

OPEN SOCIETY INSTITUTE

PROJECT ON DEATH IN AMERICA

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JANUARY 2001–DECEMBER 2003 REPORT OF ACTIVITIES

The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement in the United States through funding initiatives in professional and public education, research, clinical care, the arts and humanities, and public policy.

Project on Death In America  
Report of Activities  
January 2001 – December 2003

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The Project on Death in America is a program of the Open Society Institute, a private operating and grantmaking foundation based in New York City that serves as the hub of the Soros foundations network, a group of autonomous foundations and organizations in more than 50 countries. OSI and the network implement a range of initiatives that aim to promote open societies by shaping government policy and supporting education, media, public health, and human and women's rights, as well as social, legal, and economic reform. To diminish and prevent the negative consequences of globalization, OSI seeks to foster global open society by increasing collaboration with other nongovernmental organizations, governments, and international institutions.

OSI was founded in 1993 by investor and philanthropist George Soros to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help former communist countries in their transition to democracy. The Soros foundations network has expanded its geographic reach to include foundations and initiatives in Africa, Latin America and the Caribbean, Mongolia, Southeast Asia, Turkey, and the United States. OSI also supports selective projects in other parts of the world.

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## REFLECTIONS ON DEATH IN AMERICA

GEORGE SOROS

*Chairman, Open Society Institute*

"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 good-bye."



**M**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 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 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 the medical textbooks of the turn-of-the-century 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 healthcare 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.

Up to 80 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 costs of care for 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. 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 physician-assisted suicide 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 physician-assisted suicide 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.*





Eugene Richards' film, *but, the day came* documents the journey of an independent 92-year-old Nebraska farmer to a nursing home.

## WHAT WE HAVE LEARNED FROM THE PROJECT ON DEATH IN AMERICA

GARA LAMARCHE

*Vice President and Director of U.S. Programs,  
Open Society Institute*



**B**EFORE GEORGE SOROS was inspired in 1996 to apply his foundation's resources to a broad range of open society challenges in the United States, he started with two: to spark a debate about harsh drug laws, and to change the culture of dying. No small tasks.

Yet less than ten years later, few would deny that huge progress has been made toward those goals. Not only has a debate about drug policy taken place, but state after state has considered or adopted reforms, from easing restrictions on medicinal use of marijuana to mandating drug treatment rather than prison for first-time offenders.

With respect to the care that people receive at the end of life, a once-taboo topic is now much more widely discussed in the media and in the academy and, much more importantly, in doctors' offices and hospital corridors and in family kitchens and living rooms. The simple but profound and universal goal that George Soros had in launching the Project on Death in America barely a decade ago—to improve the way that people die—is being reached for more and more people each day.

As we end the Project on Death in America, OSI can reflect on what we have learned from PDIA's leadership, which has had an enormous impact on all our foundation programs:

**That the personal is political.** Death is universal. Everyone must deal with it throughout life, first for loved ones, eventually for oneself. Every person has a stake in the discussion, some claim to expertise. And this insight has been important for OSI's work on drug policy, where virtually everyone has an experience with some kind of drugs, and the consequences for a friend or family member or community; or our work on criminal justice, where hardly any American, particularly urban dwellers, has been untouched by crime.

**How much leadership matters.** PDIA's flagship strategy has been to create and nurture a cadre of leaders in a new field: care at the end of life. By now touching virtually every healthcare institution, many special populations, and several professional disciplines, including social work and nursing as well as medicine, these individuals have transformed the way we think about and deal with dying. Taking a page from PDIA's strategy, other U.S. Programs have created fellowship programs to foster leadership in progressive criminal justice reform, community development, and reproductive rights. Drawing on what we learned through PDIA about the enormous influence and authority that physicians have, OSI also launched a special fellowship program to pair doctors with public

interest organizations working on a range of issues from human rights to the environment.

**How a small investment can be leveraged.**

OSI spent \$5 million a year on the Project on Death in America, but the needs of the field far exceeded that amount. From the beginning, PDIA worked closely with other funders in healthcare, aging, the arts, and other areas, and before long our investment was—happily—overshadowed by that of other donors, and served as a stimulus to the allocation of staff and budget resources by governments and healthcare institutions.

**How transformative a small amount of money can be.** Many PDIA grants, as you will read in this report, were not large. But sometimes a small amount of money can spark change, especially by the recognition it provides, the legitimacy it grants, the boost it provides. We've seen this lesson over and over again in OSI's grants over the years.

**Why systemic change is important.** At the same time, dealing with a vast, complex, and contested area of the economy like healthcare, PDIA realized over time that more needed to be done than change institutions one patient, doctor, or social worker at a time. If palliative care was to be more firmly established, for example, Medicare reimbursement policies needed to be changed. And that kind of policy work takes advocacy—the mobilization of people and organizations to educate and influence decisionmakers. This path from the funding of direct services to the call

for more systemic, enduring change has been followed by many other OSI initiatives in areas from immigrant rights and indigent defense to afterschool and drug treatment programs.

**Why reflectiveness and adjustment matters.**

Finally, a foundation or any institution seeking to make change must step back from time to time, look at what it is doing, and make any adjustments that are necessary in light of experience. This requires an honest assessment of what is working and what is not. Some of PDIA's early requests-for-proposals resulted in seeding important initiatives, others resulted in efforts that seemed too scattershot or lacked the rigor to be evaluated or replicated. Changes were made, some programs abandoned. As a broader institution, OSI has done the same, and tried to share its lessons with others in philanthropy and in the particular fields we support, as in the independent report we commissioned on the work of the Emma Lazarus Fund or our work on gun violence. If we are unwilling to look at our mistakes at the same time as we trumpet our successes, we are missing an important part of the picture.

Few foundation initiatives anywhere, on any subject, have acted with the discipline, honesty, openness, and impact that the Project on Death in America has maintained from the beginning. This will continue to be reflected for many years to come not only in a transformed culture of dying in the United States, but in everything else the Open Society Institute does.

## TRANSFORMING THE CULTURE OF DYING

KATHLEEN M. FOLEY, M.D.  
*Director, Project on Death in America*



**PDIA Advisory Board**

(top, l to r) Mary Callaway, M.E., Associate Director, PDIA; Robert Burt, J.D., Yale Law School; Ana O. Dumois, Ph.D., D.S.W.; Susan Block, M.D., Harvard Medical School, Dana Farber Cancer Institute; (bottom, l to r) Robert Butler, M.D., International Longevity Center; Kathleen Foley, M.D., Memorial Sloan-Kettering Cancer Center, Weill Medical College of Cornell University; Patricia Prem, M.S.W.

**T**HIS THIRD AND FINAL three-year report describes the Project on Death in America's grantmaking program during the period 2001-2003. These grants trace the evolution of our funding strategy to sustain the field of palliative care, and to support the infrastructure of professional organizations focused on improving the care of the dying. Taken together, our three-year grant reports provide only a snapshot of PDIA's nine years of grantmaking. They cannot fully convey the dedication, inventiveness, and perseverance of the individuals who work every day to improve the care we will all need in the end.

This report also briefly describes our palliative care initiatives in Central and Eastern Europe, the former Soviet Union, and South Africa. These international initiatives exemplify the Open Society Institute's continued commitment to advocate for palliative care as a public health issue. These global efforts are an important part of the legacy of the Project on Death in America.

As this challenging and bold initiative draws to a close, we now have extraordinary advocates and leaders working to improve the care of the dying. These individuals are making a significant

difference in addressing the serious challenges of inadequate end-of-life care and our general cultural denial of death and dying.

From its beginning, PDIA focused on the vulnerable and voiceless individuals who had, in a sense, been abandoned by the healthcare system. Their suffering suggested ways in which modern high-technology medicine had lost its way. We believe that palliative care and treatment enhance the field of medicine and demonstrate that a competent professional must also be compassionate.

The amount of money we awarded—\$45 million over the course of nine years—is modest, relative to the scope of the challenges. But PDIA used this money as a catalyst to help highlight problems faced by the dying and grieving, and empower their caregivers to become agents of change within our healthcare system. The fact that the project was not going to continue indefinitely kept us focused on the goal of working to make changes at the bedside within the healthcare system—so that the work would continue beyond us.

PDIA was by no means the only grantmaker concerned with improving end-of-life care. Many other funders have come to the same conclusion as George Soros, and have devoted significant resources to the field. In fact, PDIA was part of a consortium of grantmakers who came together—formally and informally—to share information and ideas. The United Hospital Fund formed its own funders collaborative to develop community-

based palliative care networks in New York City. The Nathan Cummings Foundation paid particular attention to public engagement and spirituality at the end of life, an area that PDIA could not fully address. Likewise PDIA could never equal the Robert Wood Johnson Foundation's impact on public education and community outreach. The Emily Davie and Joseph S. Kornfeld Foundation joined PDIA in a major initiative to support palliative care fellowship training programs. These are just a few of the many foundations we worked with over the years to enhance the effectiveness of our funding.

During our time as grantmakers, our strategy was to make the issue of death and dying more transparent—to identify it, to articulate it, to highlight it as an area deserving of study and activity, as a medical specialty that needed more systematic research and attention, and as a focus for health funding and policy. Now we need to take this issue to an even broader community, with the hope that the work we supported will eventually be fully integrated into the American healthcare system and culture.

The field of palliative care is definitely much stronger than it was ten years ago. Through its support of individuals and organizations in the movement to improve end-of-life care, I believe PDIA has made major contributions to the advances that have been achieved.

PDIA's mission was challenging, and now we encourage and challenge others to continue. We have made progress, but the problems of

death and bereavement will always be with us, and they belong on the agendas of many other grantmakers. Improving end-of-life care must also be on state and federal government agendas. Until government begins to play a larger role in designing more appropriate and inclusive end-of-life care benefits and services, and in funding the training of palliative medicine as a recognized specialty, the work will depend largely on the support of philanthropy. The good news is that the government will get there eventually, as growing evidence shows that the issue is starting to get the attention it deserves. But, in the meantime, the seeds we helped plant need to be carefully tended.

As PDIA closes, we do not yet understand all the barriers to compassionate end-of-life care. The field is, in many ways, still in its infancy. We have learned much about the intense aversion people have to the subject of human mortality, but we do not fully understand the many barriers to appropriate care that arise from that aversion. There are still many challenging questions—for funders, healthcare professionals, spiritual and religious leaders, and artists to answer.

Death is inevitable, but severe suffering is not. We must all look towards the day when compassionate and skilled end-of-life care becomes so much a part of the fabric of American communities and the American healthcare system that it is not necessary to request it—it is simply offered when needed. In communities across the country, PDIA grantees are helping to bring us all closer to that day.

## 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 management; psychological, social, and spiritual support for patients and families; and communication with patients about 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 the Nursing Leadership Academy. Recognizing that mentors, role models, and peer support are essential to the educational process, PDIA invested heavily in academic faculty and clinician leaders who would spearhead change—locally and nationally.

With PDIA funding support, emerging leaders in the field are equipped to develop innovative programs in clinical care, research, education, and advocacy. PDIA's professional education initiatives have helped create an intellectually vibrant, supportive, collaborative network of colleagues working in every aspect of care for dying patients and their families.

## Faculty Scholars Program

2003 marked the end of nine years for the Faculty Scholars Program. This program has created an intellectually vibrant network of medicine and nursing faculty who are leading the development of clinical, research, and educational initiatives in academic health centers to improve care for dying patients and their families. PDIA has funded a total of 87 faculty scholars, representing 59 medical and 4 nursing schools in the United States and Canada. Scholars received up to \$76,500 of support per year, for a period of two years, enabling them to dedicate 60 percent of their time to activities aimed at improving professional practices, carrying out innovative research, and developing effective palliative care education programs. Many scholars have emerged as leaders in palliative care, and they will be responsible for training the next generation of clinicians. Scholars have established collaborative and fruitful working relationships that were developed and nurtured through the faculty scholars program.

Collectively and individually, the scholars represent much of the clinical and academic leadership in the field of palliative care today. They play critical roles in shaping the field, as leaders

of both clinical palliative care programs, and of major national initiatives including Diane Meier, Center for the Advancement of Palliative Care; David Weissman, End-of-Life Residency Education Project; Charles von Gunten, American Board of Hospice and Palliative Medicine; and James Cleary, American Academy of Hospice and Palliative Medicine. Through the work carried out as faculty scholars, as well as through the network of colleagues that has emerged through the program, the scholars are making an impact that will influence the field for future generations of health professionals, and the patients and family members for whom they care.

Collectively, the faculty scholars have garnered a total of \$113,588,653 in funding to support their work. The scholars have published prolifically, and have contributed more than 1,500 publications in 335 different sources, including leading peer-reviewed journals such as the *New England Journal of Medicine*, the *Journal of the American Medical Association*, *Annals of Internal Medicine*, and international journals such as *Lancet* and the *British Medical Journal*. Local and national media, including the *Wall Street Journal*,

the *Boston Globe*, and the *New York Times*, have featured profiles and articles about the work of faculty scholars.

Faculty scholars focus on a wide range of subjects within the field of palliative care. Holly G. Prigerson, Ph.D. of Yale University's School of Medicine is studying the prevalence and treatment of psychiatric disorders among terminally ill patients and their caregivers, the ways that mental health affects the patient's comfort at death, and the impact this may have on the caregiver's experience of grief and bereavement. The goal of her project is to determine how the diagnosis and treatment of psychiatric disorders among dying cancer patients and their caregivers affect the quality of the patient's death and the surviving caregiver's adaptation to the death. Tammie E. Quest, M.D. of Emory University's School of Medicine is leading palliative care efforts in emergency medicine. Dr. Quest is creating a directed educational model to provide emergency physicians with the appropriate skills needed to care for dying patients in the emergency department setting. Michael W. Rabow, M.D. of the University of California, San Francisco

Medical School is investigating the impact of the "hidden" or informal end-of-life care curriculum on the attitudes of medical students towards their patients, and will develop an intervention to address educational barriers to optimal training in end-of-life care.

The faculty scholars program has created a vital, mutually supportive, and cross-fertilizing network of colleagues. As we look back on the growth of the field of palliative care over the past ten years, it is clear that the scholars have been a major force in catalyzing change. They have made major contributions towards building the clinical, educational, and research infrastructure of the field, and have started to train a new generation of leaders in palliative care. The commitment, enthusiasm, dedication, and vision of these leaders will continue to be a resource for the entire field of palliative medicine for many years to come.

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



## MISSION

### Faculty Scholars Program

*The Faculty Scholars Program supports outstanding clinicians, educators, and researchers who will promote existing models of excellent care for dying patients, develop new models of care, and educate the next generation of health professionals.*



From *Aging in America* by Ed Kashi and Julie Winokur

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 2001-2003
 

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## Faculty Scholars

**Richard Brumley, M.D.**

**Kris Hillary, R.N.P., M.S.N.**

Kaiser Permanente

University of California, Irvine College of  
Medicine

Downey, CA

### *Transferring End-of-Life Knowledge in Clinical Culture*

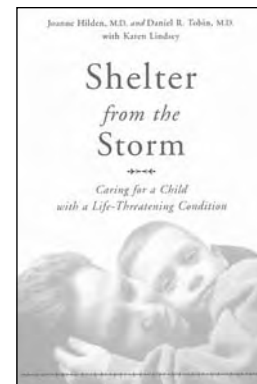
In 1997, the Kaiser Permanente TriCentral Service Area initiated an inpatient palliative care program. Modeled after Kaiser's hospice program, the palliative care program offers pain management, comfort care, and curative therapies to patients who have an estimated prognosis of less than one year. In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

**Christopher Daugherty, M.D.**

University of Chicago School of Medicine  
Chicago, IL

### *Decision Making, Information Seeking, and Awareness of Prognosis among Dying Cancer Patients and Involved Physicians*

Dr. Daugherty aims to better understand how patients with advanced cancer and their physicians communicate with each other; how patients make decisions about different forms of care in the years, months, or weeks before death; and patient awareness of their prognosis at different stages of illness. The study will consider the factors that influence choice among alternatives of care, such as hospice care or clinical trial participation.



**Joanne M. Hilden, M.D.**

Children's Hospital at the Cleveland Clinic  
Cleveland, OH

### *Children's Oncology Group: Pediatric Advanced Illness Care Coordination*

Recent research has shown that too many children suffer from treatable pain and other symptoms in the days or weeks before they die. Even when children have access to palliative care and hospice services, health professionals are rarely trained to serve the unique needs of dying children. The Children's Oncology Group (COG) is the national clinical trials unit for children with cancer; 94% of children with cancer are treated in COG. Dr. Hilden will evaluate clinical models for controlling physical symptoms and psychosocial distress throughout a child's illness. She will also develop a model of caring for terminally ill children that facilitates communication among parents, providers, and young patients.

**Daniel C. Johnson, M.D.**  
University of Colorado Health  
Sciences Center  
Denver, CO

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

Despite the availability of effective and accessible treatments, many terminally ill patients suffer unnecessarily from a range of distressing symptoms. Dr. Johnson will develop, implement, and evaluate evidence-based models of symptom management to decrease treatable symptoms that erode the quality of a dying patient's life.

**Judith A. Kitzes, M.D., M.P.H.**  
University of New Mexico Health Sciences  
Center School of Medicine  
Albuquerque, NM

*Native American End-of-Life Care*

There are an estimated 4.3 million Native Americans, including Alaska Natives, in the United States. The experiences of Native Americans at the end of life are similar to those of the general population; they tend to be protracted and separated from family and community. Dr. Kitzes will establish a Native American Collaborative Center for the Promotion of Palliative Care. This center will formalize the existing collaborative efforts of the national Federal/Tribal/Urban Indian Health Care system and the University of New Mexico Health Science Center. The center will support tribal sovereignty and self-determination in palliative care services, and evaluate palliative care training as it relates to the specific needs of Native American patients and families.

**Laurie Jean Lyckholm, M.D.**  
**Patrick Coyne, R.N., M.S.N.**  
Virginia Commonwealth University School  
of Medicine  
Richmond, VA

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

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

**Mary E. Paulk, M.D.**  
University of Texas Southwestern Medical  
Center  
Dallas, TX

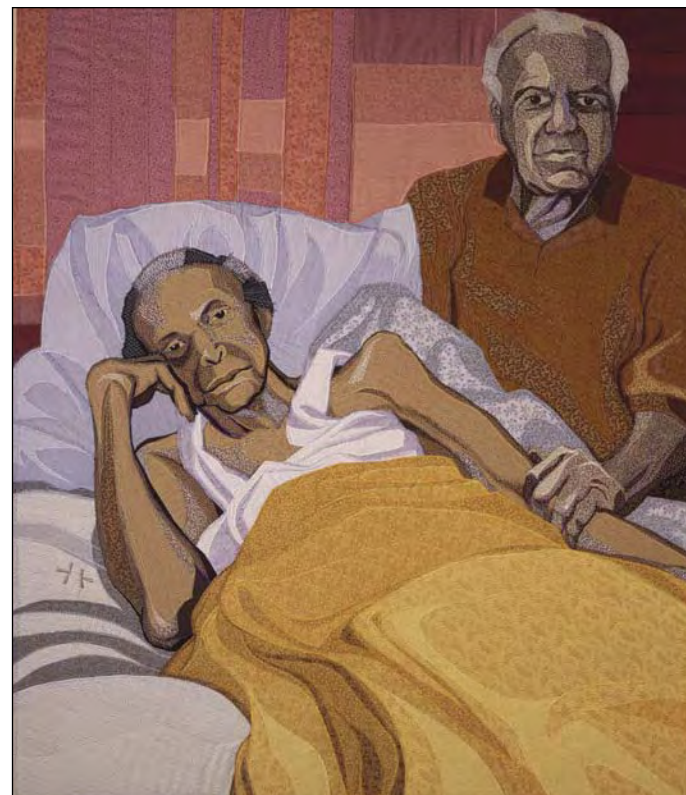
*Palliative Care for Indigent and Minority  
Patients and Investigation into the  
Constitutionality of Current Government  
Funding Practices for End-of-Life Care*

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

**Michael A. Weitzner, M.D.**  
H. Lee Moffitt Cancer Center  
University of South Florida  
College of Medicine  
Tampa, FL

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

Although many healthcare professionals view clinical depression as an inevitable part of terminal illness, other factors can cause clinical depression in dying patients, and should be addressed. Dr. Weitzner will test the explanatory value of a social cognitive model of depression in home hospice cancer patients, and create improved screening assessment tools to identify clinical depression.



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## Faculty Scholars

### **F. Amos Bailey, M.D.**

Birmingham VA Medical Center  
 University of Alabama School of Medicine  
 Birmingham, AL

#### *Integration of Palliative Care Training into the Curricula of Medical Oncology and Geriatric Medicine Fellowship Training*

Physicians trained in subspecialty programs such as medical oncology, geriatrics, pulmonary medicine, cardiology, nephrology, and neurology care for many patients with serious and life threatening illnesses, and will provide the bulk of care to our aging population. Yet, their training programs rarely include palliative medicine in the curriculum. In this project, Dr. Bailey will develop a model palliative care curriculum for subspecialty training programs, then test, evaluate, and disseminate the results.

### **Bruce Himmelstein, M.D.**

Children's Hospital of Wisconsin  
 Medical College of Wisconsin  
 Milwaukee, WI

#### *Rapid-Cycle Quality Improvement in Pediatric Palliative Care Education*

All health professionals who care for children with life threatening illnesses must be well trained in pediatric palliative care. Relevant educational materials are available, but little is known about the most effective teaching methods. In this project, Dr. Himmelstein will use rapid-cycle quality improvement methodology to improve the training and practice of interdisciplinary pediatric healthcare teams. He will also create an educational model that can be adapted to other pediatric healthcare institutions.

### **Eric Krakauer, M.D., Ph.D.**

Massachusetts General Hospital  
 Harvard Medical School  
 Boston, MA

#### *Clinical Policy Development for Optimum End-of-Life Care*

Dr. Krakauer's project aims to reduce barriers to excellent palliative care by developing and advocating for the adoption of institutional policies and clinical practice guidelines for end-of-life care. Based on evidence that such policies can improve clinical outcomes and patient satisfaction, the model policies and guidelines will be designed to be appropriate for use by institutions nationwide.

**Terri Maxwell, R.N., M.S.N.**  
 Center for Palliative Care  
 Thomas Jefferson University Hospital  
 Philadelphia, PA

*Health System-Wide Quality Improvement Initiative for Palliative Care*

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

**Susan C. Miller, Ph.D., M.B.A.**  
 Center for Gerontology and Health Care  
 Research  
 Brown University School of Medicine  
 Providence, RI

*Timely Access to Hospice Care: Understanding Barriers and Influencing Change*

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

**Holly G. Prigerson, Ph.D.**  
 Yale University School of Medicine  
 New Haven, CT

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

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

**Tammie E. Quest, M.D.**  
Emory University School of Medicine  
Atlanta, GA

*A Palliative Care Curriculum for Emergency Medicine Residents*

Many uninsured and low-income people must use emergency rooms as the source for all of their healthcare needs—including serious illness. Yet thousands of emergency physicians are trained each year without any knowledge of palliative care, and no training requirement or curriculum currently exists. Dr. Quest will create a directed educational model to provide emergency physicians with the appropriate skills needed to care for dying patients in the emergency department setting.

**Michael W. Rabow, M.D.**  
Medical Center at Mount Zion  
University of California, San Francisco  
School of Medicine  
San Francisco, CA

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

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

**Joseph S. Weiner, M.D., Ph.D.**  
Albert Einstein College of Medicine  
Long Island Jewish Medical Center  
New Hyde Park, NY

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

Many physicians are unwilling to discuss advance care planning with their patients. As a result, they may incorrectly assume or ignore patients' treatment preferences. Dr. Weiner will develop structured communication training programs in advance care planning for physicians and medical students. These programs will aim to improve knowledge, skills, and confidence so that physicians will be motivated and prepared to talk about advance care planning with their patients.

## Social Work Leadership Development Awards



Social workers often take the lead in providing essential psychological and social services to the dying and the bereaved, including counsel on advance directives, emotional support to the patient and family, and assistance in locating social, medical, financial, and community resources. Yet social workers report gaps in their end-of-life care education at the undergraduate, graduate, and post-graduate levels, as well as lack of access to leadership in practice, teaching, research, and advocacy.

The Project on Death in America established the Social Work Leadership Development Awards in January 2000 to promote the visibility and prestige of social workers committed to end-of-life care. These awards enhance their effectiveness as academic leaders, role models, and mentors for future generations of social workers. Since the program's inception, PDIA has awarded a total of \$2,940,000 to recognize 42 outstanding social work faculty and clinicians.

PDIA social work leaders were instrumental in organizing and participating in the March 2003 National Social Work Summit on End-of-Life and Palliative Care. The summit was designed to address the need for a coordinated effort focused



on palliative and end-of-life care within the social work profession. Leaders from national social work organizations, schools of social work, hospices and hospitals, government agencies, and advocacy groups attended the meeting. They helped design a social work agenda to improve care for the dying and their families. The agenda calls for organized professional leadership, standards of practice, and increased preparation at all levels of social work education.

As part of its exit strategy, PDIA has designated a grant of \$200,000 to further this agenda and establish a Social Work Council on End-of-Life and Palliative Care. The creation of this council will help social work as a field build professional consensus, create interdisciplinary partnerships, further a research agenda, collaborate on program initiatives, and build the educational structures needed to train future generations of social workers in palliative and end-of-life care.

The primary goal of the Social Work Council on End-of-Life and Palliative Care is to implement the priority agenda established at the Social Work Summit on End-of-life and Palliative Care. Comprised of relevant organizations, agencies, schools of social work, advocacy groups and

funding sources, the council will meet at two planned summits over the next two years to review progress on previously identified goals and establish next steps in building the coalition.

In addition, the council will begin to form an international initiative that builds on existing relationships with Canada and others in the international social work community through the National Association of Social Workers (NASW) the largest organization of social workers in the world. An important starting place is NASW's recent identification of palliative and end-of-life care as one of four areas of focus over the next five years.

PDIA social work leaders have established palliative and end-of-life care as a recognized specialty area within the social work profession. They have developed palliative and end-of-life care curriculum, research, and practice innovations in practice sites throughout the country. Leaders have collaboratively produced a comprehensive research agenda for the field. Social work leaders have initiated major studies to identify the needs of and create interventions for the dying and bereaved—especially vulnerable and underserved populations. They have developed educational

curriculum at all levels of social work training and successfully advocated for the requirement of end-of-life and palliative care content in all graduate level social work programs throughout the United States.

The program has successfully achieved its original goals; to enable social work experts to develop as leaders in the field, and to strengthen professional functioning by encouraging collaborative efforts between schools of social work and practice sites, collaboration between different practice sites, and collaboration between disciplines.

Now that PDIA social work leaders have succeeded in finding a place for end-of-life and palliative at the forefront of social work education, research, practice, and policy initiatives, the work of those individuals must be taken to the national and multinational organizational level to sustain and expand the movement to improve the culture of dying in all health and service organizations where social workers play a pivotal role.

**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 new 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.*

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## Social Work Leaders

**David A. Cherin, M.S.W., Ph.D.**  
 University of Washington School  
 of Social Work  
 Seattle, WA

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

In this intensive summer workshop program for social workers and other health professionals, participants design research and demonstration projects to carry out in their home institutions. Students develop a strong conceptual and practical background in palliative care services, preparing them to assume an active institutional role as they create end-of-life care practice models.

**Ellen L. Csikai, M.S.W., M.P.H., Ph.D.**  
**Mary Raymer, M.S.W., A.C.S.W.**  
 Stephen F. Austin State University School of  
 Social Work  
 Nacogdoches, TX  
 National Hospice and Palliative Care  
 Organization  
 Williamsburg, MI

*The Social Work End-of-Life Care Educational  
 Program (SWEEP)*

This project team will use a national survey of social workers in various practice settings to assess current levels of education in end-of-life care and identify barriers to effective social work intervention. Their results will inform development of an end-of-life care curriculum that provides the knowledge and skills necessary for social workers to address end-of-life care situations effectively, sensitively, and ethically. This curriculum will be widely available through a “train-the-trainers” program of continuing end-of-life care education for social workers in a variety of practice settings.

**Judith Dobrof, D.S.W.**

Department of Social Work Services  
 The Mount Sinai School of Medicine,  
 Mount Sinai Medical Center  
 New York, NY

*Caregivers and Professionals Partnership:  
 Assessing a Structured Support Program*

Nationally, 71 percent of caregivers report that they are caring for someone with a long-term or chronic illness. Effective support must be available to family members throughout the course of illness and bereavement. Judith Dobrof will evaluate the Caregivers and Professionals Partnership (CAPP), a structured support program for family caregivers. CAPP's Caregiver Resource Center provides bilingual walk-in and telephone assistance to family caregivers, as well as educational programs for health professionals to enhance their skills in working with family caregivers. Using data collected from CAPP's resource center, this initiative will explore CAPP's effect on family caregiver outcomes, and its value as a model support program for family caregivers.

**Betty J. Kramer, Ph.D.**

School of Social Work  
University of Wisconsin at Madison  
Madison, WI

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

Although social workers routinely support families and individuals coping with terminal illness, grief, loss, and bereavement in a variety of settings, educational gaps often leave them ill-prepared to competently fulfill these roles. Many advances in physician and nursing education in the past decade have come about because end-of-life content deficiencies in textbooks were identified and addressed, texts were revised and made widely available, and clear principles and guidelines for end-of-life care practice in medicine and nursing were instituted. Building on current standards used by medicine and nursing, Dr. Kramer will develop end-of-life content guidelines for the social work profession and use these guidelines to conduct a critical review of the most frequently used textbooks in social work education.

**Shirley Otis-Green, M.S.W., L.C.S.W., A.C.S.W.**

City of Hope National Medical Center  
Duarte, CA

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

Despite the high percentage of Latinos who reside in Los Angeles County, there are presently no integrated, Spanish-speaking end-of-life and bereavement support services available. This demonstration project will use focus groups of terminally ill people, the bereaved, and family caregivers to better understand the barriers to using traditional mental health services, and to develop and refine the structure of a bereavement support group (*Reflexiones*) and a general cancer group (*Compartiendo Esperanza*). Shirley Otis-Green will also develop a community partnership model appropriate for use in cancer centers nationwide.

**Amanda Sutton, M.S.W., C.S.W.****Yvette Colon, M.S.W., B.C.D.**

Cancer Care, Inc.  
New York, NY

*The End-of-Life Internet Forum*

This teaching model uses the Internet to provide focused training in end-of-life care to master's-level graduate students and social work professionals. This forum, at [www.cancercare.org](http://www.cancercare.org), is an Internet-based educational program and "virtual community" focused on end-of-life care for master's-level graduate students and postgraduate-level professionals. The coordinators teach the online curriculum, and co-facilitate the virtual support community and online chats with national specialists.

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## Social Work Leaders

**Mercedes Bern-Klug, M.S.W., M.A.**

Landon Center on Aging  
 University of Kansas Medical Center  
 Kansas City, KS

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

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

**Sheila R. Enders, M.S.W.**

University of California at Davis Medical Center  
 Sacramento, CA

*Creating a Handbook for Advance Care Planning and Decision Making at the End of Life in Populations with Low Literacy, Mild Learning Disabilities, or Mild Cognitive Deficits*

Sheila Enders will develop a handbook and test its effectiveness with inmate patients within the California state prison system. Corrections staff will learn about the concerns of special needs populations in the corrections setting. An accompanying educational video will promote understanding of key end-of-life issues. The handbook and video will be widely available to social workers, nurses, hospice, and skilled nursing facility personnel.

**Richard B. Francoeur, Ph.D.**

Columbia University School of Social Work  
 New York, NY

*Palliative Care in an Inner-City Minority Population: The Impact of Chronic Disease, Material Deprivation, and Financial Burden*

Material and economic deprivation, especially acute in minority and underserved populations, erodes quality of life and exacerbates barriers to the full assessment of patient health and their compliance with treatment for pain and symptoms. Dr. Francoeur will determine whether patients who experience material deprivation and/or financial burden are more likely to endure uncontrolled pain and experience unmet service needs.

**Barbara L. Jones, M.S.W., C.S.W.**

The Children's Hospital at Albany Medical  
Center

Albany, NY

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

This project will describe the current training of social workers in end-of-life care for children with cancer, examine the end-of-life experiences of families who have lost a child to cancer, and define crucial family support services. Barbara Jones will develop a curriculum and training program for pediatric end-of-life care that can be used by schools of social work, hospitals, and hospices.

**Jane Lindberg, L.C.S.W.**

Hinds Hospice

Fresno, CA

*Social Worker Bereavement Training Program*

This model program will provide bereavement services and support for the rural poor, especially migrant Hispanic families, living in the three rural central California counties of Fresno, Madera, and Merced. Social workers, clergy, and health professionals already working in the communities will be trained to create a network of knowledgeable, compassionate support.

**Susan Murty, A.C.S.W., M.S.W., Ph.D.**

School of Social Work

University of Iowa

Iowa City, IA

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

Dr. Murty will train students, faculty, and community partners at the University of Iowa's School of Social Work to deliver and promote effective rural social work practice in end-of-life care. Two cohorts of students will be trained as leaders in rural end-of-life care throughout the two-year social work master's curriculum. They will develop specialized knowledge and skills to work in rural communities, especially rural Latino communities. The project will disseminate models of effective service delivery for rural areas.

**Bruce A. Paradis, Ph.D.**

Salem State College Graduate School of  
Social Work  
Salem, MA

*End-of-Life Care: Birth through Old Age*

Dr. Paradis will develop an advanced M.S.W. concentration in end-of-life care and strengthen the ties between the Salem State College School of Social Work and the professional social work community. Students will complete a specialized year-long field placement in end-of-life care settings. Principal faculty members will collaborate with field placement sites and form an advisory committee. An elective course in end-of-life care will be offered via interactive video technology and simulcast to the schools of social work in New England that do not have curriculum in end-of-life care.

**Sherri Weisenfluh, L.C.S.W.**

Hospice of the Bluegrass  
Lexington, KY

*The Kentucky Project, Enhancing End-of-Life Care: A Social Work Manual for Students and Practitioners*

Kentucky has few exemplary models for social work education. Sherri Weisenfluh will create a statewide partnership of educators and service providers to address the scarcity of graduate social workers trained in end-of-life care, and will develop and disseminate a culturally sensitive training manual to students and social work practitioners throughout the state.



*Open Window* by Deidre Scherer

2003

## Social Work Leaders



From the Initiative for Pediatric Palliative Care's award-winning educational videotape series. See [www.ippcweb.org](http://www.ippcweb.org).

**David Browning, M.S.W.**  
Education Development Center  
Center for Applied Ethics & Professional  
Practice  
Newton, MA

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

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

**Karen Bullock, Ph.D.**  
School of Social Work  
University of Connecticut  
West Hartford, CT

### *Resource Enrichment Center*

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

**Elizabeth Chaitin, M.S.W., M.A., D.H.C.E.**  
University of Pittsburgh Medical Center,  
Shadyside  
Pittsburgh, PA

### *Interdisciplinary Specialty Team Training in Palliative Care*

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



**Nancy Cincotta, M.S.W.**  
 Mount Sinai Medical Center  
 New York, NY

*A National Initiative to Unite Social Workers and Families in the Interest of Dying Children*  
 Nancy Cincotta will organize a national network of social work experts in pediatric end-of-life care. Professionals and parents will partner to identify developmentally sensitive interventions, unique challenges, and opportunities to improve pediatric end-of-life care. Cincotta will create a listserv to serve as a virtual community for discussion, problem solving, resource sharing, and consultation for pediatric end-of-life care professionals.

**Elizabeth J. Clark, Ph.D., A.C.S.W., N.A.S.W.**  
 National Association of Social Workers  
 Washington, DC

*Building Social Work Practice and Policy Competencies in End of Life Care*  
 The National Association of Social Workers (NASW) is the largest professional organization for social workers in the world, and brings important institutional resources to shape both the public policy and social work practice related to the care of the dying. NASW Executive Director Elizabeth Clark has the opportunity to guide program development and mobilization within the social work profession. Dr. Clark will advance the role and competency of social workers in end-of-life care through the development of practice standards, communication, and continuing education.

**Nancy Contro, L.C.S.W.**  
 Lucile Packard Children's Hospital  
 Stanford University Medical Center  
 Palo Alto, CA

*Latino Families in Pediatric Palliative Care*  
 There is little available literature to guide health practitioners in providing family-centered palliative care for children. There is also very little literature which examines the experiences and needs of children and families from non-Anglo cultures. The goals of Latino Families in Pediatric Palliative Care at Lucile Packard Children's Hospital are to enhance understanding and provide meaningful guidance to improve care for Latino families whose children are seriously ill or dying.

**Rita Ledesma, Ph.D.**

School of Social Work  
California State University, Los Angeles  
Los Angeles, CA

*Loss and Bereavement in an American Indian and Alaska Native Community*

Dr. Ledesma will examine the impact of loss and bereavement in the American Indian and Alaska Native communities of the greater Los Angeles region. She will use qualitative methods with both community members and health and human services providers who work within the American Indian and Alaska Native community. Her findings will be used to develop training materials and curricula for social workers and allied health professionals who work with American Indians and Alaska Natives.

**Bonnie Letinich, M.S.W., L.I.C.S.W.**

Children's Hospital and Regional Medical Center  
Seattle, WA

*Pediatric Palliative Care Education for Social Workers*

The Palliative Care Consulting Service of Children's Hospital will develop a curriculum to educate social workers and other professionals about pediatric palliative care, communication, ethics, organizational change, and leadership. Educational conferences for social workers will enhance their pediatric palliative care skills and increase their ability to initiate palliative care and coordinate care for children with life-limiting conditions.

**Aloen Townsend, Ph.D.**

Mandel School of Applied Social Sciences  
Case Western Reserve University  
Cleveland, OH

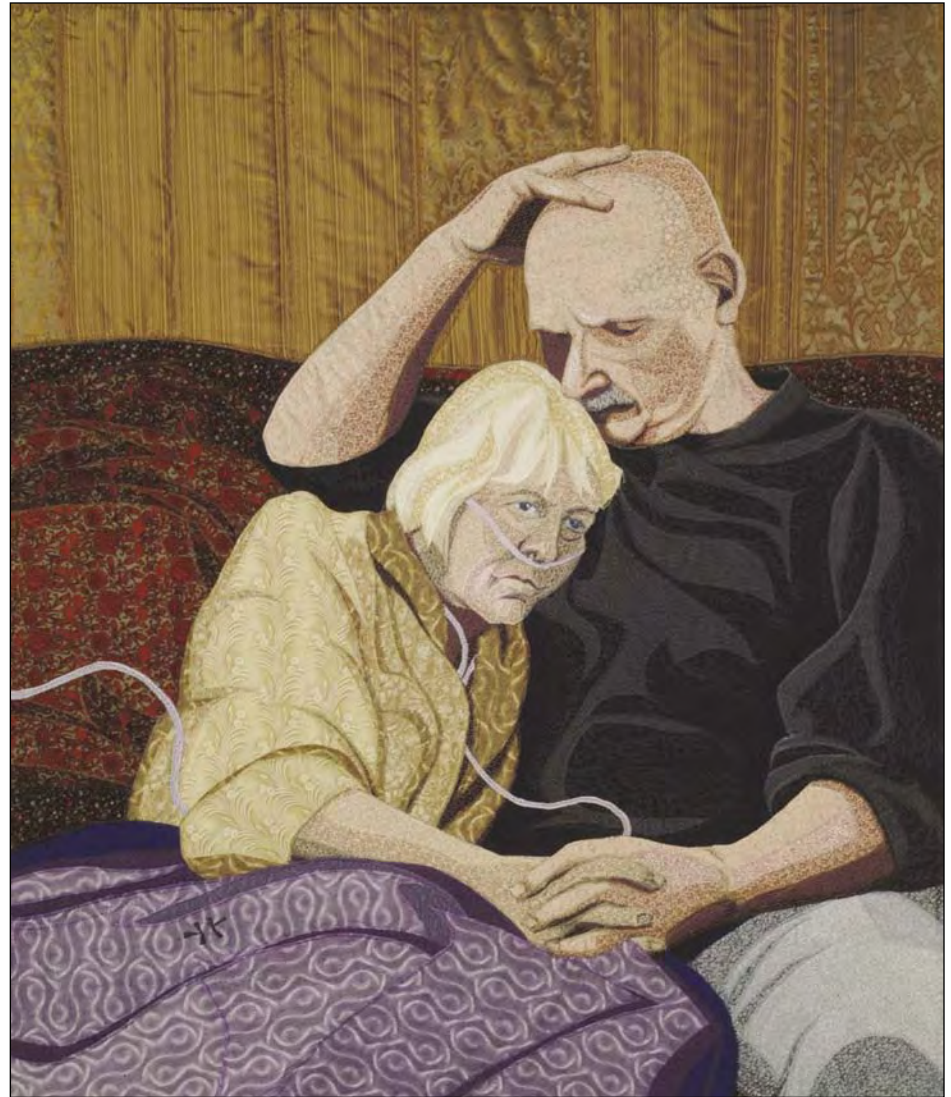
*Family Assessment Collaboration to Enhance End-of-Life Support*

Families are often an essential source of support for people with life-threatening illness. Family caregivers can have a major impact on the patient's quality of life and influence patient interactions with service providers. This project will improve methods of assessing the needs of family caregivers in order to improve end-of-life care for caregivers and patients. Dr. Townsend will address a critical gap: the lack of clinically relevant and scientifically sound measures for assessing family caregiver strain near the end of life.

**Terry A. Wolfer, Ph.D.**  
**Vicki Runnion, M.S.S.W.**  
University of South Carolina College of  
Social Work  
Columbia, SC

*Casebook on Death and Dying for Social Work  
Education*

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



*Bigger Than Each Other* by Deidre Scherer

## MISSION

### Nursing Leadership Academy

*Nurses are critically important in all practice settings of end-of-life care. In order to address the needs of the nursing profession, PDIA chose to partner with national nursing organizations to foster leadership and education.*

*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 essential knowledge and skills to appropriately care for dying patients and their families.*

The Institute for Johns Hopkins Nursing  
 Baltimore, MD  
 Cynda Hylton Rushton, R.N., D.N.Sc., F.A.A.N.  
 Kathleen Hartman Sabatier, M.S., R.N.

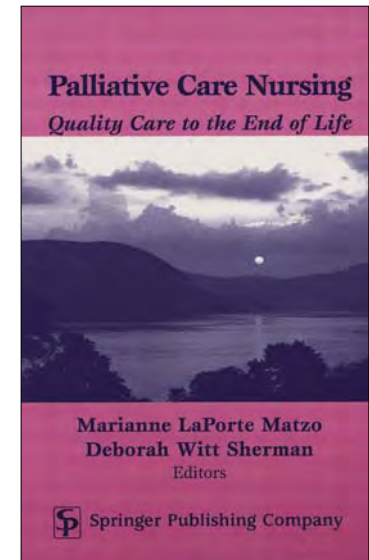
**\$394,163**

*Nursing Leadership Academy for End-of-Life Care*

This project is a continuation and extension of the 2000 Nursing Leadership Academy for End-of-Life Care. The original academy provided leadership training for nurse teams from 22 nursing specialty organizations. These emerging leaders have developed projects within their own specialty organizations that place a higher priority on palliative and end-of-life care. Academy mentors monitored and supported the teams during the post-training period. This new grant supports leadership training for a new cohort of teams from an additional 25 nursing specialty organizations.

As a result of the two meetings, academy participants and the organizations they represent have taken part in a number of initiatives locally and nationally. Their accomplishments include publication in nursing journals of 36 new articles advancing the field, the inclusion of palliative and end-of-life care on the agendas of 36 national nursing conferences, and the development of core curriculum within two specialty organizations. Participants developed collaborative partnerships, and five authored position papers. In addition, several organizations are involved in writing palliative care questions for certification exams, and a few are developing resource lists of experts and materials.

This grant also supports ongoing development of the website [www.palliativecarenursing.net](http://www.palliativecarenursing.net), which provides access to palliative care nursing resources, and provides news and networking opportunities for academy members.



## Palliative Care Fellowship Program Awards

Physicians must be well trained to provide appropriate care for seriously ill and dying patients, yet palliative care medical training lags far behind the needs of the aging U.S. population. In 2002, PDIA and the Emily Davie and Joseph S. Kornfeld Foundation joined forces to support advanced training for physicians in the principles and practice of palliative medicine. This collaborative funding initiative is designed to support professional education and increase the number of physicians trained to care for seriously-ill and dying patients.

Another goal of the program is to help palliative medicine achieve formal recognition as a medical subspecialty by the Accreditation Council for Graduate Medical Education and the American Board of Medical Specialties. A subspecialty in palliative medicine will attract leaders to the field, encourage essential research, and explicitly recognize that palliative care is an appropriate goal of medicine.

As more physicians are trained in palliative care fellowships and become certified in palliative medicine, reimbursement for palliative care

services is more likely to improve, which in turn will attract more physicians to the field. This will ultimately improve patient care. Once palliative medicine is established as a subspecialty of medicine, these programs will be eligible for federal funding, and the pressure on philanthropic support will be greatly reduced.

PDIA and Kornfeld committed a total of \$1,950,000 for thirteen grant awards to support fellowship training during 2003-2006. Kornfeld committed a total of \$600,000 and PDIA committed a total of \$1,350,000. Each selected fellowship program received \$150,000 over two years to support the training of one or more palliative care fellows.

PDIA and the Kornfeld Foundation hope to increase awareness and provide a model for other funders interested in supporting palliative medicine. As part of its exit strategy, PDIA designated part of the \$1.2 million grant to support the American Academy of Hospice and Palliative Medicine's capacity to develop and administer an ongoing grants program for palliative medicine fellowship training.



From *Aging in America* by Ed Kashi and Julie Winokur

## Palliative Care Fellowship Program Awards 2003–2006

### The Marshfield Clinic

Marshfield, WI

Michael T. Claessens, M.D.

#### *The Palliative Medicine Fellowship Program*

The Palliative Care Program at Marshfield Clinic and St. Joseph's Hospital combines strong institutional commitment to palliative care, a diverse setting, specialist faculty, and a comprehensive curriculum, all at the center of two large rural health systems. Training includes didactic core lectures, case conferences, a journal club, opportunities for research, and close faculty tutoring—all in the context of a reflective, philosophical approach to suffering and treatment. Successful fellows will become competent, caring specialist physicians and teachers of palliative medicine.

### George Washington University

Washington, DC

Elizabeth Cobbs, M.D.

#### *The Palliative Care Fellowship Program*

Palliative care fellows training at George Washington have access to a diverse collection of institutions, including the Washington D.C. Veterans Administration Medical Center, the Washington Home and Community Hospices, the Hospices of the National Capital Region, and the National Institutes of Health (NIH). Fellows train for six months in hospice inpatient settings that encourage continuity of care between inpatient and home settings. Fellows spend a month at NIH working in an expanded consultative setting where palliative care is integrated into disease modifying treatment in ongoing clinical trials. Fellows then spend three months in comprehensive palliative care program of the Veterans Administration Medical Center, which provides inpatient hospice and palliative care and consultative care to hospital and ambulatory care patients. Fellows are also encouraged to participate in both institutional and national quality improvement initiatives.

### University of New Mexico Health Sciences Center

Albuquerque, NM

Walter B. Forman, M.D.

#### *The Hospice and Palliative Medicine Training Program*

This new one-year fellowship program will offer a team-based experience that will prepare trainees to bring expert palliative medicine back to their home communities. The program will consist of an inpatient rotation at the Veterans Administration Hospital, outpatient care, a consultative rotation at the University Hospital, and an opportunity to participate in end-of-life care in the rural and Native American communities of New Mexico. Throughout the program, the trainee will be a member of the interdisciplinary team at a home care hospice program and will act as both clinical care provider and acting medical director in this setting. In addition to a research project, fellows will have the opportunity to participate in elective rotations, including pediatrics, neurology, pharmacology, geriatrics, and the congestive heart failure and respiratory failure clinics.



**Medical College of Wisconsin Affiliated Hospitals**  
 Milwaukee, WI  
 Bruce Himmelstein, M.D.

*Combined Fellowship in Pediatric and Adult Palliative Medicine*

The Combined Fellowship in Pediatric and Adult Palliative Medicine at the Medical College of Wisconsin Affiliated Hospitals provides clinical, educational, and research opportunities in both pediatric and adult palliative care. The two-year program prepares fellows to conduct academic research, and to provide palliative care to patients of all ages with a wide variety of life threatening conditions.

**University of Pittsburgh Medical Center Shadyside**  
 Pittsburgh, PA  
 Linda King, M.D.

*Palliative Care Fellowship Program*

This two-year program prepares fellows for an academic career as physician investigators in the growing specialty of palliative medicine. The fellowship combines the palliative care program's own clinical research resources with opportunities offered by the University of Pittsburgh Clinical Research Training Program.

**Cleveland Clinic Taussig Cancer Center**  
 Cleveland, OH  
 Susan LeGrand, M.D.

*The Harry R. Horvitz Center for Palliative Medicine Fellowship Program*

The mission of the Harry R. Horvitz Center for Palliative Medicine Fellowship Program is to educate physicians who will become skilled and compassionate palliative care clinicians, researchers, educators, and patient advocates. Fellows rotate every four weeks through the acute inpatient palliative medicine unit, inpatient consults, the outpatient clinic, and home and inpatient hospice care.

**Montefiore Medical Center**  
**Albert Einstein College of Medicine**  
 Bronx, NY  
**Sean O'Mahony, M.D.**  
**and Peter Selwyn, M.D., M.P.H.**

*Palliative Care Fellowship Program*

Montefiore Medical Center's Palliative Care Service offers a one- or two-year palliative medicine fellowship program in one of the country's largest teaching hospitals. Fellows rotate through the inpatient palliative care suite and consultation service, and the outpatient pain and palliative care clinic. Additional rotations in bioethics, neurology, chemical dependency, HIV, pulmonary, critical care, and pediatrics programs are available in a variety of settings. The fellowship program offers two tracks: a one-year clinician educator track including a diploma in clinical bioethics from New York University, and a two-year clinician researcher track which will include a Masters in Science at Albert Einstein College of Medicine.

**Memorial Sloan-Kettering Cancer Center**  
 New York, NY  
**Richard Payne, M.D.**

*Palliative Care Fellowship Program*

The Palliative Care Fellowship Program trains physicians to become specialists in palliative medicine with an emphasis on cancer pain management. First year fellows train with the inpatient pain consultation service and see patients in the outpatient clinic. All fellows complete a six-week rotation with clinical privileges at Calvary Hospital, a hospital for terminal cancer patients. They work with patients at the hospital and the home hospice program. Second-year fellows conduct faculty-supervised research projects.

**Duke University Medical Center**  
 Durham, NC  
**James Tulsky, M.D.**  
**and Anthony Galanos, M.D.**

*Fellowship in Palliative Medicine*

This fellowship includes a clinical year of supervised clinical rotations which expose fellows to a range of interdisciplinary palliative care venues. In the principal rotation, fellows spend six months on the inpatient palliative care service at Duke Hospital followed by a three month rotation in community-based outpatient palliative care at the Duke Community Hospice. Fellows then select three one-month rotations in various settings. The second year of the fellowship is focused on developing research skills. Fellows enroll in the clinical research training program and design and complete an independent research project under the guidance of a faculty mentor. Fellows complete with strong clinical and research skills.

### Center for Palliative Studies at San Diego Hospice

San Diego, CA

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

#### *Fellowship in Palliative Medicine Program*

San Diego Hospice is a nonprofit, community-owned program serving all of San Diego County. The hospice cares for more than 4,000 patients annually, 60% with cancer. Fellows spend three months in the inpatient care center, three months with the 550-bed acute inpatient consultation service at Scripps-Mercy Hospital, three months with home hospice care, and one month each with geriatric palliative care and the hospital consultation service. Fellows have a one-month elective to pursue individual interests. They also teach UCSD medical students and residents.

### Northwestern Memorial Hospital

Chicago, IL

Jamie H. Von Roenn, M.D.

#### *The Palliative Care and Home Hospice Program*

The Palliative Care Fellowship Program at Northwestern University trains fellows to become palliative care physician leaders. The program emphasizes symptom management, communication techniques, and interdisciplinary team skills. Fellows receive clinical experience with elective rotations in a variety of settings both within and outside of Northwestern. Fellows enroll in a formal clinical investigator training program, and conduct a mentored research project. In addition to clinical rotations and research, didactic training is integrated throughout the program. Lectures, monthly case conferences, weekly educational sessions at the Buehler Center on Aging, and other opportunities such as grand rounds expand the scope of the program.

### Children's Hospital Boston Dana Farber Cancer Institute

Boston, MA

Joanne Wolfe, M.D.

#### *Pediatric Advanced Care Team*

The Pediatric Advanced Care Team is an established interdisciplinary palliative care service at Children's Hospital Boston and the Dana Farber Cancer Institute. This one-year fellowship training opportunity includes a combination of didactic seminars and varied clinical experiences primarily involving children with advanced illnesses and their families. Fellows go on to serve as academic program developers, educators, and mentors in pediatric palliative care. They bring much-needed expertise in palliative and end-of-life care to children with advanced illness and their families, and will help to shape this newly emerging subspecialty throughout the United States.

## GRANTS PROGRAM



**D**URING THE PERIOD covered by this report, 2001-2003, the Grants Program of the Project on Death in America supported a range of programs: to examine legal, governmental, and institutional policies that affect dying patients; improve care for seriously ill children and their families; and address disparities in care for underserved communities. Through the grants program, PDIA strengthened the infrastructure and leadership capacity of important organizations in the field.

# Strengthening Organizational Capacity

## American Board of Hospice and Palliative Medicine

Silver Spring, MD  
Dale Ellen Lupu, Ph.D.

**\$219,380**

### *The Recognition and Advancement of Palliative Medicine as a Medical Subspecialty*

The American Board of Hospice and Palliative Medicine (ABHPM) is working to establish palliative medicine as a medical subspecialty. In order to obtain formal recognition by the American Board of Medical Specialties, palliative medicine must be distinguished as a distinct medical discipline with a specific core of knowledge, a strong research base, training and certification standards, and a strong professional association. The ABHPM is developing a consensus within medicine on the appropriate organizational base for a palliative medicine subspecialty. ABHPM will also seek the formation of a residency review committee within the Accreditation Council of Graduate Medical Education to implement accreditation guidelines for palliative medicine fellowship programs.

## American Pain Foundation

Baltimore, MD  
John D. Giglio, J.D.

**\$100,000**

### *Increasing the Availability of Pain Information to Consumers*

Pain experienced by the chronically, seriously, and terminally ill is vastly undertreated in the United States, especially among minority populations. The American Pain Foundation (APF) is a national nonprofit organization dedicated solely to serving the needs of people in pain. This grant will enable APF to provide increased information and assistance to pain sufferers, their caregivers, and the public by increasing Internet technology, upgrading written materials, and expanding information resources.

**The Cicely Saunders Foundation**

London, England

Irene J. Higginson, Ph.D.

**\$100,000***The Cicely Saunders Foundation: Capacity Building and Developing Standards of Care.*

The Cicely Saunders Foundation is a new charity in the UK with the mission to create a center of innovation—in research, practice, and education—to improve the care of those affected by progressive disease, whether in the hospital, hospice, or at home. The foundation is working to identify and promote best practice and research in palliative care in the UK and many other countries. The foundation will concentrate on three areas; service development research, clinical research, and sociological research. PDIA funding will help launch the foundation, support its infrastructure, and help establish it as a center of innovation.

**National Hospice and Palliative Care Organization**

Alexandria, VA

Stephen Connor, Ph.D.

**\$160,000***National Hospice and Palliative Care Organization Capacity Building Program*

The National Hospice and Palliative Care Organization (NHPCO) is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. NHPCO advocates for terminally ill people and their families. It also develops public and professional education programs to make information about hospice and palliative care widely available. This grant provides general operating support for NHPCO's initiatives to improve end-of-life care in the United States. It will also support a set of policy initiatives designed to encourage earlier palliative care intervention and increased access to hospice care.

**University of Alabama at Birmingham**

Birmingham, AL

John Shuster, M.D.

**\$10,000***Organizational Meeting for the North American Palliative Care Psychiatry/Psychology Research Consortium*

The grant supported an organizing meeting of a new North American Palliative Care Psychiatry/Psychology Research Consortium. The meeting was a first step toward the development of a multi-center palliative care research infrastructure.

## Shaping Public and Legal Policy to Improve End-of-Life Care

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

Washington, DC  
Mary Baluss, J.D.

**\$233,866**

#### *Palliative Care Law Project*

The Bazelon Center for Mental Health Law's Palliative Care Law Project uses legal advocacy to bridge the gap between recognized standards for high-quality end-of-life care and the actual experiences of terminally ill patients and their families. The project also serves as a resource to attorneys and other advocates for patients; patients and families facing legal issues relating to withdrawing treatment at the end of life; patients and families who have experienced poor pain management; and doctors and other medical professionals who want to understand their rights and obligations under state and federal law, or who are under investigation for pain management prescriptions for legitimate pain patients. The project maintains a website, [www.painlaw.org](http://www.painlaw.org).

### International Longevity Center

New York, NY  
James Nyberg, M.P.H

**\$19,075**

#### *Palliative Care Academic Career Awards: A Public-Private Partnership to Improve Care for the Most Vulnerable*

The field of palliative care has developed a substantial amount of knowledge that addresses the needs of patients and families living with serious and life threatening illness. However the dissemination of this knowledge, and the development of new research has been limited by the paucity of academic palliative care teaching and research programs in the nation's medical schools and teaching hospitals. The International Longevity Center, in collaboration with the Mount Sinai School of Medicine, is undertaking an effort to promote the development and sustainability of academic faculty in palliative care. This grant supports the promotion and distribution of a policy report on palliative care that details the need to develop and support more palliative care expert faculty who will train future generations of physicians to care for seriously ill patients and their families.

### University of Wisconsin-Madison Medical School

Madison, WI  
June L. Dahl, Ph.D.

**\$105,362**

#### *Institutionalizing Pain Management through Practice Change Programs*

The American Alliance of Cancer Pain Initiatives (AACPI) promotes cancer pain relief nationwide by supporting the efforts of state cancer pain initiatives. Cancer pain initiatives are voluntary, grassroots organizations composed of nurses, physicians, pharmacists, social workers, psychologists, and representatives of clergy, higher education, and government. Initiatives and their participants provide education and advocacy to healthcare providers, cancer patients, and their families. In this project, the AACPI will provide technical support and contract awards to two state cancer pain initiatives. Each contracted initiative will implement a program to help improve pain management practices in 20-25 healthcare organizations, including long term care facilities, home health agencies, and/or small, community-based hospitals. The programs will train teams from participating organizations in pain assessment and management, institutional planning, and evaluation of both patient and institutional outcomes.



*Three Men* by Deidre Scherer



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

**North General Hospital**  
New York, NY  
Richard Payne, M.D.

**\$399,947**

### *The Initiative to Improve Palliative Care for African Americans*

The Initiative to Improve Palliative Care for African Americans (IIPCA) is an interdisciplinary working group of African American scholars, professionals, and community leaders working together to delineate the historical, social, cultural, ethical, economic, legal, political, and medical issues that affect African Americans’ attitudes towards, access to, and use of palliative care and hospice services. IIPCA is defining and promoting an agenda in research, education, and policy to improve care for African American patients facing serious illness. IIPCA serves as a resource center for information about palliative and end-of-life care in the African American community and builds coalitions with palliative care health, education, and policy groups. IPPCA encourages educational activities and research to advance understanding of the needs of African Americans in palliative and end-of-life care, and of the socio-economic, legislative, and regulatory barriers to quality care. This grant supports a national program office located at North General Hospital in Harlem.

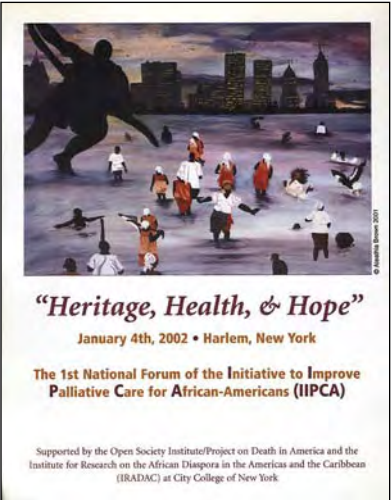
**North General Hospital**  
New York, NY  
Richard Payne, M.D.

**\$75,000**

### *The Initiative to Improve Palliative Care for African Americans National Conference*

This grant supported a 2002 national leadership meeting in Harlem, New York. The theme of this conference was “Heritage, Health, and Hope.”

*“We envision a society where African American patients facing serious and potentially fatal illness—along with their families, the communities in which they live, and the healthcare providers who serve them—have knowledge of and access to state-of-the-art palliative and hospice care. This vision includes elimination of racial and socioeconomic disparities that limit such knowledge and access.”* IIPCA mission statement



## Increasing Access to Palliative Care for Vulnerable Populations

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

**\$169,738**

### *Health Decisions for People with Disabilities*

People with disabilities and chronic illnesses and their families need access to informed, committed, and compassionate individuals to help navigate difficult health care choices, especially at the end of life. This two-year project will train members of New Jersey Health Decisions' Disability Ethics Network to conduct community-based consultation for individuals with disabilities and chronic illnesses, their families and agents, and professional staff, focusing on dispute resolution and mediation. The project will provide educational programs for professional staff and consumers in healthcare decision-making, advance directives, end-of-life care, and palliative care. Project staff will conduct research on the current provision of hospice care to people with developmental disabilities, and develop new policy and service guidelines for care. Project staff will examine care provided to people who are guardians of the state and live in state facilities or group homes. This project will provide advocacy for individuals with disabilities and their family members and agents, and create replicable models to assist them in making complex and difficult healthcare choices.

## Radio Bilingue

Fresno, CA  
Hugo Morales

**\$102,025**

### *Últimos Cuidados, Cuidados para los Desahuciados y sus Familias Final Care, Care for the Dying and their Families*

Radio Bilingue is a non-profit network of five public radio stations in California with a tradition of producing and distributing Latino news and information programming for both commercial radio and the national public radio system. It is the only national distributor of Spanish-language programming in public radio. The network's flagship station, KSJV in Fresno, California was founded in 1976 by a group of farm workers, artists, and professionals with the mission of providing access to the airwaves for the Mexican-American community. The station offers folk and diverse Latino musical styles, open discussions of Latino public affairs, and basic information services for immigrants and field workers. This grant will enable Radio Bilingue to produce a Spanish-language national radio campaign to educate Latinos about care options available for them and their families when facing a terminal illness. Radio Bilingue will develop the campaign in collaboration with state and national hospice and palliative care providers. Radio Bilingue will promote the campaign among their national affiliates and encourage them to network with local hospice providers.

University of Washington School of  
Medicine  
Seattle, WA  
J. Randall Curtis, M.D., M.P.H.

**\$47,611**

*Improving the Quality of Clinician-Family Communication in the Intensive Care Unit for Non-English-Speaking Families*  
Many seriously ill people die in the intensive care unit, and for non-English-speaking patients and families, the experience can be unnecessarily confusing and painful. In order to improve the quality of care delivered to non-English-speaking patients and families in the intensive care unit, health professionals must be trained to appropriately and effectively communicate complex health information. The goal of this project is to identify effective strategies for cross-cultural communication about end-of-life care.

Volunteers of America  
Alexandria, VA  
Margaret Ratcliff, M.S.W.

**\$66,666**

*Last Passages: Transforming the Experience of Death for Individuals with Developmental Disabilities and their Families*  
People with developmental disabilities now have life expectancies consistent with the general population, and aging and end-of-life care are emerging issues. Last Passages aims to improve care for people with developmental disabilities and their families. Last Passages will document current end-of-life care programs in each state, and develop a demonstration project based on an existing, successful care model. The project will make the model available via website, [www.volunteersofamerica.org](http://www.volunteersofamerica.org), networking, and a national conference.

## Improving Palliative Care for Children and Families

### The Life Institute

Albany, NY

Daniel Tobin, M.D.

**\$18,650**

#### *National Pediatric Palliative and End-of-Life Care Leadership Meeting*

This grant supported a 2002 National Pediatric Palliative and End-of-Life Care Meeting. The Children's Oncology End-of-Life Task Force, in collaboration with other leading pediatric organizations held a two-day meeting to create a cooperative strategy within pediatric palliative and end-of-life care that would begin to address recommendations made by the Institute of Medicine in its report *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*.

### Education Development Center, Inc. Center for Applied Ethics & Professional Practice

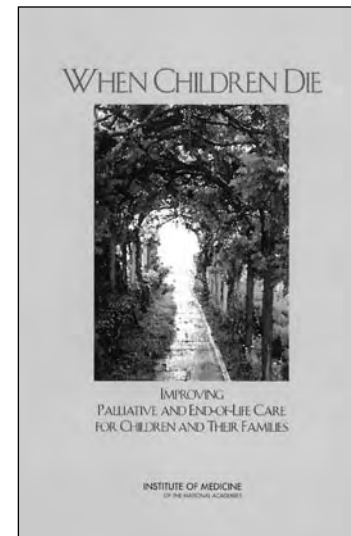
Newton, MA

Mildred Z. Solomon, Ed.D.

**\$500,000**

#### *Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions, Phase II: Moving to Action*

There is growing evidence that the healthcare system is failing seriously ill children and their families. Working in close collaboration with the National Association of Children's Hospitals and Related Institutions, the Society of Pediatric Nurses, and the New York Academy of Medicine, Education Development Center, Inc. will develop educational resources and models for children's hospitals across the United States. Six leading hospitals will pilot test program materials, implement the program's practices and policies, and measure progress toward establishing new quality indicators for family-centered pediatric palliative care.



### National Academy of Sciences

Washington, DC

Marilyn Field, Ph.D.

**\$12,193**

#### *Care for Dying Children and their Families: Preparation of a Popular Summary*

In July 2002, the Institute of Medicine published the report *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. This report includes an executive summary intended primarily for physicians, educators, researchers, administrators, and policymakers. This grant supports the preparation of a popular summary of the report for a broader audience, including family support services, advocacy groups, and families.



*My So-Called Lungs*, Laura Rothenberg's audio diary about cystic fibrosis, aired on National Public Radio in 2002.

## Other Grants

### 2001 - 2003

**Meryl Levin**  
New York, NY

**\$23,000**

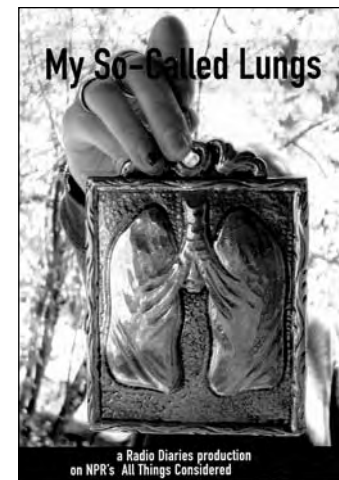
*Anatomy of Anatomy: in words and images*  
This book and traveling exhibition combines photographs of a group of medical students during their dissection of cadavers in gross anatomy class with excerpts from journals they kept during the course. Initial support from PDIA made it possible to create *Anatomy of Anatomy* in book and exhibition form, and to begin distribution free of charge to students at institutions where the exhibition travels. This additional grant will fund six additional venues to the exhibition tour.

**University of Massachusetts Medical School**  
Newton, MA  
Sandra L. Bertman, Ph.D.

**\$67,407**

*End-of-Life Care: Visions and Voices from the Arts & Humanities*  
This project will increase the visibility of the arts and humanities projects funded by the Project on Death in America in the medical and general communities. *Visions and Voices* will present photographs and excerpts from PDIA's visual, dramatic, poetic, and literary grantee projects. An anthology of these materials with accompanying print and online manuals will be available for subsequent use by clinicians and educators.

**Radio Diaries, Inc.**  
New York, NY  
Joe Richman



**\$1,250**

*Laura's Diary: My So-Called Lungs*  
*Laura's Diary: My So-Called Lungs* aired on National Public Radio's *All Things Considered* show in August 2002. The audio diary was recorded over the course of two years by 21-year-old Laura Rothenberg, who discussed her experiences living with cystic fibrosis. NPR and Radio Diaries were subsequently deluged with requests from people who want to use *Laura's Diary* for educational purposes. This grant supports the production of the CD for distribution to hospitals, hospices, medical schools, and cystic fibrosis organizations. Radio Diaries will develop educational materials to accompany the CD and will initiate an outreach and promotional campaign. The production of *My So-Called Lungs* was supported, in part, by the Summer Media Project, a 1999 grantmaking initiative of the Project on Death in America and Youth Initiatives.

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

**\$10,000**

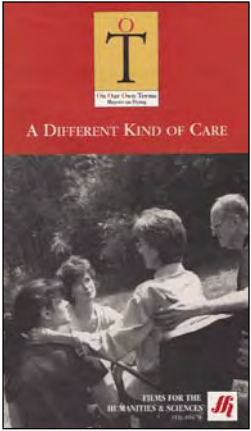
*Still Life: The Humanity of Anatomy.*  
*Support for Broadcast, Distribution, and*  
*Medical Education*

*Still Life: Humanity of Anatomy*, a film supported by a PDIA Arts and Humanities grant, explores the experiences of first-year medical students as they dissect cadavers in gross anatomy class. This grant supports broadcast, distribution, and outreach to medical educators.

**The Catticus Corporation**  
Berkeley, CA  
Pierre Valette

**\$10,000**

*Promotion and Dissemination of Ready or Not*  
*Ready or Not*, supported by a 1999 PDIA grant, is a behind-the-scenes documentary of Harvard Medical School’s course, “Living with a Life-Threatening Illness.” This grant funds outreach and free distribution of the video to the 125 allopathic and 16 osteopathic medical schools nationwide.



**Educational  
Broadcasting System**  
New York, NY  
Judith Moyers

**\$25,000**

*On Our Own Terms Re-Broadcast*  
*On Our Own Terms: Moyers on Dying* premiered on PBS in September 2000. The initial broadcast, combined with an extensive promotion and education campaign, attracted wide press coverage, strong ratings, and localized programming both on-air and online. Partnerships with more than 70 organizations and 300 community coalitions were established to encourage public discussion and action. This grant helped support the rebroadcast of the program in 2001, during National Hospice Month. Grant funds were also used to help stations create locally produced programs for broadcast and online presentations.

### American Hospice Foundation

Washington, DC

Naomi Naerman, M.P.A.

**\$136,242**

*Grief at School Training Program in  
Collaboration with the National Association of  
School Psychologists*

The Grief at School Program trains teachers, counselors, psychologists, nurses, and social workers to help grieving children in classrooms and after-school programs. Workshops train participants to identify grieving children, conduct age-appropriate lessons on loss and grief, establish school-based grief support groups, and collaborate with local hospices. In 1999 PDIA supported the Grief at School's 3-city pilot program. In response to the pilot program's success, PDIA awarded a subsequent grant to help expand the program so that members of national associations of school-based professionals could attend workshops at national and regional conferences. This third grant will make the model Grief at School training program available to members of the National Association of School Psychologists at national and state conferences.

### Center for the Advancement of Health

Washington, DC

Jessie C. Gruman, Ph.D.

**\$9,000**

*Toward More Effective Responses to Grief*

In 2000, PDIA supported the Center for the Advancement of Health with a grant for Building the Field of Grief: Improving the Evidence Base, a research and dissemination program to improve the ability of professionals and lay counselors to effectively diagnose, treat, and support grieving individuals and families. This grant supports a 2002 meeting of public and private funders to review preliminary findings and encourage continuing research in grief and bereavement.

### Hospice Foundation of America

Washington, DC

David Abrams

**\$15,000**

*2001 Living with Grief Teleconference:  
Caregiving and Loss*

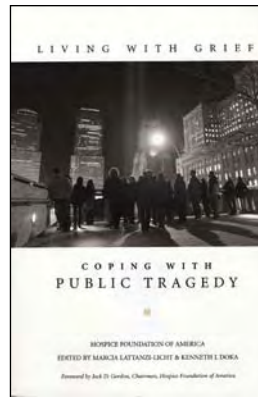
Every year the Hospice Foundation of America produces the National Living with Grief Teleconference. The teleconference is broadcast live via satellite and is accessible to organizations and communities across the country. Caregiving and loss was the 2001 theme. It is estimated that there are more than 25 million family caregivers in this country providing 80% of home care services. Caregiving is especially challenging for those coping with terminal illness and facing end-of-life decisions. This broadcast is designed to help healthcare professionals understand the unique needs of family caregivers and develop strategies to provide effective support.





*2002 Living with Grief Teleconference:  
Loss in Later Life*

Over two-thirds of all people who die in the United States are sixty-five and older, yet little professional literature addresses the effects of an elderly person's death, the needs of survivors, or the special services that elderly individuals can use to help them cope with loss. *Loss in Later Life* will focus on the ramifications of the loss of the elderly—including losses due to the death of a loved one and multiple losses experienced as a function of aging.



*2003 Living with Grief Teleconference:  
Coping with Public Tragedy*

The goal of *Coping with Public Tragedy* is to provide training and resources to healthcare workers, spiritual leaders, emergency response teams, funeral directors, and lay people so that they will be better able to help grieving people affected by human or natural disasters.

Youth Communication New York  
Center, Inc.  
New York, NY  
Keith Hefner

**\$10,350 (co-funded with OSI's Youth  
Initiatives Program for a combined award  
of \$20,750)**

*Making Peace with the Past*

Youth Communication used death as a topic of focus for a high school summer journalism workshop. Through guided discussion, readings, special presentations, and writing activities, the youth participants explored the subject of death and expressed their own feelings and experiences. Youth Communication editors and staff assembled a collection of these articles. This grant, to complete the publication, design, and printing of the finished book, is co-funded with OSI's Youth Initiatives Program. The book, *Making Peace with the Past*, will serve as a resource for educators and youth workers to facilitate conversations about grief and bereavement with young people.

# THE PROJECT ON DEATH IN AMERICA'S EXIT STRATEGY TO ADVANCE PROFESSIONAL EDUCATION, RESEARCH, AND TRAINING

O

RIGINALLY DESIGNED as a three-year \$15 million funding program, PDIA was ultimately renewed for a total of nine years of grantmaking. When PDIA closed on December 31, 2003, it had distributed \$45 million to organizations and individuals across the United States to improve care for dying patients and their families.

During PDIA's last year of funding, its board and staff reviewed the program's original funding strategies, goals, and individual initiatives. PDIA hosted roundtable discussions and individual meetings, actively engaging palliative care leaders including former board members, faculty scholars, nursing and social work leaders, grantees, organizations, associations, experts in the field, and other funders to help frame PDIA's exit strategy.

The overwhelming consensus was that PDIA's exit strategy should be consistent with the project's long standing focus on professional development for healthcare professionals in palliative care.

This includes the need to strengthen existing professional associations' capacity to affect health policy, financing, education, research, and clinical training in palliative care. It also recognizes the importance of encouraging other funders to include palliative care on their funding agendas.

With this consensus, PDIA has chosen to make its final grant awards to enhance the organizational capacity and sustainability of the following organizations: the American Academy of Hospice and Palliative Medicine, the National Hospice and Palliative Care Organization, the American Board of Hospice and Palliative Medicine, the Hospice and Palliative Nurses Association, the Social Work Summit, Harvard Medical School's Program in Palliative Care Education and Practice, and Grantmakers Concerned with Care at the End of Life.

## The American Academy of Hospice and Palliative Medicine

Glenview, IL

**\$1,200,000**

The American Academy of Hospice and Palliative Medicine (AAHPM) is the leading physician-based professional organization dedicated to advancing practice, research, and education in hospice and palliative medicine. AAHPM members come from many medical specialties and are committed to improving hospice and palliative care for patients with life-limiting illness and their families.

This grant will support AAHPM's infrastructure, and strengthen its ability to serve the needs of palliative care professionals across disciplines and borders. The funds will enable AAHPM to develop an academic "college" to continue the legacy and leadership of the PDIA Faculty Scholars; strengthen AAHPM's capacity to support and nurture academic leaders and scientists who will establish palliative care as a well-recognized field in medicine, nursing, and social work; raise the level of interaction and influence with other organizations; and expand the role of the AAHPM as a leader in interdisciplinary professional education in palliative care. The grant will also enable AAHPM to assume responsibility for recruiting and coordinating a consortium of foundations to support palliative care fellowship training programs.

## The Hospice and Palliative Nurses Association

Pittsburgh, PA

**\$200,000**

The Hospice and Palliative Nurses Association (HPNA), a 5,500 member organization for licensed nurses and certified nursing assistants, is committed to promoting excellence in end-of-life-nursing care. HPNA will use PDIA's grant to advance professional nursing education by building on the work of the Johns Hopkins Nursing Leadership Academy on End-of-Life Care, and the End-of-Life Nursing Education Consortium (ELNEC.)

HPNA has recognized that providing palliative and end-of-life care for people in nursing homes and long-term care settings receives little attention. HPNA will use the funding to initiate ELNEC courses with a goal of recruiting 450 participants—50 percent from the long term care setting. Upon course completion, participants will become members of a newly established "Community of Practice" to meet their ongoing needs for support and education.

## Social Work Summit on Palliative and End-of-Life Care

New York, NY

**\$200,000**

In March 2002, leaders from national social work organizations, schools of social work, hospices, hospitals, government agencies, and end-of-life advocacy groups gathered for a summit meeting to design a social work agenda to improve care for the dying and their families. The group represented more than 30 organizations and over 160,000 practicing social workers.

PDIA's grant will further this agenda for organized professional leadership, standards of practice, and increased preparation at all levels of social work education. The goal is to help social work as a field be better prepared to build professional consensus, create interdisciplinary partnerships, further a research agenda, collaborate on program initiatives, and build the educational structures needed to train future generations of social workers in palliative and end-of-life care.

### The National Hospice and Palliative Care Organization

Alexandria, VA

**\$200,000**

The National Hospice and Palliative Care Organization (NHPCO) is the oldest and largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America.

This grant will help NHPCO strengthen its organizational infrastructure and expand its reach into diverse communities. The grant will support NHPCO's efforts to encourage appropriate end-of-life care further upstream within the healthcare system. It will also enable NHPCO to build relationships with long term care providers, extend the work of the Veteran's Administration Hospice and Palliative Care Initiative, and establish an office of diversity to expand palliative care access and outreach to communities of color.

### Harvard Medical School's Program in Palliative Care Education and Practice

Boston, MA

**\$100,000**

Harvard Medical School's Program in Palliative Care Education and Practice (PCEP) is an international faculty development program. PCEP offers intensive learning experiences for physician and nurse-educators who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, and to gain expertise in leading and managing improved palliative care education and practice at their own institutions. Faculty who complete the training program are prepared to teach other faculty, practitioners, and trainees in medical and nursing about end-of-life care, create innovative educational programs, and to lead clinical service reform, including building new palliative care programs.

PDIA's grant will support scholarships for healthcare professionals from minority or underserved communities to attend PCEP's faculty development program. These scholarships will allow PCEP to continue to recruit a diverse population of health professional educators from sites across the country, and help assure that underserved and minority communities have access to their expertise.

### The American Board of Hospice and Palliative Medicine

Silver Spring, MD

**\$99,984**

Since its inception in 1996, the American Board of Hospice and Palliative Medicine (ABHPM) has worked to bring recognition to the emerging field of palliative medicine. ABHPM develops standards for training and practice in palliative medicine and establishes the requirements for certification and recertification. ABHPM is an independent, non-profit organization whose certificate is recognized as signifying a high level of physician competence in the discipline of palliative medicine. Members of the ABHPM Board and Examination Committee are nationally recognized leaders in clinical practice, academic medicine, medical education, and research in the field of palliative medicine.

PDIA's grant will enable ABHPM to implement standards for fellowship training programs in palliative care and to begin the lengthy subspecialty application process for palliative medicine. ABHPM's long-term goal is recognition of palliative medicine as an official subspecialty by the American Board of Medical Specialties and the American Osteopathic Association. ABHPM is collaborating closely with the American Academy of Hospice and Palliative Medicine to jointly lead the campaign for recognition of the specialty. Many other individuals and groups are also working toward this goal.

## Grantmakers Concerned with Care at the End of Life

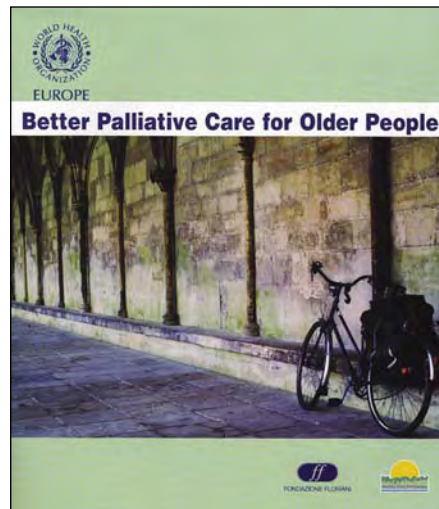
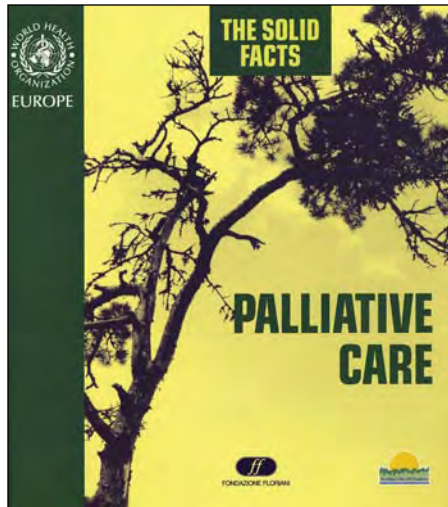
New York, NY

PDIA will support the activities of Grantmakers Concerned with Care at the End of Life (GCCEL) through 2004. GCCEL is based at the Open Society Institute and serves as a resource center for other funders who need information or advice about funding in the field. GCCEL works within the foundation community to encourage a wide range of funders—community foundations, family foundations, individuals, and private foundations—to support palliative and end-of-life care locally and nationally.



Family remembering their father and grandfather, outside of Window Rock, AZ.

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



**I**N CENTRAL AND EASTERN EUROPE and the former Soviet Union, public health experts are increasingly aware that an aging population, a growing incidence of cancer, and an emerging HIV/AIDS epidemic will create enormous medical, social, and economic challenges, and that the quality of care for patients and families must be seen as an international public health issue.

In January 2000, the Open Society Institute announced a \$500,000 per year initiative to enhance hospice and palliative care in Central and Eastern Europe (CEE) and the countries of the former Soviet Union (FSU). A joint initiative of OSI's Network Public Health Program and US Program's Project on Death in America, the Palliative Care Initiative for CEE and FSU provides matching funds to National Soros Foundations for palliative care development. Additional non-matching funds support palliative care initiatives outside the Soros Foundation Network. Funding is used to support governmental and professional

organizations, individuals, and foundations to expand the capacity of programs and activities in this region to improve care of the dying.

The goal of the Palliative Care Initiative for CEE and FSU is to improve end-of-life care for patients and families with a special focus on vulnerable populations including the elderly, children, and patients with cancer or HIV/AIDS.

The initiative has four objectives:

- to increase public awareness about end-of-life care issues;
- to provide palliative care education to healthcare professionals and support the integration of palliative care into medical, social work, and nursing school curricula;
- to make essential drugs for pain and symptom management easily available, and
- to integrate palliative care into national healthcare plans, policies, and systems of care.

The initiative has made over 100 grants in the region to individuals, non-governmental organizations, national and international professional associations, and the World Health Organization. The main funding strategy of the initiative has been to map the wide range of existing palliative care services in the region and to support their capacity for development and sustainability. The initiative has also supported efforts to improve governmental health policies that affect the delivery of palliative care services.

Funding examples include:

- Establishing seven Palliative Care Resource Training Centers to support professional and public education, reduce barriers to opioid availability, and integrate palliative care into national health care policies and systems.
- Sponsoring national and regional education programs for physicians, nurses, social workers, clergy, and health care policymakers in the region.
- Awarding scholarships for health professionals to train at internationally

recognized centers of excellence in palliative care.

- Supporting translation and distribution of existing palliative care texts and educational materials.
- Supporting research to improve national drug availability laws and regulations in order to guarantee the medical use and availability of opioid analgesics and other essential medications for pain and symptom management.
- Supporting an International Observatory on End of Life Care that provides country reports on palliative care development for researchers, health policymakers, and funders. ([www.eolc-observatory.net](http://www.eolc-observatory.net))

The Palliative Care Initiative serves as a resource to establish an international network of individuals and organizations committed to improving care for patients with life-limiting illness and their families. In the coming years, the initiative will expand its reach to additional countries, and previously-funded programs will continue to receive technical assistance.

## THE INTERNATIONAL PALLIATIVE CARE INITIATIVE: SOUTH AFRICA



Newly orphaned child in the KwaZulu Natal Province of South Africa, where the HIV infection rate in the ante-natal clinics is at 38 percent.

**T**HE QUALITY OF LIFE of hundreds of thousands of HIV/AIDS patients and their families could be dramatically improved just by making existing knowledge of pain management, symptom control, and psychosocial support widely accessible to community-based HIV/AIDS programs. These programs provide a range of essential services, including HIV testing, counseling, palliative care, social support, food, clothing, housing, orphan care, daycare centers, and income-generating initiatives.

In 2002, the Open Society Institute expanded its International Palliative Care Initiative to South Africa with a \$1 million, three-year matching funds initiative. This initiative is designed to serve as a catalyst to advance programs in palliative care education, training, and service delivery; and to advocate for their full integration into national HIV/AIDS prevention, care, and treatment programs.

The Palliative Care Initiative in South



Africa has identified three non-governmental organizations that focus on professional and public education and have expertise, experience, and proven community organizing skills. These groups are steadily developing the capacity to advocate for more integrated community-based palliative care programs for HIV/AIDS. Professional and public education is a major focus of these programs in order to help build a workforce of community health volunteers and professionals who treat and care for patients with HIV/AIDS. The community-based, non-governmental organizations are far ahead of the government in addressing the palliative care needs of dying HIV/AIDS patients and their families, especially at a grassroots level.

The Palliative Care Initiative in South Africa currently provides funding to three organizations. In 2002, The Open Society Institute granted \$300,000 to support these programs and secured an additional \$240,000 in matching funds through an unrestricted one-year grant from Pfizer, USA. A total of \$540,000 was distributed among these organizations in 2002. The Palliative Care Initiative in South Africa will continue through 2004.

#### *Foundation for Medical Education for South African Blacks (MESAB)*

- Uses its healthcare professional training network to advance palliative care.
- Offers a model curriculum for community home care workers, doctors, and nurses in collaboration with the South Coast Hospice Training Program.
- Supports the ACTS Center in Mpumalanga to develop four short stay palliative care units in rural areas, which serve as local training centers for community health workers.
- Advocates for palliative care education in medical and nursing schools and graduate medical training programs.

#### *Hospice Association of South Africa (HASA)*

- Offers a hospice mentorship program. Five hospices serve as resource training centers for community caregivers, families, and health professionals. Each of the five hospices mentors three smaller hospice programs in order to increase the availability of palliative care

services for patients and families, and to integrate HIV/AIDS care into community healthcare models based on the HASA/government guidelines.

- Increases the availability of palliative care services and helps integrate HIV/AIDS care into community healthcare models based on the HASA/government guidelines.

#### *Foundation for Hospices in Sub-Saharan Africa (FHSSA)*

- Operates the Hospice-to-Hospice Partnership Program, which links South African and American hospice and palliative care programs to share information, advice, and moral support. There are currently 50 hospices in the United States and Africa participating in this program.
- Supports international advocacy efforts with other foundations and non-governmental organizations to develop and sustain palliative care initiatives in South Africa.

## COMMUNICATIONS

Ongoing public discussion is essential to a better understanding of modern experiences 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 raises awareness of the work done by our grantees to improve care for patients and families through media activities, publications, and a website.

### *Media Outreach*

In addition to grant support for public and professional education efforts, PDIA serves as a resource center for print, radio, television, and online media outlets, supplying reporters and editors with current research, background materials, and access to an extensive roster of researchers, clinicians, and educators.

PDIA grantees frequently publish original articles, commentaries, and editorials on the psychiatric, social, medical, legal, and economic issues confronting patients with serious illness. They have helped frame the critical research information necessary to improve hospital

policies, professional education programs, and the economics of palliative care.

### *Publications*

PDIA's newsletter, press releases, and research briefs all serve to inform public discussion. PDIA's website at [www.soros.org/initiatives/pdia](http://www.soros.org/initiatives/pdia) is a collection of information about PDIA initiatives and a gateway to resources on palliative care, death and dying, and bereavement. It includes detailed information on grant programs, a complete listing of all grants funded, information about ongoing developments in the field, and extensive links to other websites and resources on end-of-life care.

In addition to this final PDIA 3-year report of activities, PDIA will create and distribute two other significant publications:

- A special report for other funders will document the development of PDIA's grantmaking strategy over the past nine years and define future challenges and opportunities. The report offers specific recommendations for future funding

with the hope that other foundations and individuals will benefit from our grantmaking experience in this field as they decide how to use their own grantmaking dollars most effectively.

- A book by medical sociologist David Clark will trace PDIA's history and examine how PDIA—and other private funders—influenced the development of palliative and hospice care in the United States. Clark directs the International Observatory on End of Life Care and is Professor of Medical Sociology at Lancaster University in the U.K. His research concerns palliative care policy development, the international growth of palliative care, and related ethical issues.

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“For most of human history, people died fast. Now suddenly, we have the opportunity to grow old, to have an illness for a long period of time, and to know what’s coming. We could make this an important phase of life.”

Joanne Lynn, M.D.

Americans for Better Care of the Dying



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