen has created an ambitious educational program to address denial of death by dialysis patients and nephrology staff and to widen the community and institutional role in end-of-life care for this population.

**Frank D. Ferris, M.D.****San Diego Hospice**

University of California, San Diego, School of  
Medicine  
San Diego, CA

*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 and standards of practice that would reduce variability among the many hospice and palliative care programs that have been developed in the last 25 years. The San Diego 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 the principles in order to create a model against which all hospice and palliative care programs can be measured. A new document outlining nationally accepted principles of practice will result from this process, and will be available on the CPCA website ([www.cPCA.net](http://www.cPCA.net)) by November 2001.

**Linda Ganzini, M.D.****Portland VA Research Foundation  
Medical Center**

Oregon Health Sciences University  
Portland, OR

*Legalization of 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 is being closely watched. The project examined cancer patients' requests for lethal prescriptions, the characteristics of patients who make the requests, the physicians' processes for assessing patients, and the impact of the experience on the physician, family, and other health care professionals. Dr. Ganzini surveyed physicians about their experiences with explicit requests for assisted suicide in order to compare current attitudes to those from a 1995 survey.

**Jean A. Linzau, M.D.**  
**Michelle Grant Ervin, M.D.**  
 Howard University Health Sciences Center  
 Howard University Hospital  
 Washington, DC

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

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



**1998–2000 Faculty Scholars**

(top, l to r) Jeffrey Burak, Jean Linzau, Deborah Witt Sherman, Lewis Cohen, Robert Pearlman  
 (bottom, l to r) Anthony Back, Linda Ganzini, Michelle Grant Ervin, Frank Ferris, Steven Pantilat, James Cleary (not shown: Samuel Payne)

**Steven Z. Pantilat, M.D.**  
 University of California at San Francisco  
 Medical Center  
 University of California, San Francisco,  
 School of Medicine  
 San Francisco, CA

*A Palliative Care Curriculum for Medicine  
 Residents and Hospitalist Trainees*

Sixty-three percent of patients die in hospitals and many die in pain. Hospitalists, internists who spend at least 25 percent of their time caring for inpatients in place of a patient's primary care provider, provide much of the care for these patients, but are largely untrained in palliative care. Dr. Pantilat will develop, implement, and evaluate a palliative care curriculum for medicine residents and fellows training to specialize as hospitalists at UCSF.

**Samuel K. Payne, M.D.**  
 University of Iowa Hospitals and Clinics  
 University of Iowa College of Medicine  
 Iowa City, IA

*The Development and Evaluation of Telemedicine  
 Applications in Palliative Care*

The population of Iowa is spread out over a large, mostly rural area, and ranks first in the nation in the percentage of its population over 85 years old. Advances in communications technology provide new opportunities for health care providers to extend care from the hospital to patients' homes. Using telemedicine to enhance hospice and palliative care may help improve health care service to remote areas of the state. Dr. Payne will create a series of interactive telemedicine seminars in palliative care for physicians, nurses, and allied health providers throughout the state. He will evaluate telemedicine as a tool to allow clinicians to follow patients after they are discharged from the hospital into the home, and to monitor the challenges of home care for the patient, the family, and the health care team.

**Deborah Witt Sherman, Ph.D., R.N.,  
 A.N.P., C.S.**  
 Mount Sinai — New York University  
 Health System  
 New York University, School of Education,  
 Division of Nursing  
 New York, NY

*Implementation, Evaluation, and Refinement  
 of an Advanced Practice Palliative Care  
 Nursing Program*

Addressing the complex physical, emotional, social, and spiritual needs of patients with life-threatening, progressive illness and their families requires nurses with advanced knowledge of palliative care. Dr. Sherman established an advanced practice palliative care master's program in nursing, the first program in the nation to prepare palliative care nurse practitioners. The program focuses on the philosophy and principles of palliative care, death and grief education, pain and symptom management, and related legal and ethical issues.



Day of the Dead ceremony  
San Francisco, CA

1999–2001

**FACULTY SCHOLARS****LaVera M. Crawley, M.D.****Barbara Koenig, R.N., Ph.D.**Stanford University Center for Biomedical  
EthicsStanford University School of Medicine  
Palo Alto, CA*Improving End-of-Life Care for the Underserved  
through Targeted Continuing Education for  
African American Physicians*

Among African Americans, attitudes towards end-of-life care are influenced by a unique sociohistoric perspective. This project builds on the team's ongoing ethnographic research on death and dying in an African American community in the San Francisco Bay Area. The information from that study revealed specific cases where effective end-of-life care was hindered by language and cultural barriers, racial bias, and mistrust. Such cases highlight the need to provide culturally competent care, and African American providers may be more favorably situated to bring that care to their African American patients. By developing a series of continuing education programs on end-of-life care aimed specifically at African American physicians, this project will increase the network of physicians capable of providing comprehensive end-of-life care to traditionally underserved communities.

**Lachlan Forrow, M.D.****Beth Israel Deaconess Medical Center**Harvard Medical School  
Boston, MA*Expanding a Palliative Care Initiative at Beth  
Israel Deaconess Medical Center and CareGroup*

Dr. Forrow created a comprehensive palliative care program for Beth Israel Deaconess Medical Center and CareGroup including a consultation service, educational programs for clinical staff, bereavement services, public education, and partnerships with other Massachusetts health care initiatives.

**Judith Eve Nelson, M.D., J.D.****Mount Sinai Medical Center**Mount Sinai School of Medicine  
New York, NY*Integrating Palliative Care in the  
Intensive Care Unit*

Patients admitted to Intensive Care Units arrive with the hope, shared by their caregivers, of reversing at least the immediate illness, if not the underlying disease. Nevertheless, 15 to 20 percent of adult patients admitted to an ICU in the United States do not survive hospital discharge. Often, death is impossible to anticipate in time to permit a shift from cure-oriented to comfort-oriented care. This project aims to examine and improve the experience of critically ill cancer patients and their families in the ICU. This new model will demonstrate that palliative care is not simply a sequel to intensive care but an essential component of comprehensive intensive care, provided concurrently to all patients.

**Steven D. Passik, Ph.D.**  
 Indiana Community Cancer Care Foundation  
 Indiana University School of Medicine  
 Indianapolis, IN

*The Oncology Symptom Control and Research Program: Creating a Palliative Care Clinical, Educational, and Research Initiative in a Community-Based, Rural, Oncology Setting*

In order to improve the quality of cancer treatment for rural patients in their own communities, this project will establish a palliative care service. The service will develop educational ties, especially with mental health programs throughout the state, to expose trainees in psychology, psychiatry, and social work to palliative care early in their careers. Through research and education, the project will increase oncologists' palliative care skills, train new practitioners, make promising palliative care research treatments available to rural communities, and contribute to the evidence base supporting palliative care interventions by monitoring patients throughout their care.

**Thomas J. Prendergast, M.D.**  
 Collaborative Medical Research Corporation  
 VA Medical Center—White River Junction  
 Dartmouth Medical School  
 White River Junction, VT

*Improving End-of-Life Care within the Intensive Care Unit*

Intensive Care Units exist to rescue desperately ill patients from imminent death. The unpredictability of the setting and the urgency of decisionmaking create a unique set of problems in the care of the dying. Physicians who specialize in critical care medicine require training in the philosophy and practice of palliative care. Dr. Prendergast 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 techniques.

**Myles N. Sheehan, S.J., M.D.**  
 Loyola University Medical Center  
 Loyola University Chicago Stritch School of Medicine  
 Maywood, IL

*Improving Care of the Dying in the American Catholic Community*

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



**1999–2001 Faculty Scholars**

(top, l to r) Lachlan Forrow, Steven Passik, LaVera Crawley, Myles Sheehan  
(bottom, l to r) Barbara Koenig, Thomas Prendergast, Joanne Wolfe,  
Judith Nelson

**Joanne Wolfe, M.D., M.P.H.**  
Dana-Farber Cancer Institute  
Harvard Medical School  
Boston, MA

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

Cancer is the leading cause of nonaccidental death in childhood. There has, however, been little evaluation of the overall experience of children who are dying of cancer or of their symptoms other than pain. Recent survey data demonstrates that the dying child experiences substantial suffering during the last month of life, frequently because physicians, intent on aggressive, curative therapies, do not focus on palliative care, even when there is little hope of a cure. This multi-institutional study will evaluate the quality of care provided to children with advanced cancer; describe the epidemiology of dying in children with cancer; examine the experiences of parents throughout the child's illness and death, and address the challenges of parent-physician communication.

2000–2002

**FACULTY SCHOLARS****Victor T. Chang, M.D.****Shirley S. Hwang, R.N., AOCN, M.S.**

VA New Jersey Health Care System

University of Medicine and Dentistry of New Jersey  
Newark, NJ*Study of Outcome Measurement in Terminal Cancer Patients*

Symptoms such as pain, fatigue, breathing difficulty, or weight loss may affect patient quality of life by interfering with function and causing distress. Care of the dying could be significantly improved if a system for providing symptom assessment and management were available and integrated into palliative care. In addition, the development of an evidence-based system of palliative care medicine is of great importance to the field. Such a system relies upon the availability of outcomes, which can be assessed and compared. This project will contribute to the development and testing of systems and outcomes for symptom management in palliative care of patients with advanced cancer.

**Anthony N. Galanos, M.D.****Duke University Medical Center, Center for the Study of Aging and Human Development**

Duke Institute on Care at the End of Life

Duke University Medical School

Durham, NC

*A Study to Determine Specific Barriers to a Good Death at a Tertiary Care, Academic Medical Center and to Initiate Change*

Communication and symptom management have always been problems when dealing with end-of-life care work. Family and staff satisfaction and closure are important issues. Dr. Galanos will define the epidemiology of death at a tertiary, academic medical center and elicit feedback from providers and families on the care and resultant level of satisfaction at the end of life. The information will be used to identify and overcome barriers to a “good death.”

**Jerome E. Kurent, M.D., M.P.H.****Center for the Study of Aging**

Medical University of South Carolina

Charleston, SC

*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. Dr. Kurent will develop and organize an easily accessible, comprehensive educational resource in end-of-life care for health care professionals and members of the community. Key content areas will include pain management, utilization of advance directives and DNR orders, spirituality in end-of-life care, and the role of the faith community in achieving a “good death.”

**Anne C. Mosenthal, M.D., F.A.C.S.**  
**Patricia A. Murphy, Ph.D., R.N., C.S., F.A.A.N.**  
 University of Medicine and Dentistry of New Jersey and University Hospital  
 Newark, NJ

*Palliative Care in an Inner City Trauma Service*

An urban inner city environment poses unique challenges to the delivery of high-quality palliative care. 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 team will design and implement systemic and replicable improvements in end-of-life care within an urban trauma service at UMDNJ's University Hospital.

**J. Cameron Muir, M.D.**  
 Palliative Care and Home Hospice Program  
 Northwestern University Medical School  
 Chicago, IL

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

Given the current economic environment in health care, emphasis on the delivery of efficient, cost-effective medicine is increasing. Dr. Muir will develop an interdisciplinary outpatient clinic for palliative care including pain and symptom management, advance care planning, and coping with advanced disease. The project seeks to evaluate and implement the development of a facility 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 the Palliative Care and Home Hospice Program.

**Kendra Peterson, M.D.**  
 Stanford University Medical Center  
 Stanford University Medical School  
 Stanford, CA

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

Little is known about the experience and needs of patients dying with malignant brain tumors. Dr. Peterson will characterize the experience of such patients and their caregivers in order to facilitate the development of improved models of care. This study is expected to generate novel insights about patient and caregiver experience and positively effect the future practices of trainees and faculty at Stanford Medical Center and providers around the country.

**Kathleen Puntillo, R.N., DNSc., F.A.A.N.**  
 University of California, San Francisco  
 School of Nursing  
 San Francisco, CA

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

People who die in Intensive Care Units suffer greatly from distressing symptoms, such as pain, difficulty breathing, and agitation. Despite advances in symptom control in other medical settings, limited research in end-of-life care in the ICU and the incomplete application of palliative care practices to this setting contribute to poor symptom control. This project will describe symptom assessment and management practices for dying patients in ICUs and use this information to design, implement, and evaluate an academic course in symptom assessment and management in the ICU.

**Kenneth E. Rosenfeld, M.D.**  
 VA Greater Los Angeles Healthcare System  
 University of California, Los Angeles  
 School of Medicine  
 Los Angeles, CA

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

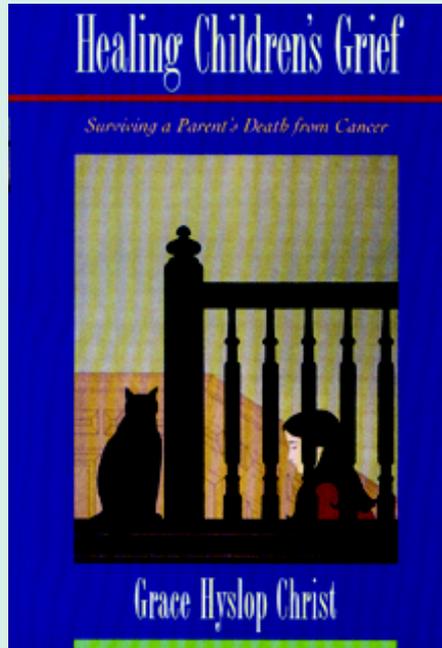
The VA Greater Los Angeles Healthcare System is the largest VA health care system in the country, serving over 70,000 veterans. The goal of this project is to implement an institution-wide quality improvement program to provide comprehensive palliative care to patients with poor prognosis conditions at the Greater Los Angeles Healthcare System. Dr. Rosenfeld will develop an organization-wide case management system to coordinate patient care, expand a home-based primary care program to serve the needs of the functionally homebound, create an inpatient hospice, develop a palliative care curriculum for clinicians, and evaluate the impact of the quality improvement program on patient care.



**2000–2002 Faculty Scholars**

(top, l to r) J. Cameron Muir, Jerome Kurent  
 (middle, l to r) Anne Mosenenthal, Shirley Huang, Kathleen Puntillo, Patricia Murphy;  
 (bottom, l to r) Victor Chang, Kenneth Rosenfeld, Kendra Peterson, Anthony Galanos

## Social Work Leadership Development Awards



Social workers provide essential psychosocial support to terminally ill patients and their families. They also provide counseling, case management, and advocacy services for the dying within numerous agencies and institutions. Social workers themselves, however, have reported gaps in graduate and post-graduate training in end-of-life care, identifying needs in the following areas of professional development:

- Clearer definition of roles and functions;
- Better preparation at the master's level;
- Continuing education for advanced knowledge and skills;
- Ongoing program innovation and evaluation;
- Development of a solid infrastructure of leaders in the field.

The Social Work Leadership Development Initiative is designed to reduce the sense of professional isolation experienced by social workers, expand their knowledge base, and improve professional practice through collaborative efforts between schools and practice sites, among practice sites, and among disciplines.

Since the program's inception in January 2000, 31 social work leaders have been selected. The awards of \$30,000 per year provide up to two years of support for projects that will strengthen professional practices and

promote innovative research, training, and policy development in end-of-life care.

These social workers represent expertise in end-of-life care in a broad range of populations: older adults, persons with AIDS, oncology patients, persons with disabilities, members of minority communities and disadvantaged groups, pediatric patients, and incarcerated adults. They work with or within child welfare services, state regulatory agencies, bioethics organizations, hospice and palliative care programs, and community services. Many of the social work leaders also have served as program administrators, teachers, researchers, and policy developers.

During the first year and a half of the program, social work leaders developed new educational and training opportunities for social workers and other health professionals in end-of-life care; technologically innovative forums for the cross fertilization of ideas; a knowledge base that will support new models of care and policy improvements; and new approaches to ethnically diverse, disadvantaged, and vulnerable populations.

This initiative has given the social work leaders the support, visibility, and recognition they have needed to be more effective leaders within their institutions, schools, and agencies. As a result, there has been a dramatic increase in the number of programs, presentations, books, articles,

and funded projects being developed. The reciprocal organizational support from their institutions and schools, the national social work organizations, and other funding agencies has been extraordinary.

Among the initiatives undertaken by these leaders are projects national in scope, such as the highly successful Social Work and End-of-Life Care Symposium organized in November 2000 by Susan Blacker of the Johns Hopkins Oncology Center. A second meeting planned for 2001 will examine the educational role of social workers for patients, families, and other professionals addressing psychosocial challenges at the end of life. Another leader, Barbara Dane of New York University's Ehrenkranz School of Social Work, has developed a curriculum for social work professionals that highlights such topics as children's grief, spirituality, ethnicity and diverse populations, and ethics. At the Smith College for Social Work, Joan Berzoff has developed a program leading to a post-master's training certificate in end-of-life care.

Pursuing the means to sustain these projects and institutionalize the social work leaders' programs is already a focus of many discussions. Collaborations have been initiated with such philanthropies as the Last Acts Campaign of the Robert Wood Johnson Foundation, the Hartford Foundation Geriatric Social Work Initiative, and the

Duke Institute on Care at the End of Life. Social work organizations have also expressed interest in helping to formalize this collaborative and supportive effort within the profession, and improve the organization, delivery, and quality of care to those who are dying and bereaved.

*Grace Christ, D.S.W.*

*Project Director, Social Work Leadership Development Awards*

**MISSION**

## Social Work Leadership Development Awards

*The Social Work Leadership Development Awards encourage innovative research and training projects that reflect collaboration between schools of social work and practice sites to advance the ongoing development of social work practice, education, and training in the care of the dying. These awards promote the visibility and prestige of social workers committed to end-of-life care and enhance their effectiveness as academic leaders, role models, and mentors for future generations of social workers.*



Bailey-Boushay House in Seattle, WA, was planned, funded, and built solely to meet the needs of people living with AIDS.

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 2000–2001

## SOCIAL WORK LEADERS

**Joan Berzoff, M.S.W., Ed.D.**  
 Smith College School for Social Work  
 Center for Innovative Practice  
 Northampton, MA

*Developing a Certificate Program and Textbook  
 in End-of-Life Care*

Dr. Berzoff has developed a certificate program in end-of-life care for post-master's level social workers serving terminally ill patients and their families in hospitals, nursing homes, hospices, and in outpatient bereavement care. The program includes an innovative continuing education curriculum taught over two summers, punctuated by an eight-month supervised clinical internship. Berzoff has also developed a course on end-of-life care in the school's master's program and a textbook that will serve as an educational resource for social workers throughout the United States.

**Susan Blacker, M.S.W., L.C.S.W.-C.**  
 Johns Hopkins Oncology Center  
 Baltimore, MD

*Social Work and End-of-Life Care:  
 An Educational Initiative*

To promote the critical role of social work in end-of-life care, Susan Blacker is developing continuing education materials for social workers practicing in end-of-life care, including two national conferences. The initiative includes an intensive post-master's training opportunity to encourage new social work graduates to specialize in palliative care, and establish a social work network to promote collaboration and training.

**Iris Cohen, M.S.W., A.C.S.W., L.I.C.S.W.**  
 Beth Israel Deaconess Medical Center  
 Boston, MA

*Multidisciplinary Care Tools: Teamwork and  
 Family Conferences in Palliative Care*

Palliative care is widely accepted as multidisciplinary, but few opportunities are available for members of the disciplines to learn about each other's unique contributions to the team. This program trains social workers and medical staff together in teamwork and family conferencing skills within the context of palliative care. The training for graduate and medical students is primarily experiential and designed to enable social workers to be role models and leaders within interdisciplinary teams and across treatment sites.



**Social Work Leaders 2000–2001**

(top, l to r) Jim Keresztury, Iris Cohen, Gary L. Stein;  
(bottom, l to r) Mary Sormanti, Joan Berzoff, Barbara  
Dane, Susan Blacker

**Barbara Dane, Ph.D.**  
New York University-Ehrenkranz School  
of Social Work  
New York, NY

*University/Agency Collaboration to Advance  
Training in End-of-Life Care*

In order to improve postgraduate training for social workers, Dr. Dane will bring 10 agency-based social work experts together with NYU faculty members to design a new palliative care curriculum. The curriculum will pay particular attention to pain management and ways to address spirituality and culture in various service settings.

**Jim Keresztury, L.C.S.W., A.C.S.W., M.B.A.**  
Center for Health Ethics and Law  
West Virginia University School of Social Work  
West Virginia University School of Medicine  
Morgantown, WV

*Social Work End-of-Life Training — A Network  
Approach*

Jim Keresztury will establish a statewide network for social workers in end-of-life care, provide yearly training opportunities for social work students and practitioners, publish quarterly newsletters, and provide ongoing support and consultations on end-of-life care issues to social workers in diverse health care settings. Keresztury will develop a graduate and postgraduate curriculum to address gaps in knowledge in social work education throughout the state.

**Mary Sormanti, M.S.W., Ph.D.**  
Columbia University School of Social Work  
New York, NY

*State-of-the-Art Psychosocial Care for the Dying  
and Those Who Love Them*

In order to maintain the highest quality care in a complex health care environment, social workers are challenged to develop innovative, cost-effective methods of outreach and intervention for patients and family members whose relative isolation from formal supports puts them at greater risk for psychosocial dysfunction. Dr. Sormanti will develop, implement, and evaluate telephone support groups for cancer patients and their families. The project will develop evaluation tools to assess the efficacy of these support groups, and to serve as a model for measurement of new technologies in social work programs.



From the PBS series *Our Own Terms: Moyers on Dying*



**Social Work Leaders 2000–2002**

(top, l to r) John F. Linder; Margo Okazawa-Rey, Terry Altilio, Susan Taylor-Brown;  
(bottom, l to r) Katherine Walsh-Burke, Norma del Rio, Elisabeth Mayfield Arnold,  
June Simmons

**Gary L. Stein, M.S.W., J.D.**  
New Jersey Health Decisions  
Verona, NJ

*The Excellence in End-of-Life Care Fellowship for  
Social Workers*

In partnership with the Kean University Department of Social Work, this fellowship will develop, pilot, evaluate, and disseminate a model palliative care curriculum to improve the professional education and practice of social workers in palliative care services and end-of-life care for the elderly and people with disabilities. This will be New Jersey's first comprehensive initiative to educate social work practitioners in end-of-life care.

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 2000–2002
 

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## SOCIAL WORK LEADERS

**Terry Altilio, A.C.S.W.**  
 Department of Pain Medicine and  
 Palliative Care  
 Beth Israel Health Care System  
 New York, NY

### *A Multidimensional Intervention for Social Workers in Palliative and End-of-Life Care*

A collaboration among social workers and the multidisciplinary staff of a major pain medicine and palliative care facility, this project will create a six-month social work fellowship program, which will include rotations through an inpatient palliative care and hospice unit, consultation service, and ambulatory practice. To facilitate communication, Terry Altilio will create an email listserv and specific Internet teaching modules on pain and symptom management and principles of palliative care.

**Elizabeth Mayfield Arnold, L.C.S.W., Ph.D.**  
 School of Social Work  
 The University of North Carolina at  
 Chapel Hill  
 Chapel Hill, NC  
 Duke Institute on Care at the End of Life  
 Durham, NC

### *Unmet Patient Needs at the End of Life: The Hospice Social Work Response*

The School of Social Work at UNC-CH and the Carolinas Center for Hospice and End-of-Life Care will collaborate to survey hospice social workers on their experiences with patients who expressed unmet needs at the end of life, including those who expressed a desire to hasten death. An interdisciplinary team representing social work, nursing, pastoral care, and medicine will use these findings to develop a training curriculum for practicing social workers and students in the two-state area. The team will also develop guidelines for social work practice in hospice settings when patients express a desire to hasten death.

**John F. Linder, L.C.S.W.**  
 University of California, Davis, Health System  
 West Coast Center for Palliative Education  
 and Research  
 Department of Internal Medicine and UC  
 Davis Cancer Center  
 Sacramento, CA

### *Fostering Interdisciplinary Cooperation in the Delivery of Enhanced End-of-Life Care Through a Collaborative Social Work/Clergy Graduate Curriculum*

John Linder 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 University of California, Berkeley, School of Social Welfare, in conjunction with Berkeley's Graduate Theological Union. Using a combination of didactic and experiential approaches, participants will be encouraged to examine their personal beliefs about mortality, and develop social work/clergy collaborative approaches to caring for dying patients and their families.

**Margo Okazawa-Rey, M.S.S.S., Ed.D.**  
**Norma del Rio, M.S.W.**  
 Institute for Multicultural Research and  
 Social Work Practice  
 San Francisco State University  
 San Francisco, CA

*Multicultural Social Work Practice with Clients  
 at the End of Life*

The threat of terminal illness often causes patients, families, and caregivers to experience fear, frustration, anger, and hopelessness. The project team surveys the needs of social work practitioners doing cross-cultural practice with clients at the end of life, individuals who are facing a progressive life-threatening illness, and directors of agencies providing end-of-life care and/or social services in the project's target populations from African American, Chinese, Latino, and Russian communities. The goal is to develop a multicultural assessment tool for use by medical social workers and to design a course on multicultural end-of-life care for graduate students at San Francisco State University School of Social Work.

**W. June Simmons, M.S.W., L.C.S.W.**  
 Partners in Care Foundation  
 Burbank, CA

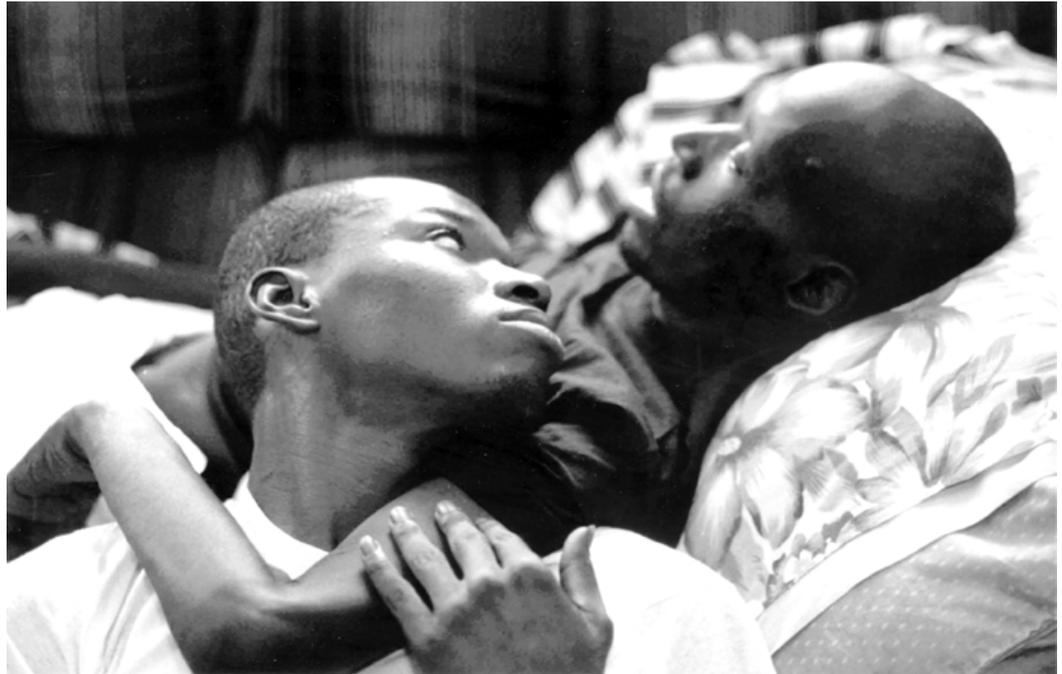
*End-of-Life Social Work Field Education Project*

Seeking to address the national need for defined core competencies, training, and field programs for social workers in end-of-life care, a regional coalition of agencies and graduate schools of social work in the Los Angeles area will develop, implement, and disseminate an integrated model of graduate level social work field and academic training. This academic/practice partnership, involving the University of Southern California, the University of California, Los Angeles, and the California State Universities at Long Beach and at Los Angeles, will serve as a new model to influence social work end-of-life care programming in graduate education nationally by shaping optimal practice standards.

**Susan Taylor-Brown, Ph.D., M.P.H., A.C.S.W.**  
 Greater Rochester Collaborative  
 M.S.W. Program  
 Nazareth College — State University of New  
 York College at Brockport  
 University of Rochester Medical School  
 Rochester, NY

*Enhancing the Care of Families Living with HIV/  
 AIDS: A Clinical, Educational, and Research  
 Initiative in a Community-Based HIV Care  
 Facility with a Family Camping Component*

The Greater Rochester Collaborative M.S.W. Program, the Community Health Network 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 series of learning opportunities delivered at the outpatient treatment facility will improve the ability of social work students, practitioners, and educators to work with families experiencing death and loss related to HIV/AIDS. An intensive family camp experience will enhance learning opportunities for social workers.



**Katherine Walsh-Burke, M.S.W., Ph.D.**  
Association of Oncology Social Work  
Springfield College School of Social Work  
Springfield, MA

*Internet-based Continuing Education Curriculum*

Dr Walsh-Burke will develop an Internet-based continuing education program for social workers affiliated with the 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.

**MISSION**

## Nursing Leaders

*Nurses in all practice settings and roles are faced with the daily challenges of providing humane, dignified end-of-life care to patients and their families. The Project on Death in America is committed to supporting role model nursing leaders through a Nursing Leadership Consortium and Educational Initiative.*

*This initiative aims to develop a cadre of expert nursing educators, to coordinate national nursing efforts in end-of-life care, and to facilitate the dissemination of a core curriculum that provides practicing nurses with the basic knowledge and skills needed to appropriately care for dying patients.*



*Child* by Deidre Scherer

### **American Association of Critical Care Nurses**

Aliso Viejo, CA

*Cynthia Hylton Rushton, DNSc, R.N., F.A.A.N.*

**\$97,550**

#### *Nursing Leadership Consortium on End-of-Life Care*

In 1999, the Consortium brought together leading nursing organizations to develop a coordinated and collaborative agenda within the areas of practice, policy, research, and education to improve care at the end of life. The group identified the needs related to end-of-life care, chose options that should receive the most attention, and gained preliminary commitment from participants to pursue the prioritized agenda. The group summarized priorities for the profession in the following categories: issues in education, professionalism, and clinical patient care; research; patient and family advocacy; decision making; culture; systems of care; resource allocation; and policy.

### **Johns Hopkins University**

Baltimore, MD

*Cynthia Hylton Rushton, DNSc, R.N., F.A.A.N.*

*Kathleen Hartman Sabatier, M.S., R.N.*

**\$200,000**

#### *Nursing Leadership Academy in End-of-Life Care*

Leaders from 22 national nursing organizations representing 463,000 nurses attended the 2000 Nursing Leadership Academy in End-of-Life Care. The academy built on the commitment and strength demonstrated by nursing specialty organizations at the 1999 Nursing Leadership Consortium by educating, training, and organizing a network of nursing leaders to advance the priorities established by the consortium. Nomination to the academy was competitive, and designed to identify those nurses most likely to successfully implement changes to improve the care of dying patients and advance the field of palliative care. Nurse participants and the organizations that nominated them were required to commit to a minimum of two years of activity related to the improvement of palliative care. Leadership Academy participants developed specific plans for their respective organizations designed to generate the greatest impact on the field as a whole. Plans and accomplishments thus far include:

- The Oncology Nursing Society and the Oncology Nursing Society Foundation committed \$20,000 in seed money to initiate ten grassroots community projects on end-of-life issues, using the Bill Moyers PBS series *On Our Own Terms* as a model.
- The Hospice and Palliative Nurses Association is developing a network of nursing experts in end-of-life care to serve as resources to nursing leaders nationwide.
- The Association of Pediatric Oncology Nurses will conduct a pilot study to determine beliefs and attitudes that affect the ability of pediatric nurses to provide quality palliative care.

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**“Every person has the right to die with dignity in a manner he or she feels is appropriate. Nurses confront end-of-life issues every day, and understand the dire need for quality palliative care. This Nursing Academy showed us how critical it is for all nurses to stand behind this issue as a unifying force for the profession. If we speak with one voice, nurses can make a difference in the way palliative care is delivered to individuals, families, and communities.”**

Marcia Kucler, the Academy of Medical Surgical Nurses

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## **New York University**

New York, NY

*Deborah Witt Sherman, Ph.D., R.N., A.N.P., C.S.*

**\$50,000**

### *Advance Practice Palliative Care Credentialing Examination*

Training graduate nurses as expert practitioners in palliative care is critical to improving the well-being of the seriously ill and dying in America. Most states require that a nurse practitioner be certified in order to practice in a specialty area. Furthermore, nurse practitioners will no longer be eligible for Medicare reimbursement in the year 2001 unless they have passed the certification examination in their specialty area. Currently, there is no such certification process in advanced palliative care, which constitutes a serious obstacle in recruiting nurses to pursue advanced practice in this area. This grant supports the creation of a nationally recognized nursing certification examination in advanced practice palliative care.

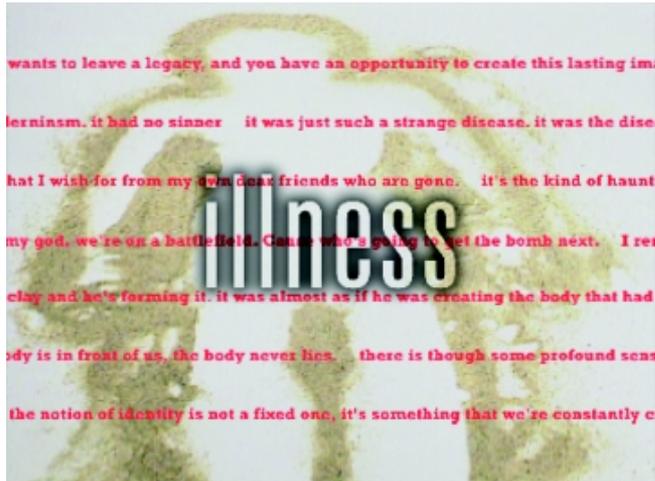
- The American Association of Critical Care Nurses will develop standard practice guidelines to apply to end-of-life care, identify gaps in knowledge, and propose new directions for research on topics such as patient comfort, compassionate care, symptom management, and withholding and withdrawing life sustaining treatments.
- The Institute for Johns Hopkins Nursing has created a web site hosted by Sigma Theta Tau, the nursing honor society, to centralize access to information and resources related to palliative care nursing. For more information, see [www.palliativecarenursing.net](http://www.palliativecarenursing.net).

## ARTS AND HUMANITIES INITIATIVE



From *Singing Myself a Lullaby*

INDIVIDUALS working in the fields of the humanities, the fine arts, and the performing arts give form through language and image to experiences at the end of life. The Project on Death in America developed an Arts and Humanities Initiative in 1998 to encourage creative expression of illness, death, and mourning in order to help us understand cultural attitudes and metaphors shaping our diverse experiences of death and dying. Such work helps to identify leverage points for change within our society.



From *Singing Myself a Lullaby*

**Ellen Bromberg**  
**Douglas Rosenberg**  
 Tucson, AZ

**\$47,401**

### *Singing Myself a Lullaby*

This video documentary chronicles the creation and performance of a multimedia work by John Henry, a dancer with AIDS. An investigation of identity, *Lullaby* presents vignettes from the dancer's life, commentary by friends, family, and colleagues, and the movement rituals created by John Henry. The documentary explores one man's use of dance to make sense of his life and impending death.

**Thomas R. Cole, Ph.D.**  
 University of Texas Medical Branch  
 Galveston, TX

**\$50,000**

### *Anatomy & Humanity: Conversations with Donors and Dissectors*

This film explores the relationship between willed body donors and the medical students who rely on them to learn anatomy. In interviews, donors share their life stories, explain their decision to donate their bodies, and express their hopes for the future learning of the students. Medical students describe the emotional, moral, and spiritual struggles that accompany this sanctioned violation of the interior space of another's body.

**Sandra M. Gilbert, Ph.D.**  
 Berkeley, CA

**\$50,000**

### *Inventions of Farewell: A Book of Elegies and Death's Door: Mourning, Modernity, and the Poetics of Memory*

The central question of this two-book project is: how do poets mourn in an age of mounting theological and social confusion? The first book, *Inventions of Farewell* collects English language poems of mourning from the late Middle Ages to the present. Aesthetic assumptions and poetic styles have altered over the centuries, yet the great and often terrifying themes of time, change, age, and death are timeless. The poems here — from Emily Dickinson, Wallace Stevens, and Edna St. Vincent Millay to Sharon Olds, Stanley Kunitz, and W.S. Merwin — trace the trajectory of grief, and illustrate how the deepest sorrow has produced countless poignant and resonant works of art. The second arm of this project, a book entitled *Death's Door: Mourning, Modernity, and the Poetics of Memory* will examine literary modes of mourning through a combination of memoir and meditation, cultural criticism and literary analysis.

**Richard Kamler**

Berkeley, CA

**\$49,700***The Waiting Room*

This interactive art installation, built to the exact specifications of the death row visiting room at San Quentin Prison in California, uses sound, image, and experience to evoke thought and conversation about the various ways that the death penalty contributes to our collective cultural perceptions of death and dying. Along with its standing as a major new piece of interactive installation art, *The Waiting Room* will serve as a gathering place for a series of interrelated community conversations about crime, punishment, and democracy. These community conversations will bring together parents of death row inmates, survivors of violent crime, ex-offenders, youth groups, workers from the correctional community, activists, politicians, and religious leaders to discuss the effects of the senseless infliction of death upon our culture.

**Ed Kashi  
Julie Winokur**

San Francisco, CA

**\$50,000***Aging in America*

*Aging in America* is a compilation of photographs and essays exploring the unprecedented strains placed on the elderly and their caregivers. The work examines innovative solutions being pioneered to deal with the end stages of life. Using words and pictures, the project documents the experiences of elderly prisoners and veterans, the upsurge of elderly immigrants who follow their children to America, semi-independent living for the frail elderly, and the impact of natural disasters on seniors.

**Meryl Levin**

New York, NY

**\$37,350***Anatomy of Anatomy: In Words and Images*

A book and traveling exhibition, this project 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. Levin's images and text are touring medical education centers across the country as a springboard for reflection and discussion. This project challenges students early in their training to learn more than simply the names and actions of the muscles and nerves in the body. It encourages them to come to terms with the mortality of others, and through that, their own.



Wong Wah Po, 104, is pushed through the streets of San Francisco's Chinatown by an 86-year-old volunteer. Po currently lives at On Lok, an organization that has become a national model for keeping elders out of nursing homes by providing health care, day care, and social services. From *Aging in America*.



*Magic Frequencies* by Meredith Monk

**Nancy Mairs, Ph.D.**  
Southwest Institute for Research on Women  
University of Arizona  
Tucson, AZ

**\$50,000**

*Life's Worth: Rethinking How We Live and Die*

This project resulted in a book entitled *A Troubled Guest, Life and Death Stories*. Nancy Mairs's personal essays, informed by theology, disability studies, and feminist theory, deal with the deaths of her parents and son, her attempted suicide, and her growing relationship with a young man on death row.

**Meredith Monk**  
House Foundation for the Arts, Inc.  
New York, NY

**\$50,000**

*Magic Frequencies*

Meredith Monk's interdisciplinary performance work examines life and death through visitations of beings from other realms. It considers the idea of several different realities existing simultaneously. This grant also supports a series of conversations on death and dying that will become part of the touring component of the piece.

**Eugene Richards**  
Many Voices, Inc.  
Brooklyn, NY

**\$50,000**

*but, the day came*

This video documentary interweaves color and black-and-white images, still and moving pictures, natural sounds, music, and interviews to document the journey of a fiercely independent 92-year-old from his Nebraska farm into a nursing home. Begun as a chronicle of a man's life in productive old age, the work speaks to what it means to lose one's homestead, one's fragile hold on the past, and one's reason for living.

**\$50,000**

*Long as I Remember* and *All That's Sacred*

These films address the complicated experiences we face at the end of life. The first takes the viewer inside the same nursing home that the aged farmer in *but, the day came* wished to avoid. It documents the lives of residents, touching at first on the events and decision-making that preceded their placement. *All That's Sacred* was inspired by the death of the filmmaker's father-in-law. It will study the effect of one person's death on the fabric of a community.



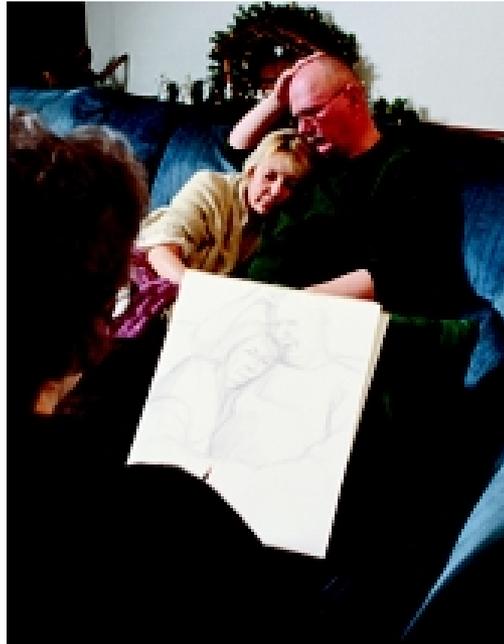
**Deidre Scherer**

Williamsville, VT

**\$50,000**

*Surrounded by Family and Friends*

Through the unusual medium of fabric-and-thread panels, the artist evokes how families and friends, in offering support to the dying, behold the most powerful of life's events. The work consists of six life-sized panels portraying the richness and complexity of our relationships at the end of life.



*Bigger Than Each Other*  
by Deidre Scherer

**Lisa J. Schnell, Ph.D.**

Burlington, VT

**\$50,000**

*Learning How to Tell*

The brief life and death of Lisa Schnell's youngest daughter, Claire Margaret, who suffered from a rare birth defect called lissencephaly, introduced Schnell to a world of tremendous suffering that produced in her a sense of exile from her own life story. This book records the mother's intellectual and spiritual journey through a life of immeasurable loss and love.

**David R. Slavitt**

Philadelphia, PA

**\$50,000**

*Translation of the Book of Lamentations*

Loss and grief were once acknowledged and institutionalized in our religious and cultural life as an inevitable part of human experience. This new translation of the *Book of Lamentations* — one of the most important expressions of these dark but vital truths — places the biblical text in a social and historical context, and helps the reader make connections to personal encounters with grief.

**Alan Shapiro**

Chapel Hill, NC

**\$50,000***The Dead Alive and Busy*

The author's poems deal 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. They 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. Shapiro continues to explore these themes in another book of poems, *Song and Dance*, due to be published in 2002.

**Sleet**

*What was it like before the doctor got there?*

Till then, we were in the back seat of the warm dark bubble of the old Buick. We were where we'd never not been, no matter where we were.

*And when the doctor got there?*

Everything outside was in a rage of wind and sleet, we were children, brothers, safe in the back seat, for once not fighting, just listening, watching the storm.

*Weren't you afraid that something bad might happen?*

Our father held the wheel with just two fingers, even though the car skidded and fishtailed, and the chains clanged raggedly over ice and asphalt.

*Weren't you afraid at all?*

Dad sang for someone to fly him to the moon, to let him play among the stars, while mom held up the lighter to another Marlboro.

*But when the doctor started speaking...*

The tip of the Marlboro was a bright red star. Her lips pursed and she released the ring of Saturn, which dissolved as we caught at it, as my dad sang Mars.

*When you realized what the doctor was saying...*

They were closer to the storm in the front seat. The high beams weak as the steam against the walled swirling only illuminated what we couldn't see.

*When he described it, the tumor in his brain and what it meant...*

See, we were children. Then we weren't. Or my brother wasn't. He was driving now, he gripped the steering wheel with both hands and stared hard at the panicked wipers.

*What did you feel?*

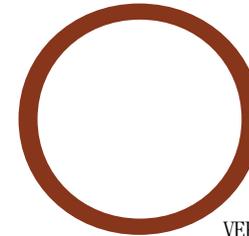
Just sleet, the slick road, the car going way too fast, no brother beside me in the back seat, no singing father; no mother; no ring of Saturn to catch at as it floats.

*Alan Shapiro, from his forthcoming book Song and Dance*

## COMMUNITY SUPPORT FOR GRIEF AND BEREAVEMENT



AIDS quilt in Washington, D.C.



OVER 25 million individuals die in the United States each year. Estimates vary widely as to how many people are directly affected by these deaths, and it is even more difficult to estimate how many people will experience compromised health due to grief and bereavement.

A significant cause of needless suffering is the inadequacy of contemporary support for the experience and expression of grief. Death is impersonalized in the move from home to hospital, and geographic mobility and age-segregated living arrangements have eroded the personal bonds of family and other societal connections that formerly served to support the grieving. Too many people grieve alone, and this isolation intensifies fears about the loneliness of their own deaths. Some particular communities, moreover, have experienced so many deaths that the need for sustained support in bereavement has increased accordingly. The goal of this funding initiative is to enhance the capacity of individuals and of communities to grieve and to support one another in the experience of grief.

### American Hospice Foundation, Inc.

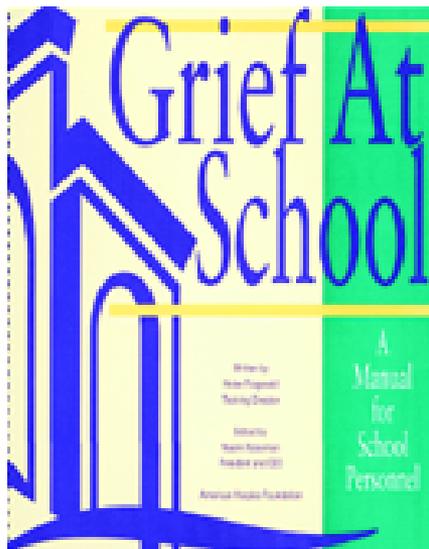
Washington, DC

*Naomi Naierman, M.P.A.*

**\$80,000**

#### *Grief-at-School Training Program*

Each year, millions of children and adolescents grieve over the death of a loved one. It is well documented that most Americans are not comfortable talking about death and grief, and this discomfort can have grave consequences for children who may receive little help developing constructive coping skills from the adults around them. For all children, school plays a vital role in shaping social skills; for a growing number of children, school fills the void left by family breakups. School personnel understand the burdens that children bring to school, but they are not adequately trained to respond. This project will expand an existing program by training members of national associations of school-based professionals. The program offers a 15-hour workshop to prepare schoolteachers, counselors, psychologists, nurses, and social workers to help grieving children in the classroom and after school. Participants learn to identify grieving children, conduct age-appropriate classroom lessons on loss and grief, establish school-based grief support groups, and use hospices as a local resource for grief expertise.



**\$52,876**

#### *Toward a Model Grief-at-School Training and Education Program*

The American Hospice Foundation designed and tested a model for a school-based grief program in 14 schools in Phoenix, Arizona and Washington, D.C. The model included training workshops for school personnel, after-school support programs for grieving students, and comprehensive, age-appropriate grief curricula.

### Baptist Health Systems of South Florida Foundation, Inc.

Miami, FL

*Rev. Dale A. Young*

**\$74,870**

#### *CHAMPS for Supportive Services*

The population of South Miami-Dade is largely comprised of new immigrants from multi-racial and multi-cultural backgrounds. The experience of death and grief can be especially complicated for the culturally and socially uprooted, who are often isolated from familiar support systems. 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.

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**“I was sleeping in my bed one night and gun shots woke me up. My heart was beating fast and I pulled my covers close to me. After a few minutes I started thinking how I’m going to die, how I want to die, and I’m scared to die.”**

Caroline Adeoye, age 14

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**Boston University School of Medicine  
Department of Pediatrics**

Boston, MA

*Marie Trozzi, M.Ed.*

**\$75,000**

***The CIRCLE: A Good Grief Program to Provide Support Groups and Consultation for Children and Families***

Located in Boston’s South End, the department of pediatrics and its affiliated teaching hospital serve a predominantly minority constituency of the poor, working poor, and lower-middle class. The children in this community are exposed to a disproportionately high number of deaths compared to their peers in surrounding suburbs, and they are vulnerable to the pervasive stresses associated with poverty and minority status. The CIRCLE will make grief support available to these children and their families through peer support groups, trained volunteers, community outreach, and clinical counseling services within individual neighborhoods of the city.

**The Cooper Green Hospital Foundation, Inc.**

Birmingham, AL

*F.Amos Bailey, M.D., FA.C.P.*

**\$65,835**

***Bereavement in the Balm of Gilead***

The Balm of Gilead program, the hospital’s palliative care initiative, will identify the needs of the bereaved in a low-income population served by the program, develop collaborations and new resources to address these needs, and evaluate the effectiveness of different bereavement response strategies. This comprehensive bereavement program will allow researchers to gather information with significant programmatic and policy implications for addressing vital needs in a typically underserved segment of the nation’s health consumer population.

**Harbor Hospital Center, Inc.**

Baltimore, MD

*Howard Reznick, L.C.S.W.-C.*

**\$57,000**

***Maryland Parish Nurses Network Bereavement Training Program***

This project represents a collaboration of Harbor Hospital Center, Psychiatry Services’ Safe Harbor Counseling, and the Maryland Parish Nurses Network. The 150 highly committed, primarily volunteer nurses in this parish provide screening, education, and direct delivery of health care services to members of their church or faith community. Their experience in addressing the physical and spiritual needs of people make them well suited to provide bereavement support. This project will fund ongoing clinical support and a series of learning opportunities to allow the nurses to acquire grief counseling skills.

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

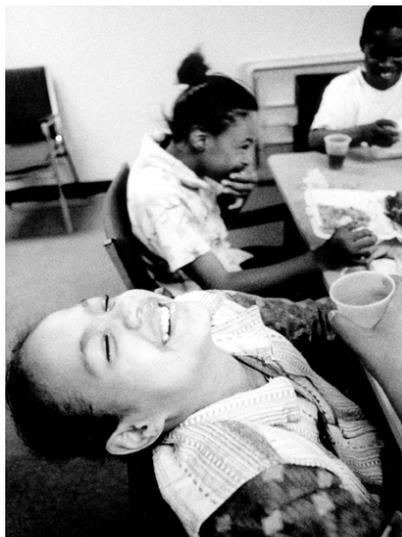
Duluth, MN

*Ben Wolfe, M.Ed., L.I.C.S.W.*

**\$69,500**

***Hospital-Based Grief and Bereavement Community Programming***

This project will establish a hospital-based community grief and bereavement program, collaborating with local, regional, and state agencies and organizations to educate more than 2,500 professionals about grief and bereavement. The training is designed to facilitate the creation or improvement of end-of-life and bereavement support groups. Participants will be encouraged to develop and collaborate on grief education programs within their own health care settings, organizations, or religious communities.



Interfaith Neighbors Children's Bereavement Project, East Harlem, NY

**Service Employees International Union LA Homecare Workers 434**

Los Angeles, CA

*Tyrone Freeman*

**\$75,000**

***Homecare Workers Grief and Education Project***

The more than 74,000 members of this ethnically diverse union of homecare workers help tens of thousands of low-income elderly, disabled, and terminally ill people live out their lives in their own homes. This project will educate homecare workers about managing the grief and bereavement they regularly experience in their work and improve the quality of care they provide to their dying clients.

**University of Hawaii**

Honolulu, HI

*Kathryn L. Braun, Dr.PH., M.P.H.*

**\$75,000**

***Care for the Bereaved***

Sponsored collaboratively by the University's 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 faced by grieving individuals and ensure that the quality of their care will be culturally and spiritually competent.

**University of South Carolina**  
Columbia, SC

*Lois Wright, M.S.S.W., Ed.D.*

**\$74,811**

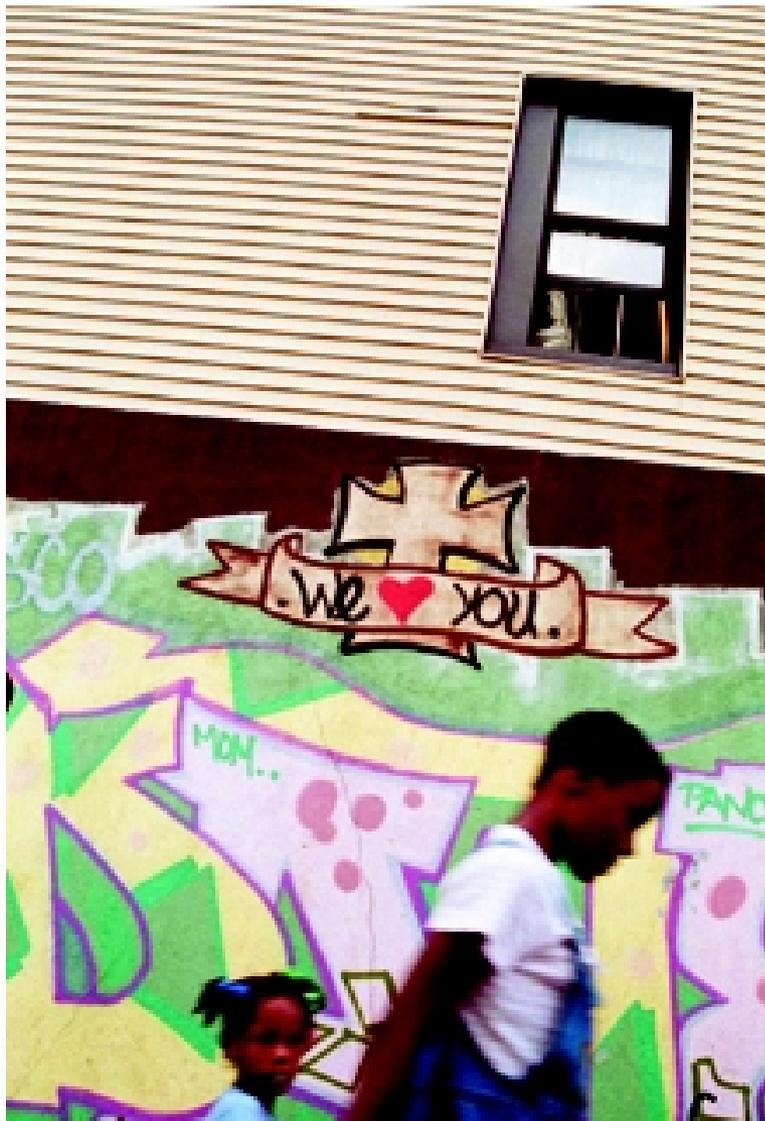
*Dying Well — An Interfaith Approach for  
Community Volunteers*

The University's Center for Child and Family Studies will partner with interfaith community-based groups including the South Carolina Coalition of Black Church leaders, the Christian Action Council, and the Palmetto Faith and Health Consortium to design and develop an interfaith, interdisciplinary information resource center.

The project will also train volunteers of various faith communities to enhance their ability to help others effectively deal with death and bereavement.



Family remembering their father and grandfather who served in the army, outside of Window Rock, AZ.



The Ethnographic Gaze: Teenagers Journey through Walls of Loss

### Virginia Mason Medical Center

Seattle, WA

*Edward K. Rynearson, M.D.*

**\$75,000**

#### *The Echo Glen Project*

Many incarcerated youths are too familiar with violence, and often experience traumatic and retaliatory responses to violent deaths. This project will focus on providing incarcerated adolescents with a short-term educational program to diminish the pervasive dysfunctional effects of their experiences. Learning healthier responses to violent dying will help these young people return to their communities and serve as healthy and productive role models. This project will collect pre- and post-treatment data documenting changes over time, and use this data to form the basis for a more comprehensive, controlled study of the stability of effects and recidivism rates.

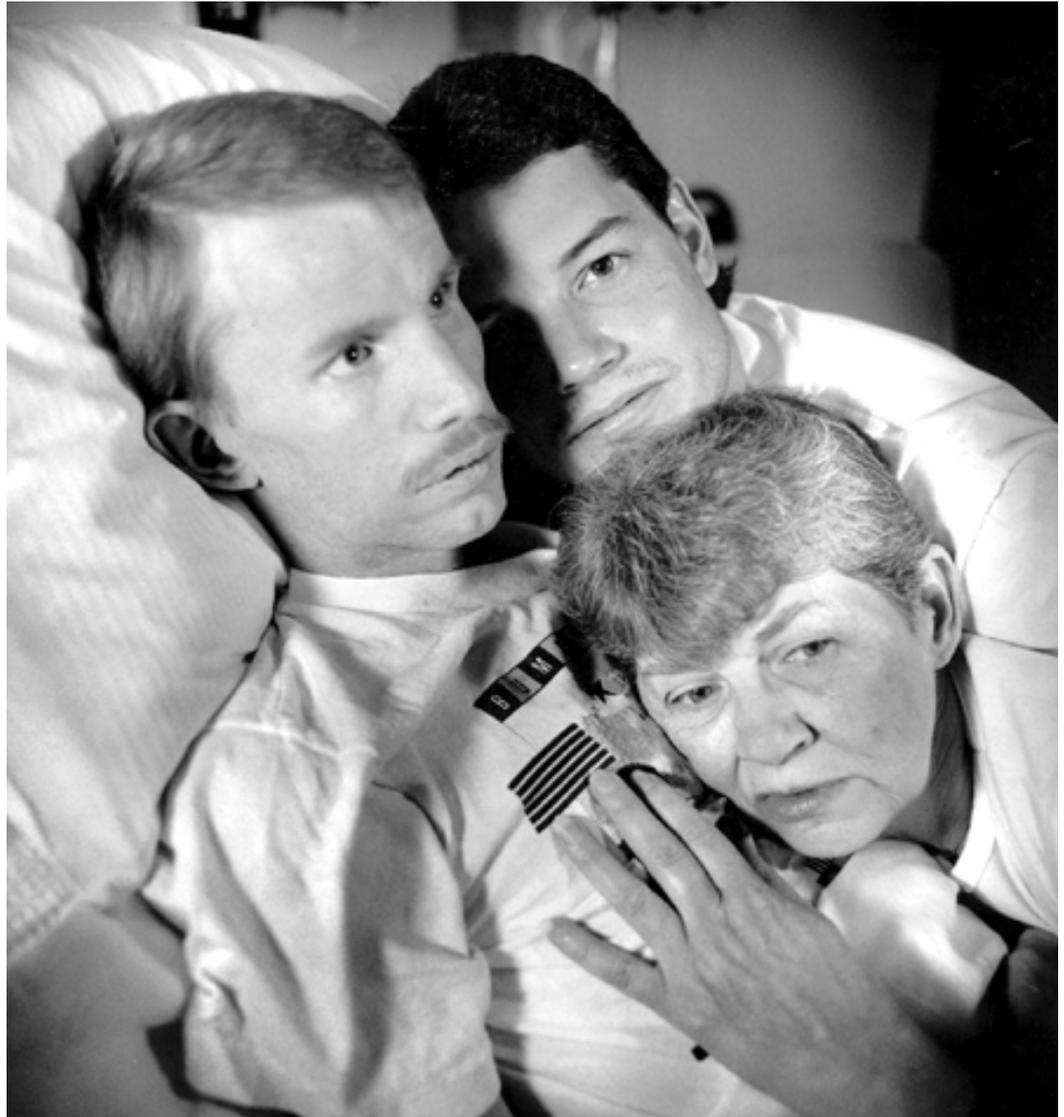
**William Wendt Center for Loss and Healing**  
Washington, DC

*Duane T. Bowers, L.P.C.*

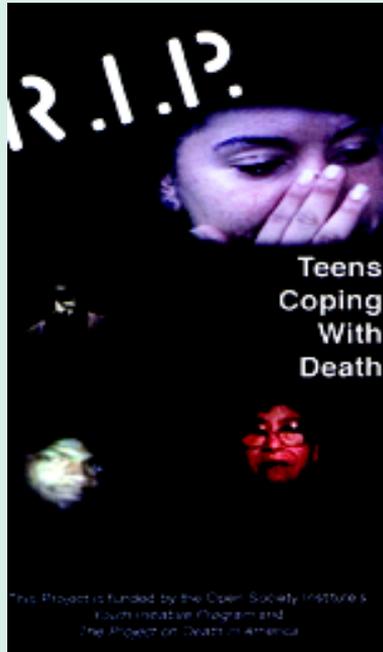
**\$75,000**

*Recover*

In urban settings such as the District of Columbia, as many as 35 percent of deaths occur as the result of accident, homicide, or other sudden causes. Many individuals, families, and children who are required to identify the deceased at the D.C. Office of the Chief Medical Examiner must grapple not only with the complexities of the sudden death of a family member, but also with the constant exposure to violence in their communities. Working collaboratively with the D.C. Office of the Chief Medical Examiner, the William Wendt Center provides immediate and ongoing support for families throughout and after the identification process. This program offers professional grief counseling services supplemented by practical and emotional support by trained, supervised volunteers.



## Youth Media Project: Teenage Experiences of Death



*In July 1999, the Open Society Institute's Youth Initiatives Program, led by Program Director Erlin Ibrek, and the Project on Death in America launched a joint initiative, Teenage Experiences of Death. Eight New York City youth media organizations were funded to document the texture and variety of teen experiences with death and grief.*

*Teenage Experiences of Death connects youth perspectives to a broader debate about one of the toughest human issues. The fresh, direct, and perceptive insights of the youth participants provide a powerful collection of materials that inform the work of professionals who work with young people, as well as the young people themselves. The projects — in video, print, radio, photography, and the Internet — have aired or been exhibited throughout 2000 on public television and in communities throughout the country. The Project on Death in America and the Youth Initiatives Program also supported a half-hour special for the In the Mix PBS series.*



### *In the Mix*

New York, NY

*Sue Castle*

**\$35,000**

### *Dealing with Death*

*In the Mix*, a weekly PBS series for teens, produced the thirty-minute television program *Dealing with Death*. Including excerpts of projects produced by the Arthur Ashe Institute for Urban Health, Harlem Writers Crew, and DCTV, the show explores how young people in our society grapple with death. *Dealing with Death* is enhanced by a teacher discussion guide and a website ([www.pbs.org/inthemix](http://www.pbs.org/inthemix)) that includes youth-produced writing, photography, contact information, and resources. The website provides a message board that serves as an outlet for young people to discuss death.

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**“I’ve always seen my own life as a way to communicate to others about what I’ve seen in the world, about my experiences in the hospital, about dealing with illness, being able to get through something tough that kinda sucks, you know? I think I helped my friends in high school as much as they were helping me, you know? I think they had a better time in high school — in life — on a day-to-day basis because they knew what a gift they had.”**

Laura, 19-year-old college student with cystic fibrosis, from *In the Mix*

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### Arthur Ashe Institute for Urban Health, Inc.

New York, NY

*Ruth C. Browne, M.P.H.*

**\$5,950**

### *Special Issue: Urban Health Chronicles*

The institute, which provides health education in traditional and nontraditional settings, published a special issue of its youth-produced newspaper, *Urban Health Chronicles* ([www.soros.org/death/uhc.pdf](http://www.soros.org/death/uhc.pdf)), that examined how young people experience and cope with death. Teenage staff members explored their personal experiences through poetry, interviewed family members and close friends, and investigated the scientific and sociological factors that relate to loss and bereavement.

### Downtown Community Television Center, Inc.

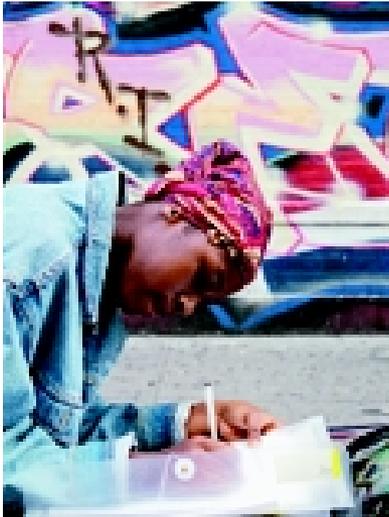
New York, NY

*Hye-Jung Park*

**\$6,000**

### *R.I.P. — Teens Coping with Death*

Downtown Community Television ([www.dctvny.org](http://www.dctvny.org)) teaches members of low-income and minority communities to produce insightful and artistic television. In this 23-minute documentary, *R.I.P. — Teens Coping with Death*, teen producers interview peers from their community about their experiences with death.



Harlem Writers Crew

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**“The project is just about taking death into our own terms and explaining how we feel about it. We just went around New York like Manhattan, Brooklyn, the Bronx, takin’ pictures of a lot of R.I.P. graffiti, and just talking about what we think of that picture. R.I.P. murals in New York City are just like remembrances of the person from the hood. Like people who die, kids, old people, everybody so the hood can remember them, and make sure people won’t forget them.”**

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Reynold Lewis, member of the Harlem Writers Crew

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### Educational Video Center, Inc.

New York, NY  
*Steven Goodman*

**\$6,000**

#### *At One Time or Another: How Teens Grieve*

Through the center’s video production workshop, New York City public high school students gained hands-on production experience and learned how to interview peers about their experiences with death. The resulting documentary ([www.evc.org](http://www.evc.org)) explores their different feelings when faced with the loss of a loved one. The video was screened in individual high school classes in New York City, and is excerpted in the PBS *In the Mix* special, *Dealing with Death*.

### Global Action Project, Inc.

New York, NY  
*Susan Siegel*

**\$6,000**

#### *Project: webShop — Teenage Experiences of Death and Loss*

Students attending an eight-week multimedia summer workshop produced *webShop — Teenage Experiences of Death and Loss* ([www.global-action.org/webshop](http://www.global-action.org/webshop)), a website that documents their research and personal explorations of death and bereavement.

### Harlem Writers Crew Project Foundation, Inc.

New York, NY  
*Terry Williams*

**\$6,000**

#### *The Ethnographic Gaze: Teenagers Journey through Walls of Loss*

The Harlem Writers Crew, a community-based mentoring program, works with young people to enhance their capabilities for self-analysis and self-expression. By examining the sociological implications of street art, the Crew determined that death-related memorial murals, known as R.I.P.s, are a significant form of expression for members of marginalized communities that frequently deal with violent death. The findings were represented in an exhibit, *The Ethnographic Gaze: Teenagers Journey through Walls of Loss*, at the New School University and at OSI.



Harlem Writers Crew

### Photographic Center of Harlem

New York, NY

*Jim Belfon*

**\$6,000**

#### *Summer Media Project: Photographic Journal*

The center introduces Harlem youth to photography as a recreational activity, fine art, and viable career option. Ten participants, ages 12 to 14, who were dealing with the recent or impending death of a family member used photography, writing, and other modes of expression to document their feelings of loss.

### Radio Diaries, Inc.

New York, NY

*Joe Richman*

**\$5,755**

#### *Diary of a Goodbye*

RadioDiaries ([www.radiodiaries.org](http://www.radiodiaries.org)) is producing a 30-minute documentary called *Diary of a Goodbye*. Through an audio journal/diary, the radio piece will follow the life of a teenage girl who is living with a terminal illness. The diary will help to open up discussion of death in the media and will give the young person a forum to candidly discuss her experiences.

### Youth Communication New York Center, Inc.

New York, NY

*Keith Hefner*

**\$6,000**

#### *Making Peace with the Past*

Youth Communication ([www.youthcomm.org](http://www.youthcomm.org)) used death as a topic for its high school summer journalism workshops. Through guided discussion, readings, special presentations, and writing activities, the youth participants were exposed to the subject of death and expressed their own feelings on the issue. In addition, Youth Communication editors and staff assembled a collection of articles from *New Youth Connection* and *Foster Care Youth United* that discuss death. The booklet, which is a work-in-progress called *Making Peace with the Past*, will serve as a useful tool and resource for educators and youth workers facilitating conversations about grief and bereavement.

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**“You know, for a long time I thought that when someone dies they come back  
alive the next week or next year. I didn’t know it was forever.”**

Michael Lewis, age 14

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Harlem Writers Crew

## GRANTS PROGRAM



**D**URING the period covered by this report, 1998–2000, the Grants Program of the Project on Death in America included projects that address legal, governmental, and institutional policy, strengthen care for children and their families, build the infrastructure and leadership capacity of organizations, improve palliative and end-of-life care in African American communities, and examine the care of the dying in prisons and jails.

## Initiative to Improve End-of-Life Care in the African American Community

*Many African Americans do not receive optimal health care, starting before birth and extending through the dying process. Among African Americans, national statistics document higher infant mortality rates, inadequate preventative health care, and higher death rates for cardiovascular diseases, cancer, and AIDS.*

*Like other minority groups, African Americans underuse palliative and hospice care, even when they have full access. The historical denial of access to health care, de jure and de facto segregation laws, and highly publicized ethical atrocities in medical research may contribute to a general mistrust of the health care system. From this perspective, offers of palliative and hospice care can seem like procedures to further deny access to full medical treatment, particularly when sensitive and difficult discussions occur in a context where few health care providers, especially physicians, are African American. Although there is much speculation about the underuse of palliative and hospice services in the African American community, there is little data available to provide a basis for solutions.*

*This initiative was created to delineate the historical, social, cultural, ethical, economic, legal, and medical issues that affect African American attitudes toward, acceptance of, access to, and use of palliative and hospice services.*

## Memorial Sloan-Kettering Cancer Center North General Hospital

New York, NY

*Richard Payne, M.D.*

*Harold P. Freeman, M.D.*

**\$24,204**

### *Initiative to Improve End-of-Life Care in the African American Community*

The initiative will address the following objectives:

- To create a resource center for individuals and organizations working to address the barriers to adequate end-of-life care for patients and families in the African American community;
- To provide information on end-of-life care issues, forge links between organizations, broaden the base and the level of interest in the issues, and build constituencies and coalitions;
- To develop and maintain an Internet website with links to multifaceted agencies and programs;
- To facilitate the collection, evaluation, and dissemination of information about palliative care in the African American community, highlighting historical information and summarizing current activities in end-of-life care for African Americans,



without duplicating such efforts as those undertaken by the Last Acts coalition, the National Hospice and Palliative Care Organization, the Tuskegee National Bioethics Center, or the National Medical Association;

- To meet with such organizations as the Intercultural Cancer Council, the NAACP, the National Medical Association, and the

Congressional Black Caucus, encouraging them to include African American end-of-life care issues on their national agendas;

- To continue to expand and support the development of a network of multiple organizations currently interested in addressing end-of-life care issues in the African American community.

## Shaping Governmental and Institutional Policy

*The Project on Death in America's interests in this category include evaluation and improvement of federal, state, and local government policies around dying and bereavement; the role of large, health care delivery systems; government reimbursement issues; the development and maintenance of an appropriate workforce through such practices as the establishment of accreditation and certification standards; the role of professional clinical practice guidelines; and the implications of health care reform for the care of the dying and bereaved.*

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**“Controlled substances are essential to the quality of life of millions of patients. A balanced drug policy should provide ample authority to address diversion problems, but this should be done without interfering in the use of controlled substances in the medical care of patients. Drug laws have a dual purpose; achieving both ends must be emphasized, for only in this way will the greatest health benefit be realized.”**

David E. Joranson, director of the Pain & Policy Studies Group

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## University of Wisconsin

Madison, WI

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

**\$225,000**

### *Evaluating Public Pain Policy*

The Pain & Policy Studies Group of the university's Comprehensive Cancer Center works to improve care by evaluating the extent to which the regulation, or perception of regulation, of drugs and professional practice affects pain management. It identifies and addresses the barriers to medical use of narcotic drugs, which are essential to chronic pain management and palliative care. This grant will increase the group's capacity to meet the needs of the growing number of individuals and organizations advocating for improved public policy relating to pain management.



## Building Organizational Capacity

*Creating social change requires the development of organizations that can provide the professional activities necessary to sustain and maintain the growing field of palliative care. The Project on Death in America is working with public and professional organizations to identify strategic and innovative projects that will increase their leadership and advocacy capacity, engage new audiences, and expand their collaborative efforts to institutionalize quality care as a public health issue.*

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**“In order to be taken seriously by health professionals and researchers, and ultimately, by those who allocate research and treatment monies, we need a more coherent picture of grief and its impact on health. We need a fuller understanding of the epidemiology of grief, the physical — endocrine, immune, neurological, cardiovascular, metabolic, cognitive, and emotional — effects of grief, and the development and testing of psychological and pharmacological treatments.”**

Janice Genevro, project director of the Center for the Advancement of Health

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## Grantmakers Concerned with Care at the End of Life

In 1996, the Project on Death in America, the Commonwealth Fund, the Nathan Cummings Foundation, the Robert Wood Johnson Foundation, and the Rockefeller Family Office together created Grantmakers Concerned with Care at the End of Life (GCCEL). This initiative works to expand funding in end-of-life care and serves as a resource to foundations about end-of-life care issues. Currently, GCCEL is placing major emphasis on targeting new audiences as potential supporters, bridging diverse interests of grantmakers in order to include end-of-life care in their funding priorities, forming corporate partnerships, and promoting end-of-life care activities by providing recommendations for worthwhile initiatives and examples of successful projects to interested grantmaking bodies. GCCEL intends to provide a forum for the rational debate of all end-of-life issues and to increase interfoundation communications about projects funded and knowledge acquired.

## Canadian Palliative Care Association

Ottawa, Ontario, Canada

*Janet Dunbrack, M.Sc.*

**\$175,000**

### *Canadian Palliative Care Initiative*

A report from the National Research Advisory Committee of the Canadian Palliative Care Association noted a concern among Canadians that they will receive inadequate care when they are dying and identified increased research as a primary strategy for improving care for dying patients and their families. This two-year grant funds the development of a Canadian Palliative Care Initiative, a comprehensive, long-term national strategy to support interdisciplinary research, education, and program development.

## Center for the Advancement of Health

Washington, DC

*Jessie C. Gruman, Ph.D.*

**\$357,153**

### *Building the Field of Grief: Improving the Evidence Base*

A broad research and dissemination program is required to improve the ability of professionals and lay counselors to effectively diagnose, treat, and support grieving individuals and families. The focus of this project is to strengthen research on grief and bereavement, improve scientific understanding of grief, develop and test treatment interventions, and disseminate the results of these scientific explorations in useful formats to medical and mental health professionals as well as lay and faith-based counselors.

**Medicare Rights Center, Inc.**

New York, NY

*Diane Archer, J.D.***\$100,000*****Web-Based Interactive Information and Training on Medicare Hospice and Home Health Benefits***

The center will develop the online Home Care Channel, [www.medicarerights.org](http://www.medicarerights.org), designed to educate consumers, their families, caregivers, professional counselors, and clinicians about Medicare hospice and home health benefits for those with advanced illnesses.

**National Hospice and Palliative Care Organization, Inc.**

Alexandria, VA

*Karen A. Davie***\$150,000*****Developing a National Infrastructure***

NHPCO, the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States, is committed to improving end-of-life care and expanding access to hospice care. It will create an infrastructure development program that will generate funding to increase its ability to provide education, research, communication, and information for hospices, palliative care programs, and consumers in order to advance its goal of profoundly enhancing the quality of life for people dying in America and their loved ones.

**New York State Hospice Association**

Albany, NY

*Kathy A. McMahon***\$50,000*****Data Matrix on Services and Cost***

With advances in information management skills and technology, it is now feasible to create and maintain a comprehensive database on hospice services and costs to use in overcoming some of the barriers to full extension of end-of-life care services. This project will provide access to current, accurate data about hospice care in New York State, relieve hospice providers of the burden of generating routine reports, create a resource to support research about hospice care, establish a fact base for public policy initiatives, and produce a model program capable of replication in other states.

At the July 4th Wakpamni powwow, an elderly veteran stands near some younger members of the tribe. From *Elders of Pine Ridge*.



### Partnership for Caring, Inc.

Washington, DC

*Karen Orloff Kaplan, M.P.H., Sc.D.*

**\$59,977**

#### *No Pain, All Gain!*

For its national consumer-based education and legislative pain initiative, No Pain, All Gain! the partnership will create and disseminate an educational kit for state legislators and their staff. The kit will include nonpartisan analyses of the pain crisis in this country, results of research about pain management, contact information for technical assistance, and a description of educational efforts legislators can implement to inform their constituents about good pain management.

### United Hospital Fund of New York

New York, NY

*David A. Gould, Ph.D.*

**\$300,000**

#### *Community-Oriented Palliative Care Initiative*

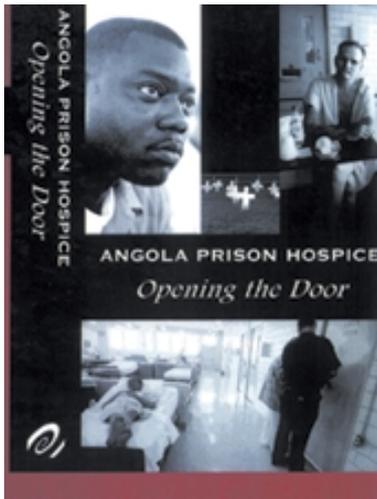
Over a three-year period, the United Hospital Fund will significantly extend its earlier work to stimulate the development of palliative care services in New York City hospitals. While continuing to work with hospitals to strengthen inpatient care, it will focus analytic and grantmaking resources on the development of at least two major palliative care networks comprising partnerships among hospitals, hospices, home care agencies, nursing homes, and community-based service and religious organizations.

## Improving the Care of the Dying in Prisons and Jails

*In 1998, when 1.83 million men and women were incarcerated, more than 2,500 prisoners died of natural causes in state and federal correctional facilities. Longer sentences and fewer paroles, coupled with the increasing age of prisoners and an AIDS epidemic, appear to contribute to the increasing numbers of terminally ill inmates. In 1998, the Project on Death in America and the Center on Crime, Communities and Culture of the Open Society Institute co-sponsored the first-ever meeting devoted to the growing problem of caring for the dying in prisons and jails. Those in attendance explored possible avenues for action and discussed the development of initiatives to meet the needs of different prison populations with serious life-limiting illnesses.*



Inmates at the Hamilton, Alabama Prison for the Aged and Infirm take their twice-daily inhalation therapy to alleviate the suffering from heart and lung problems. Opened in 1981 to address the growing demand for housing elderly inmates, this prison was designed to hold 250 convicts but now houses almost 400.



### Albert Schweitzer Institute for the Humanities

Wallingford, CT

*Harold E. Robles, Dr.h.c.*

**\$9,650**

#### *Conference on Hospice Care in Connecticut Prisons*

Inspired by Albert Schweitzer's exemplary humanitarian service and reverence for life, the institute supports health care initiatives that improve the lives of underserved populations. It conducts interactive conferences to explore clinical, public health, human rights, and ethical issues. This grant supported a 1998 meeting, *Finding Common Ground for Hospice Care in Connecticut Prisons*.

### American Society for Law, Medicine & Ethics, Inc.

Boston, MA

*Benjamin W. Moulton, J.D., M.P.H.*

**\$15,500**

#### *Special Edition of the ASLME Journal of Law, Medicine & Ethics*

This grant supports publication and distribution of the Fall 1999 issue of the ASLME journal. The issue presents a selected group of manuscripts from the *First National Conference on Death and Dying in Prisons and Jails: Caring for Prisoners, Families and Caregivers*, co-sponsored by OSI's Center on Crime, Communities and Culture and the Project on Death in America. Topics include palliative and hospice care in correctional facilities, the New York State compassionate release program for dying inmates, the ethics of end-of-life care for inmates, prevention of inmate suicide, and informed consent and the refusal of treatment in the correctional setting.



Hospice: Louisiana State Penitentiary at Angola

### Angola Prison Hospice: Opening the Door Directed by Edgar Barens

*Produced by the Center on Crime, Communities &  
Culture and the Project on Death in America*

Half of the 5,000 inmates at the maximum-security Louisiana State Penitentiary at Angola are serving life sentences, and it is estimated that 85 percent of them will grow old and die there. Edgar Baren's documentary examines one of the nation's first prison-based hospice programs, a program that notably incorporates inmate volunteers into the care of other dying inmates.

**National Prison Hospice Association**

Boulder, CO  
*Elizabeth Craig*

**\$46,882**

*Hospice Care for Terminally Ill Inmates and their Families*

The NPHA promotes the development of hospice and palliative care programs to serve terminally ill prisoners and their families. The project helps correctional professionals begin new palliative care programs or improve existing ones, and facilitates cooperative relationships between the corrections and hospice communities.

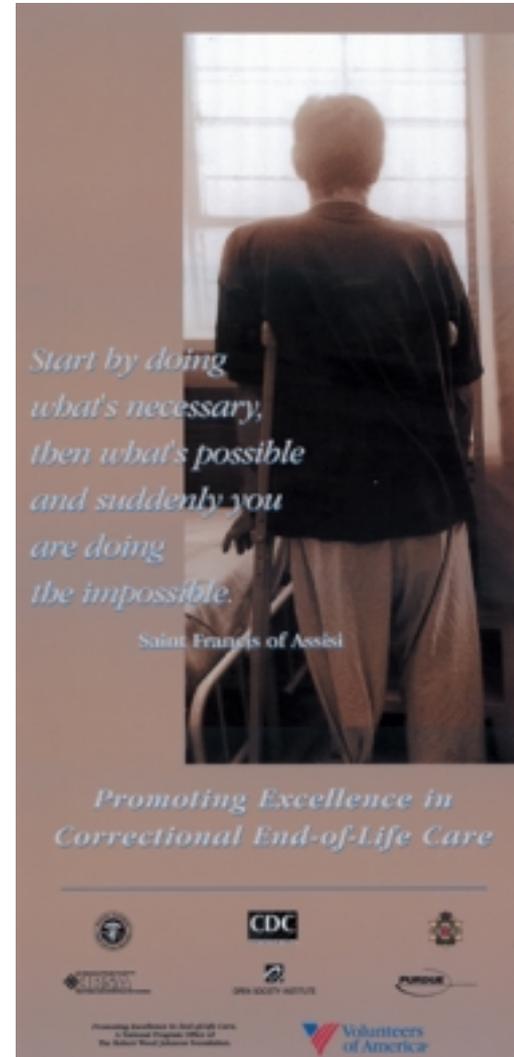
**Volunteers of America, Inc.**

Alexandria, VA  
*Margaret Ratcliff*

**\$54,000**

*Developing a North American Conference on Death and Dying in Prisons and Jails*

This conference, where professionals from a wide range of disciplines can discuss correctional end-of-life care issues, will follow up the First National Conference on Dying in Prisons and Jails held in 1998. Volunteers of America, which has more than 100 years of experience in community corrections and other services, will develop the conference through its successful GRACE Project (Guiding Responsive Action for Corrections at the End of Life). This grant supports the conference, and the dissemination of conference proceedings, to provide information and technical assistance to correctional facilities.



## Legal Initiative

*The pursuit of providing palliative care to ameliorate the pain and suffering of terminally ill individuals is infused at every level with legal issues and concerns. In January of 1998, the Project on Death in America invited a group of lawyers representing the broad spectrum of right-to-life, right-to-die, disability, and civil liberty advocacy groups to an exploratory meeting to assess the desirability and possibility for litigation to address state and federal legal barriers to adequate care at the end of life. On the recommendation of these experts, the Project on Death in America's Board of Directors decided to fund the position of a palliative care lawyer at the Bazelon Center for Mental Health Law in Washington, D.C.*

*The activities supported by the legal initiative provide background information and legal expertise to health care professionals and their lawyers on issues of appropriate pain management, the withholding and withdrawing of care, and end-of-life decision making and comfort care practices.*

**Judge David L. Bazelon Center for  
Mental Health Law**

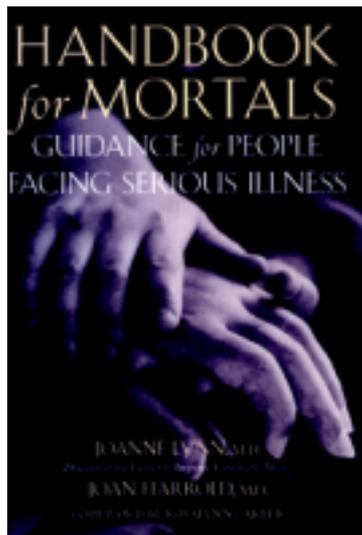
Washington, DC

*Ira A. Burnim*

**\$239,272**

*A Litigation Campaign to Establish Palliative  
Care Rights*

Barriers to pain management stand out among a plethora of problems that inhibit the ability of health care professionals to provide adequate palliative care to people with terminal illnesses. These barriers include outdated attitudes about the use of opioids fostered by unfounded concerns about addiction, inadequate training of physicians, and unnecessarily restrictive regulatory policies. The Bazelon Center has undertaken an examination of how litigation might be used to secure the rights of terminally ill patients to receive adequate palliative care. One area of inquiry is the Medicare Hospice Benefit requirement that a patient must have a prognosis of six months or less to live in order to qualify. A second area is whether regulatory restrictions on the prescription of opioids to terminally ill patients improperly impede a physician's ability to effectively manage pain. While litigation is not a panacea, properly targeted legal action can be a needed antidote to practices that deprive terminally ill individuals of appropriate palliative care.



**\$81,576**

*Pain and Palliative Care Law Reporter  
on the Internet*

The Palliative Care Reporter ([www.painlaw.org](http://www.painlaw.org)) collects and disseminates legal materials and links that will assist attorneys and other advocates for patients who are in pain or who have a terminal illness, patients and families facing legal issues relating to withdrawing treatment at the end of life, patients and families who have experienced poor pain management by their HMOs or doctors, doctors and other medical professionals who want to understand their rights and obligations under state and federal law, and doctors or other medical persons who are under investigation for pain management prescription for legitimate pain patients.

**Americans for Better Care of the Dying**

Washington, DC

*Joanne Lynn, M.D., M.A., M.S.*

**\$10,000**

*Breaking Down the Barriers to End-of-Life Care:  
Exploring the Role of Litigation*

Americans for Better Care of the Dying is dedicated to social, professional, and policy reform, and to education designed to improve services for patients with serious illness and their families. This grant enabled ABCD to prepare a briefing book for PDIA's meeting, *Legal Initiatives to Improve End-of-Life Care*, held in Washington, D.C., in September 1998.

## Other Grants Funded 1998 – 2000

### Bath Brunswick Hospice, Inc./Hospice of Midcoast Maine

Brunswick, ME

*John A. Norton and Michael J. Murphy, Ph.D.*

**\$25,000**

#### *Coalition for Dialogue on Death and Dying*

A coalition of community organizations will work to improve the culture of dying by delivering services more effectively to dying persons and their families during the period of illness and bereavement, and by serving as a catalyst for systemic change by bringing together hospitals and other providers of medical care, insurance companies, major employers, and citizens in midcoast Maine.

### The Caticus Corporation

Boston, MA

*Pierre Valette*

**\$30,000**

#### *Ready or Not!*

This grant supports *Ready or Not!* a behind-the-scenes documentary of a Harvard Medical School course, *Living with a Life-Threatening Illness*. The course attempts to demystify death and terminal illness by pairing first-year medical students with patients who are living with life-threatening illnesses. The students learn to regard such patients as whole people with needs beyond the medical treatment of their disease. During the course, the students begin the long process of learning how to listen and be present for their patients.

### Educational Broadcasting Corporation, Thirteen/WNET New York

New York, NY

*Richard D. Heffner*

**\$40,000**

#### *The Open Mind*

The grant sponsors a series of episodes of this weekly, half-hour interview and discussion broadcast. One two-part program features George Washington University geriatrician Dr. Joanne Lynn discussing her book, *Handbook for Mortals: Guidance for People Facing Serious Illness*. In another, Pulitzer Prize-winning author Robert N. Butler, a physician, gerontologist, and psychiatrist, discusses his concern that old age in America can be a tragedy, and that few consider it “because it reminds us of our own mortality.” Daniel Callahan, co-founder and director of the Hastings Center, discusses his article, *Death and the Research Imperative*, in one episode. Callahan fears a “research imperative” that assumes that “death is the principal evil of human life.” In three episodes, the Project on Death in America’s director, Dr. Kathleen M. Foley and *Open Mind* host Richard D. Heffner renew an on-air discussion they began in 1995 on such issues as how the experience of dying has changed with more Americans enduring prolonged and painful deaths; whether American culture should redefine its understanding of the relationship between life and death; and what has and has not been accomplished in the area of end-of-life care.

## Grantmakers in Aging

New York, NY

*Brian F. Hofland, Ph.D.*

**\$12,500**

### *GIA 1999 Annual Conference on Family Caregiving and GIA Newsletter*

Grantmakers in Aging is an educational membership group of foundation and corporate grantmakers committed to promoting and strengthening grantmaking for an aging society. This grant went to support inclusion of end-of-life content in GIA's October 1999 annual conference in Chicago, *Family Caregiving in an Aging America: Challenges and Creative Responses for Philanthropy*; and GIA's newsletter, *Aging Matters*.

**\$20,000**

### *GIA 2000 Annual Conference on Elder-Friendly Communities: An Opportunity for Creative Grantmaking*

The Project on Death in America co-sponsored the October 2000 GIA annual conference in New York City, *Elder-Friendly Communities: An Opportunity for Creative Grantmaking*. Planned by members of the philanthropic community, the program offered a variety of approaches for more effective grantmaking in an aging society. With a special emphasis on health, community, education, and family programs, the meeting was designed to provide opportunities for collaboration among foundations and among different program areas.

## Hackensack Health and Hospital Foundation

Hackensack, NJ

*R. Knight Steele, M.D.*

**\$50,217**

### *A Standardized Assessment Tool and Text for End-of-Life Care for Worldwide Distribution*

To assure comprehensive assessment and targeted care of individuals at the end of life, it is necessary to have a comprehensive standardized assessment capability. The assessment tool must be sufficiently universal in order to address the needs of the increasing numbers of elders around the world afflicted with various illnesses, and to compare outcomes across settings and even among nations. This grant supports the design of a standardized assessment tool that can “cross-talk” with existing systems such as the Minimum Data Set — now mandated for use in every nursing home in the United States and many worldwide, and a text for end-of-life care. The grant also supports evaluation, implementation, and public distribution worldwide.

## Hospice Foundation of America, Inc.

Washington, DC

*Jack D. Gordon*

**\$25,000**

### *2000 National Bereavement Teleconference — Living with Grief: Children, Adolescents and Loss*

This annual teleconference, the Hospice Foundation of America's largest educational program, focuses on some aspect of grief and bereavement and is broadcast live via satellite to any interested downlink. This 7th annual program was broadcast on April 26, 2000 to more than 2000 communities in the United States and Canada. The program emphasized practical intervention techniques that health care professionals, counselors, parents, and teachers can use to empower children and adolescents as they cope with loss and grief. The foundation published a companion book with an extensive bibliography of children's literature dealing with death and loss as well as special issues of its bereavement newsletter focusing on the subject.

The July 4th parade in Kyle, SD, honors veterans among Lakota Sioux. From *Elders of Pine Ridge*.



**McGill University**  
Montreal, Quebec, Canada  
*Balfour M. Mount, M.D.*

**\$50,000**

***Integrated Whole Person Care at the End of Life***

This project will develop a center for whole person, palliative care at the university. Its specific objectives are: developing a language to discuss the “inner life” that transcends specific cultural and religious world views and is appropriate for use in a pluralistic society; systematically reviewing the existing literature relating to spirituality and health; publishing the proceedings of the 1998 Wholeness and Healing in Health Care Seminar that was convened in Montreal in conjunction with the International Congress on Care of the Terminally Ill; and improving quantitative and qualitative research and methodologies to deepen our understanding of the determinants of quality of life and suffering — with particular reference to the contributions of spirituality and the inner life — so as to inform a theoretical framework for whole person clinical care, research, and teaching.

**In Loving Memory**

Reston, VA  
*Linda C. Nielsen*

**\$10,000**

***1999 Conference for Parents with No Surviving Children: Common Threads — Healing Hearts***

The fourth *In Loving Memory* conference, held in May 1999 in Vienna, Virginia, provided a forum of support for the intense grief at the death of parents’ only or all of their children. The conference provided networking opportunities and workshops focused on practical skills for coping, recovery, and positive reinvestment.

**Midwest Bioethics Center, Inc.**

Kansas City, MO  
*Myra J. Christopher*

**\$75,000**

***Pilot Project to Improve End-of-Life Care in Nursing Homes***

This project aims to effect attitudinal and behavioral changes in the staff of selected facilities through an intervention program that includes palliative care education, technical assistance, videotaped in-service programs, case consultation, and information on medication.



Carmen McCain, founder of Mothers Against Violence, whose son, Bonkey, was killed in a drive-by shooting in Birmingham, AL.

### National Academy of Sciences

Institute of Medicine

Washington, DC

*Marilyn J. Field, Ph.D.*

**\$150,000**

#### *Care for Dying Children and their Families*

This study will build on the 1997 Institute of Medicine Report *Approaching Death: Improving Care at the End of Life* by examining the special challenges of providing good end-of-life care for children and their families. The study will consider both acute and chronic medical problems, and intensive as well as palliative care provided in different settings to children with different economic, cultural, and religious backgrounds. It will develop recommendations to strengthen the research and knowledge base for compassionate and effective care, and to promote actions to improve the use of existing knowledge. It will inform federal and state policymakers, researchers, clinicians, medical educators, interest and advocacy groups, and the general public and promote changes that will improve end-of-life care for children and families.

### Mount Sinai Medical Center

New York, NY

*Christine K. Cassel, M.D.*

**\$70,000**

#### *Funding Hospital-Based Palliative Care: Exploring the Alternatives*

While there is widespread national consensus concerning the need for hospital-based palliative care, there remains significant uncertainty and controversy about the best method of supporting these important services in the acute care hospital setting. In conjunction with the American Hospital Association, this grant supports a mail survey to identify existing hospital-based programs, what palliative care services are provided, and how they are funded.

### Northwestern University

Chicago, IL

*Linda Emanuel, M.D., Ph.D.*

**\$43,775**

#### *Education for Physicians on End-of-life Care Conference Webcast*

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

**Pennsylvania State University College of  
Medicine**

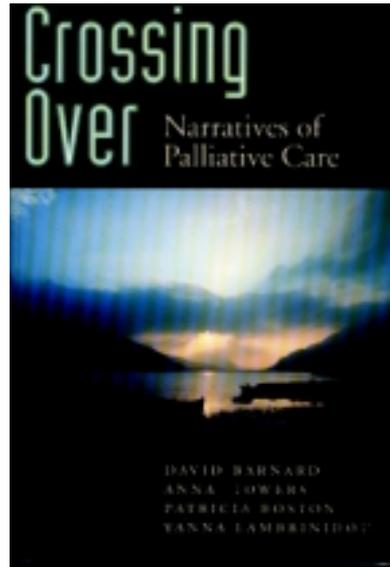
Hershey, PA

*David Barnard, Ph.D.*

**\$34,303**

***Crossing Over: Narratives of Palliative Care***

This grant provided additional support for the completion and publication of a previously funded book project that was released by Oxford University Press in 2000. Using a variety of qualitative research methods — including participant observation, interviews, and personal journals — *Crossing Over* provides a narrative view as patients, families, and their caregivers strive to maintain comfort and hope in the face of incurable illness. The book depicts the experiences of daily life in patients' homes and in the palliative care unit. It explores the diversity of people's aspirations and ideals as they face death and the often challenging conflicts between their views of death and the views of the professionals who care for them.



**University of Michigan**

Ann Arbor, MI

*Richard O. Lempert, J.D., Ph.D.*

**\$6,020**

***Conference on Death and Its Enemies,  
December 2000***

Over the course of the 20th century, the average age of death in the U.S. has increased. Recent scientific discoveries open the possibility of dramatic extensions of longevity. This public conference, co-sponsored by the university's Life Sciences, Values and Society Program and the Project on Death in America, explores the social and ethical implications of these new possibilities.

**Vermont Ethics Network, Inc.**

Montpelier, VT

*Arnold Golodetz, M.D.*

**\$15,000**

***Journey's End: Vermont Voices on Death  
and Dying***

The network, a nonprofit educational organization promoting awareness and understanding of health care choices, held a total of 42 community forums to discuss what Vermonters, based on their own experiences, think about the care of the dying and what recommendations they have to improve that care. A report on the forums, identifying such areas of concern as communication needs, public policy implementation, and the support for spiritual growth, was widely distributed through hospital, home health, community library, and other educational networks. This grant supports a series of presentations at Vermont hospitals to review findings of the Vermont Voices report with practitioners, ethics committee members, trustees, and others from the regional health care delivery system. A multidisciplinary study group under network leadership will develop curricula for the lay public, counselors, and other health care providers.

## PALLIATIVE CARE INITIATIVE: EASTERN EUROPE AND THE FORMER SOVIET UNION

In January 2000, the Open Society Institute announced a new initiative to enhance hospice and palliative care in Eastern Europe and the former Soviet Union — a three-year program co-sponsored by OSI's Public Health Program and the Project on Death in America. The initiative provides \$500,000 each year for health care professionals, associations, and organizations working to expand the capacity of programs in the countries of Eastern Europe to improve the care of the dying in this region.

The Eastern Europe Palliative Care Initiative has targeted initial funding efforts in the following program areas:

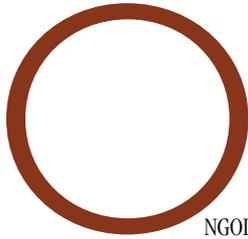
- Regional resource and training centers for professional education;
- Regional policy-maker meetings to convene health ministers, drug regulators, and economists to discuss health care policy and drug regulation and reform;
- Regional professional education programs to provide local and regional educational

opportunities for physicians, nurses, social workers, and pastoral care providers;

- National professional education programs to provide opportunities for physicians, nurses, social workers, and pastoral care providers;
- Palliative care scholarships for end-of-life care experts to spend time training at centers of excellence;
- Travel grants for health care professionals to attend international conferences;
- Grants to translate existing palliative care educational materials into local languages.

Of 200 applications for the first award-cycle, the EEPIC Initiative awarded 53 grants in Albania, Azerbaijan, Bosnia, Bulgaria, Croatia, Hungary, Latvia, Lithuania, Macedonia, Moldova, Mongolia, Poland, Romania, Russia, Slovenia, Ukraine, and Yugoslavia.

## COMMUNICATIONS



ONGOING public discussion is essential to a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death. The Project on Death in America's communications program serves as the underpinning of our public information plan, conveying the mission of the project, and raising awareness of the work done by our grantees to improve care of the dying.

### Public and Professional Media

In the last six years the media has gone from treating death as a “taboo subject” to identifying both death and palliative care as topics of broad interest. PDIA serves as a resource center for the media, providing reporters and editors with the latest research and an extensive and knowledgeable roster of researchers, clinicians, educators, and direct service providers. PDIA's communications efforts have helped to expand knowledge and coverage of dying beyond the debate over physician-assisted suicide.

The PBS program *On Our Own Terms: Moyers on Dying*, which ran in September 2000, reached over 19

million viewers and featured over a dozen PDIA grantees and faculty scholars. The series drew an enormous audience, strong viewer reactions, and extensive media coverage. The series encouraged open, balanced national discourse that represents the complex issues patients and families face as they care for family members at home or in the hospital.

On a weekly and monthly basis, every major medical journal has had at least one, if not several, articles written by one of our faculty scholars, grantees, or board members. These original articles, commentaries, and editorials span discussions of the psychiatric, social, medical, legal, and economic issues confronting patients with serious life-threatening illness and have helped to frame the critical research information necessary to change hospital policies, professional education programs, and the economics of care.

### Publications

PDIA's newsletter, press releases, and research briefs comprise another component of efforts to address the national discourse. These materials are available on our website and are distributed to 8,000 individuals and organizations.

PDIA's website, [www.soros.org/death](http://www.soros.org/death), visited by over 500 people a day, is a continually expanding collection of information about the Project on Death in America and a gateway to resources on palliative care, dying, and bereavement. It includes detailed information on grant programs, including current funding initiative deadlines, application materials, a complete listing of grants funded, information about ongoing developments in the field, and extensive links to other initiatives and resources in end-of-life care.

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## INDEX OF GRANTEES

- Albert Schweitzer Institute for the Humanities, 69  
Altilio, Terry, 33  
American Association of Critical Care Nurses, 38  
American Hospice Foundation, Inc., 48  
American Society for Law, Medicine & Ethics, Inc., 69  
Americans for Better Care of the Dying, 72  
Angola Prison Hospice, 69  
Arnold, Elizabeth Mayfield, 33  
Arthur Ashe Institute for Urban Health, Inc., 55
- Back, Anthony, 15  
Baptist Health Systems of South Florida Foundation, Inc., 48  
Bath Brunswick Hospice, Inc./Hospice of Midcoast Maine, 73  
Berzoff, Joan, 29  
Blacker, Susan, 29  
Boston University School of Medicine Department of Pediatrics, 49  
Bromberg, Ellen, 41  
Burack, Jeffrey H., 15
- Canadian Palliative Care Association, 65  
Catticus Corporation, 73  
Center for the Advancement of Health, 65  
Chang, Victor T., 23  
Cleary, James E., 15  
Cohen, Iris, 29  
Cohen, Lewis M., 16
- Cole, Thomas R., 41  
Cooper Green Hospital Foundation, Inc., 49  
Crawley, LaVera M., 20
- Dane, Barbara, 30  
del Rio, Norma, 34  
Downtown Community Television Center, Inc., 55
- Educational Broadcasting Corporation, Thirteen/WNET New York, 73  
Educational Video Center, Inc., 56
- Ferris, Frank D., 16  
Forrow, Lachlan, 20
- Galanos, Anthony N., 23  
Ganzini, Linda, 16  
Gilbert, Sandra M., 41  
Global Action Project, Inc., 56  
Grant Ervin, Michelle, 17  
Grantmakers Concerned with Care at the End of Life, 65  
Grantmakers in Aging, 74
- Hackensack Health and Hospital Foundation, 74  
Harbor Hospital Center, Inc., 49  
Harlem Writers Crew Project Foundation, Inc., 56  
Hospice Foundation of America, Inc., 74  
Hwang, Shirley S., 23
- In Loving Memory, 75  
*In the Mix*, 55
- Johns Hopkins University, 38  
Judge David L. Bazelon Center for Mental Health Law, 72
- Kamler, Richard, 42  
Kashi, Ed, 42  
Keresztury, Jim, 30  
Koenig, Barbara, 20  
Kurent, Jerome E., 23
- Levin, Meryl, 42  
Linder, John F., 33  
Linzau, Jean A., 17
- Mairs, Nancy, 44  
McGill University, 75  
Medicare Rights Center, Inc., 66  
Memorial Sloan-Kettering Cancer Center, 61  
Midwest Bioethics Center, Inc., 75  
Monk, Meredith, 44  
Mosenthal, Anne C., 24  
Mount Sinai Medical Center, 76  
Muir, J. Cameron, 24  
Murphy, Patricia A., 24

- National Academy of Sciences, 76  
 National Hospice and Palliative Care Organization, Inc., 66  
 National Prison Hospice Association, 70  
 Nelson, Judith Eve, 20  
 New York State Hospice Association, 66  
 New York University, 39  
 North General Hospital, 61  
 Northwestern University, 76
- Okazawa-Rey, Margo, 34
- Pantilat, Steven Z., 18  
 Partnership for Caring, Inc., 67  
 Passik, Steven D., 21  
 Payne, Samuel K., 18  
 Pearlman, Robert, 15  
 Pennsylvania State University College of Medicine, 77  
 Peterson, Kendra, 24  
 Photographic Center of Harlem, 57  
 Prendergast, Thomas J., 21  
 Puntillo, Kathleen, 25
- Radio Diaries, Inc., 57  
 Richards, Eugene, 44  
 Rosenberg, Douglas, 41  
 Rosenfeld, Kenneth E., 25
- Scherer, Deidre, 45  
 Schnell, Lisa J., 45  
 Service Employees International Union LAHomecareWorkers 434, 50  
 Shapiro, Alan, 46  
 Sheehan, Myles N., 21  
 Sherman, Deborah Witt, 18  
 Simmons, W. June, 34  
 Slavitt, David R., 45  
 Sormanti, Mary, 31  
 St. Mary's/Duluth Clinic Health System's Grief Support Center, 50  
 Stein, Gary L., 32
- Taylor-Brown, Susan, 34
- United Hospital Fund of New York, 67  
 University of Hawaii, 50  
 University of Michigan, 77  
 University of South Carolina, 51  
 University of Wisconsin, 63
- Vermont Ethics Network, Inc., 77  
 Virginia Mason Medical Center, 52  
 Volunteers of America, Inc., 70
- Walsh-Burke, Katherine, 35  
 William Wendt Center for Loss and Healing, 53  
 Winokur, Julie, 42  
 Wolfe, Joanne, 22
- Youth Communication New York Center, Inc., 57

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