

# TRANSFORMING

## THE CULTURE OF DYING


THE PROJECT ON DEATH IN AMERICA

OCTOBER 1994 TO DECEMBER 2003

OPEN SOCIETY INSTITUTE

From 1994 to 2003, the mission of the Project on Death in America was 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, arts and humanities, and public policy.

PDIA completed all grantmaking at the end of 2003, having distributed \$45 million in grant awards to organizations and individuals working to improve care for dying patients and their families. This report traces the development of PDIA's grantmaking strategies and considers lessons learned over the course of nine years of targeted funding. The report also includes specific recommendations for future funding with the hope that other foundations and individuals will benefit from PDIA's experience in this field as they decide how to use their own grantmaking dollars most effectively.



Any foundation concerned with alleviating human suffering can help improve end-of-life care for patients and their families—regardless of geographic focus, grant size, or funding priority. In the end, every funder has a personal stake in the quality of the end-of-life care system we create.

**TRANSFORMING**

**THE CULTURE OF DYING**

**THE PROJECT ON DEATH IN AMERICA**

**OCTOBER 1994 TO DECEMBER 2003**

**OPEN SOCIETY INSTITUTE**

The Project on Death in America was 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 networks, 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.

© 2004 Open Society Institute

Project on Death in America  
400 West 59th Street  
New York, NY 10019  
Tel: 212-548-0150  
Fax: 212-548-4613  
E-mail: [pdia@sorosny.org](mailto:pdia@sorosny.org)  
Website: [www.soros.org/initiatives/pdia](http://www.soros.org/initiatives/pdia)

# CONTENTS

- 4** Preface
  
- 6** An Open Letter to the Grantmaking Community  
*Kathleen M. Foley, M.D., Director, Project on Death in America*
  
- 12** The Project on Death in America: 1994 to 2003
  
- 22** Exit Strategy and Final Grants
  
- 30** PDIA's Grantmaking Strategies  
and Recommendations to Funders
  
- 32** Professional Education
- 40** Research
- 46** Clinical Care
- 52** Public Policy
- 56** Public Engagement
  
- 62** The Years Ahead
  
- 66** Selected Online Resources
  
- 68** Advisory Board and Staff

## PREFACE

In 1994, the Open Society Institute (OSI) launched a new grantmaking program called the Project on Death in America (PDIA). Its goal was ambitious: to help transform the experience of dying in the United States. George Soros established the project—one of his first U.S.-based philanthropic initiatives—in response to his personal experiences with the deaths of his parents. Over the course of nine years, PDIA created funding initiatives in professional and public education, the arts, research, clinical care, and public policy. PDIA and its grantees have helped build and shape this important and growing field, and have helped place improved care for the dying on the public agenda.

PDIA completed all grantmaking on December 31, 2003, having distributed \$45 million in grant awards to organizations and individuals working to improve care for dying patients and their families. PDIA was one of many OSI programs to close at the end of its funding cycle, two years after George Soros announced a significant reorganization of OSI and the Soros foundations network. PDIA was not closed because it had achieved its goal of cultural transformation or because its work was not making enough of an impact. In fact, the loss of PDIA funding leaves a vibrant but still fragile field in need of ongoing philanthropic support.

The Project on Death in America has helped lay a strong foundation for the field of palliative care, and PDIA grantees throughout the United States will continue to advocate for compassionate, skilled care of patients and families as they mentor, teach, and lead future generations of healthcare professionals.

The goal of this report is to inform the grantmaking community about PDIA and what we have learned during the past nine years. We also offer specific recommendations for future funding with the hope that other foundations and individuals will benefit from our experience in this field as they decide how to use their own grantmaking dollars most effectively.

Everyone benefits when we improve the way we take care of seriously ill patients and their families. Ultimately, we all will need the end-of-life care system that we collectively create, whether as family members, friends, or patients.

My 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 kind of 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 give 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 her and be there as she prepared to die. And this time we did maintain good contact right to the end.

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 two 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.

George Soros

# An Open Letter to





# the Grantmaking Community

Kathleen M. Foley, M.D.

Director, Project on Death in America

**In 1994,** after we first announced the formation of the Project on Death in America, we received a wonderful letter. It was from a woman who had read the New York *Daily News* column about philanthropist George Soros, who, inspired by the experiences of his parents' deaths, founded and financed PDIA. In the letter, the woman wrote about her husband, a New York City firefighter who died from the devastating burns he sustained during a heroic rescue attempt. The *Daily News* had run a front-page article telling his story and a picture of him in a burn unit in a New York hospital. He was so badly burned he couldn't stand the pain. He just wanted to die. I had seen the article when it first ran, and it was such a telling and dramatic story, I used the photograph in presentations about the challenges of managing intractable burn pain.

What Mr. Soros should do, the woman wrote, is exactly what the New York City Fire Department had done for her. A firefighter from her husband's firehouse came to her home every day and drove her to the hospital to visit her dying husband. The department sent another firefighter to watch her children while she was at the hospital. What everyone in America who is struggling with a terminal illness or grief needs, she suggested, is a "firefighter"—someone to provide compassion and support in the face of death.

As this challenging, engaging, thought-provoking, and bold initiative draws to the close of its decade-long history of advocacy, leadership, and grantmaking efforts to improve the care of the dying, I find myself thinking about that letter. To me, it illustrates the power of the individual to make a real difference when confronting such large-scale challenges as inadequate end-of-life care and our cultural denial of death and dying.

Philanthropist George Soros devoted his attention and support to these problems—and through his leadership inspired many others to do so too. Each PDIA faculty scholar creates a ripple of influence within his or her institution and profession and each will affect

many other people in the course of his or her career. In communities across the country, individuals—professionals and laypeople—quietly assist their dying and grieving neighbors. And, we hope, individuals in each of the many projects we funded will create multiple ripples of influence as they help patients and families cope with death and bereavement.

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.

PDIA had a vision and a bold approach right from the start. Most of us on the advisory board had no firsthand experience as philanthropists, so we were willing to attempt things that more experienced foundation professionals might have known were too ambitious. The fact that the project was not going to continue indefinitely kept us focused on our goal of working to make changes at the bedside within the healthcare system—so that the work would continue beyond us.

Our earnestness, our naiveté, our enthusiasm, our belief that we might really be able to do something about this issue—all these were central to our work. The grandiose mission to “transform the culture” was there from the start, and each of us had a can-do attitude that helped us pursue a dream that we knew was possible. Supporting other individuals who shared that dream—and could actually make it a reality—was what PDIA was all about.

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 to

empower their caregivers to become agents of change within our healthcare system.

PDIA was by no means the only grantmaker concerned with improving end-of-life care. Many other funders have reached the same conclusion George Soros did, and they 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 Nathan Cummings Foundation paid particular attention to 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 supporting palliative care fellowship training programs. These are just a few of the many foundations we worked with through the years to make the most of our funding.

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

I am by nature an optimist and believe that we as a society are headed in the right direction. The field of palliative care is definitely much stronger than it was 10 years ago, before we began. 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. But the job is by no means done. There is an enormous opportunity

for other grantmakers to make daring and effective contributions to the field. This report describes the key areas in which we found that targeted support can yield measurable results.

PDIA's mission was challenging, and now we encourage and challenge others to continue this work. We have all made progress, but the problems of death and bereavement will always be with us, and they belong on the agendas of many other grantmakers and the U.S. government. Until the government plays a larger role in designing more appropriate and inclusive end-of-life care benefits and services and in funding 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 still do not 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 don't fully understand the many barriers to appropriate care that arise from that aversion. There are still many challenging questions—for funders, physicians, psychologists, spiritual and religious leaders, and artists to answer.

Death is inevitable, but severe suffering is not. We must all look toward the day when compassionate and skilled end-of-life care becomes such a part of the fabric of American communities and the American healthcare system that we won't need to request it—it will simply be offered when needed. As grantmakers, we have the opportunities and resources to help bring us all closer to that day.

# The Project on Death in America:



1994 to 2003

**THE PROJECT ON DEATH IN  
AMERICA ADVISORY BOARD**

**Susan Block, M.D.**

Dana-Farber Cancer Institute,  
Harvard Medical School

**Robert A. Burt, J.D.**

Yale University

**Robert N. Butler, M.D.**

International Longevity Center—USA

**Ana O. Dumois, Ph.D., D.S.W.**

**Kathleen Foley, M.D.**

Memorial Sloan-Kettering Cancer Center,  
Weill Medical College of Cornell University

**Patricia Prem, M.S.W.**

**FORMER ADVISORY  
BOARD MEMBERS**

**William Zabel, J.D.**

Schulte Roth Et Zabel, LLP

**David Rothman, Ph.D.**

Columbia University College of  
Physicians and Surgeons, Center for the  
Study of Society and Medicine

**Joanne Lynn, M.D.**

Americans for Better Care of the Dying,  
the Washington Home Center for  
Palliative Care Studies, and RAND Health

**Velvet Miller, Ph.D.**

New Jersey State Department  
of Human Resources

## The experience of dying has changed over the past several decades.

A century ago, most people died quickly, of sudden illness or injury. People generally lived their last days at home, cared for by family members. Advances in medical technology and public health now allow people to live longer, healthier lives. Most Americans now survive into old age, although many live for years with a chronic illness or serious disability.

For the dying and those who care for them, the end of life frequently is a time filled with pain, feelings of abandonment, isolation, and suffering—physical, emotional, and spiritual. Although most people would prefer to die at home, free from pain and in the company of their loved ones, the vast majority of Americans die in hospitals and nursing homes. About half of conscious hospitalized patients experience severe pain in the days before they die. The American medical system, intent on curing disease and prolonging life, often fails to provide the support and relief people need during this critical phase of life.



All people with serious or advanced illness should expect and receive reliable, skillful, and supportive palliative care. Palliative care aggressively relieves pain and other physical symptoms to give patients the highest quality of life possible at all stages of serious illness. Palliative care is best delivered by an interdisciplinary healthcare team that can provide integrated attention to physical, psychological, social, spiritual, and practical problems. Palliative care supports families throughout the patient's illness and is sensitive to the importance of religious, spiritual, and cultural responses to death and bereavement.

Why doesn't everyone have access to excellent care at the end of life? One of the greatest—yet most easily surmountable—barriers is inadequate training. Medical professionals are not routinely trained to manage the debilitating pain and other symptoms commonly experienced by dying patients. They are not trained to provide essential psychological, social, or spiritual support for patients and families. They are not taught how to talk with patients and families about terminal illness or options for palliative care.

Other significant barriers include weak institutional commitment to end-of-life care, the absence of appropriate financing structures, the lack of quality measures, and major gaps in the research base. George Soros established PDIA to help identify and dismantle these barriers and find patient- and family-centered solutions.

Shortly after PDIA's launch, the *Journal of the American Medical Association* published results from the largest national study ever conducted of end-of-life care. The groundbreaking "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment," dubbed SUPPORT, was the first rigorous, widely reported study to document serious deficiencies in the care of dying people and their families. This \$28 million study, supported by the Robert Wood Johnson Foundation, revealed the shortcomings in the medical care of seriously ill Americans.

The study found that far too many people needlessly suffer physically, psychologically, and spiritually at the end of life. Communication between doctors and patients is poor, and individuals' preferences regarding care are routinely ignored. Families are often left in emotional despair and financial ruin. The SUPPORT data left no doubt that George Soros had established PDIA at just the right time.

## Developing a Funding Strategy

In October 1994, George Soros appointed an advisory board for PDIA, led by Kathleen Foley, M.D., a neurologist and chief of the pain and palliative care service at Memorial Sloan-Kettering Cancer Center in New York City. Advisory board members were chosen to represent a range of expertise in the complex issues surrounding the care of the dying.

From the very beginning, the PDIA advisory board sought to act as a catalyst by fostering cooperation and collaboration among the various professionals already working in nursing, medicine, social work, ethics, policy, financing, and other areas. The board developed a regular practice of identifying experts from different disciplines and convening these experts to collectively map the field and determine the most pressing needs.

"When I look back to the very beginning of this enterprise, what I remember most is a sense of something being really broken in the system of how we cared for the dying. There was no road map. No one really knew how to approach it. There were few real experts. We also sensed that doing things better was a very real possibility—that we could create a system that addressed the real needs of dying patients and families."

Susan Block, M.D., PDIA Advisory Board

"We were given virtually complete freedom to formulate our own agenda for transforming the culture of death and care of the dying. In our initial thinking, two problems were dominant: the harms inflicted by the medical system on dying people and the harms caused by public attitudes about death itself—the so-called denial of death."

Robert Burt, J.D., PDIA Advisory Board

In 1995, PDIA announced a grants program to address seven priority areas for funding, hoping to cast a broad enough net to address the significant areas of need:

- ▶ The epidemiology, ethnography, and history of dying and bereavement in the United States
- ▶ The physical, emotional, spiritual, and existential components of dying and bereavement
- ▶ The contribution of the arts and humanities
- ▶ New service-delivery models for the dying and their families and friends
- ▶ Educational programs for the public about death and dying
- ▶ Educational programs for the healthcare professions
- ▶ The shaping of governmental and institutional policy

In its first three years, PDIA received more than 2,000 grant requests over four grant cycles and funded 122 projects in the seven priority areas. The grant amounts ranged from \$5,000 to \$400,000 and represented many different approaches to the subject of dying—from the medical to the philosophical to the political. The board and staff used the deluge of grant requests as an opportunity to informally survey the field and to understand the scope of need, the level of interest, and the current range of expertise. In the process of reviewing the grant proposals, they formed a picture of the diverse, needy, creative, and struggling field of palliative care. The board chose to fund a broad range of initiatives to reflect the complexity of the medical and societal challenge to provide appropriate, compassionate care of the dying.

From the beginning, the PDIA board understood that it was essential to change the culture of medicine in hospitals and nursing homes, where almost 70 percent of Americans die. PDIA created the Faculty Scholars Program to identify and support outstanding clinical and academic leaders in medicine and nursing who could change medical culture from the inside. The board envisioned a national network of role-model healthcare professionals—nurses, physicians, and social workers—who would serve as champions of palliative care in their institutions. More than half of PDIA’s total grant funds were used to support professional development initiatives.

In 1995, PDIA joined forces with the Robert Wood Johnson Foundation, the Nathan Cummings Foundation, the Rockefeller Family Office, and the Commonwealth Fund to form Grantmakers Concerned with Care at the End of Life.

"Social workers are integral members of the interdisciplinary palliative care team. They advocate for the patient and the family within the healthcare team and can also effect change in health policy. It is imperative that the discipline of social work is supported with education, research, and solid practice guidelines."

Patricia Prem, M.S.W., PDIA Advisory Board

"We knew we couldn't solve all the problems of the dying on our own. We tried to use our funding as a catalyst. We knew we could help validate dying as a problem—and to validate those who take care of the dying as people who could make a profound difference in the lives of patients and families."

Kathleen Foley, M.D., PDIA Advisory Board

"Medical students learn by watching interns, residents, and faculty who are further along in their careers. That's what will take time. The culture will change when these role models embrace palliative care."

Peter Selwyn, M.D., M.P.H., Montefiore Medical Center

This coalition organized conferences and shared information in order to inform funders about the major social, economic, and medical issues in end-of-life care and to encourage them to address those issues in their grantmaking.

## **Building Critical Mass: 1998 to 2000**

In 1997, George Soros and OSI's Board of Trustees reviewed PDIA's progress and enthusiastically endorsed another three years of funding. During PDIA's second funding phase, the board expanded its commitment to professional education. With the guidance of board member Patricia Prem, M.S.W., PDIA created the Social Work Leadership Development Awards to strengthen professional practice and promote research, training, and policy development for social workers. PDIA also created a special funding initiative to support nursing leadership.

In 1998, PDIA launched an arts and humanities initiative, chaired by board member David Rothman, Ph.D. Grantees produced video, photography, poetry, essays, dance, and artwork to express individual and community experiences of illness, death, and grief and to encourage conversation and thoughtful reflection.

In 1999, PDIA advisory board member Robert Burt, J.D., led the development of a community grief and bereavement initiative. Grantees created model programs—including interfaith, community-based, and school-based programs and programs for special groups such as incarcerated youth or union home healthcare workers—to support individual and community bereavement.

PDIA also chose to address challenging legal and economic barriers and to improve access to care for particularly vulnerable populations—groups that are even more likely to have bad death experiences or to whom the system regularly fails to respond. These underserved groups include children, the elderly, non-English speakers, the incarcerated, the homeless, members of racial and cultural minorities, and people with physical or developmental disabilities.

## **Institutionalizing Change: 2001 to 2003**

In 2000, George Soros and the OSI Board of Trustees authorized three more years of funding. PDIA focused on building a sustainable field of palliative care, with the sufficient infrastructure and leadership to dismantle the barriers that still kept people from receiving excellent care.

In 2002, PDIA and the Emily Davie and Joseph S. Kornfeld Foundation formed the Funders Consortium to Advance Palliative Medicine to support existing and new palliative care fellowship training programs. The goal of this funding initiative is to help increase the numbers of physicians with advanced training in palliative medicine, which will help palliative medicine achieve formal recognition as a

"One way to transform end-of-life care is to transform the actual care people receive. Another way is to make it an established field of research, so that new knowledge arises and end-of-life care becomes a recognized domain of medicine. We pursued both of those strategies, but we also wanted to have an impact on the larger culture through avenues such as the arts and humanities. There is no magic button that can be pushed to promote cultural transformation. You need to select a variety of strategies."

David Rothman, Ph.D., PDIA Advisory Board

"Death is the great equalizer. Every person, no matter what his or her social or economic status, has to face it. At the same time, each person's experience of dying is utterly unique. We were interested in both the universality and individuality of death. PDIA grantmaking promoted equal access to good care—regardless of race, class, or religion."

Ana O. Dumois, Ph.D., D.S.W., PDIA Advisory Board

medical subspecialty by the Accreditation Council for Graduate Medical Education and the American Board of Medical Specialties.

In 2002, Soros announced the reorganization of his international network of foundations. PDIA would close at the end of 2003, and during its final year, the PDIA board devoted a great deal of energy to developing an effective exit strategy.

For a listing of all PDIA grants, see [www.soros.org/initiatives/pdia](http://www.soros.org/initiatives/pdia).





# Exit Strategy and Final Grants

## During the final year of PDIA's operation, the advisory board and staff reviewed

the original funding strategies, goals, and individual initiatives. They hosted roundtable discussions and individual meetings, actively engaging palliative care leaders—including former advisory board members, faculty scholars, nursing and social work leaders, grantees, organizations, associations, experts in the field, and other funders—to help frame an exit strategy.

The overwhelming consensus was that PDIA's exit strategy should be consistent with the project's longstanding focus on supporting the professional development of healthcare providers. It should center on strengthening the capacity of existing professional associations to affect health policy, financing, education, research, and clinical training in palliative care. It should also recognize the importance of encouraging other funders to include palliative care on their funding agendas. With this mandate in mind, PDIA made final grant awards to enhance the organizational capacity and sustainability of the following organizations.

## The American Academy of Hospice and Palliative Medicine

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

PDIA awarded a \$1.2-million grant to AAHPM to support its infrastructure and strengthen its ability to serve the needs of palliative care professionals across disciplines and borders. PDIA believes that supporting AAHPM will advance the development of palliative medicine within academic medicine. The funds will enable AAHPM to develop an academic “college” that will house the legacy and leadership of the PDIA Faculty Scholars, strengthen AAHPM’s capacity to support and nurture academic leaders in all fields, and expand the role of AAHPM as a leader in interdisciplinary professional education in palliative care. This grant support will also enable AAHPM to assume responsibility for recruiting and coordinating a consortium of grantmakers to support fellowship training programs in palliative care.

## The Hospice and Palliative Nurses Association

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 of \$200,000 to advance professional nursing education by building on the work of the End-of-Life Nursing Education Consortium (ELNEC) and the Johns Hopkins Nursing Leadership Academy on End-of-Life Care.

ELNEC provides nursing education nationally to hundreds of nursing educators and to nursing specialists in geriatrics, pediatrics, oncology, and hospice and palliative care. Johns Hopkins has supported nursing leadership development and has helped these leaders integrate palliative and end-of-life care into 44 nursing-specialty organizations.

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

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

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 more than 160,000 practicing social workers.

PDIA has designated \$200,000 to further this agenda for organized professional leadership, high standards of practice, and increased preparation at all levels of social work education. The goal is to help the field of social work 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**

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.

PDIA has designated a \$200,000 grant to help NHPCO strengthen its organizational infrastructure and expand its reach into diverse communities. 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 access to end-of-life care and reach out to underserved communities.

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

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 who also wish to gain expertise in leading and managing improved palliative care education and practice in their own institutions. Faculty who complete the training program are prepared to teach other faculty, practitioners, and trainees in medicine and nursing about end-of-life care; create innovative educational programs; and initiate reforms in clinical service, including the creation of new palliative care programs. In its first four years, 160 physicians and nurses have participated in the program.

PDIA's \$100,000 grant will support scholarships to enable 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 throughout the country and will help ensure that underserved and minority communities have access to their expertise.

## The American Board of Hospice and Palliative Medicine

The American Board of Hospice and Palliative Medicine (ABHPM) has developed standards for training and practice in palliative medicine and has established the requirements for certification and recertification. ABHPM is an independent, non-profit organization whose certificate signifies 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 awarded \$100,000 to ABHPM to implement standards for fellowship training programs in palliative care and to begin the lengthy application to establish palliative medicine as a subspecialty. ABHPM's long-term goal is the recognition of palliative medicine as an official subspecialty by the American Board of Medical Specialties and the Accreditation Council for Graduate Medical

Education. ABHPM is collaborating closely with the American Academy of Hospice and Palliative Medicine to lead a joint campaign for recognition of the specialty.

## **Grantmakers Concerned with Care at the End of Life**

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 funders who need information or advice about funding in the field. GCCEL works within the foundation community to encourage a wide range of funders—including community foundations, family foundations, individuals, and private foundations—to support palliative and end-of-life care locally and nationally.

"The good news is that nobody is against us—nobody thinks it's a bad idea to improve care for the dying. But not many people can face the fact that someday they will actually be one of "the dying" themselves. The big question now is whether other funders, large and small, will step in and fill the gap left by PDIA's departure and make it possible for the field to keep moving forward."

Mary Callaway, M.E., Associate Director, PDIA

"More than anything else, we need reliability. We need a care system that we can count on, not just a virtuoso performance in a hospital operating room or an elegant diagnostic procedure, but enduring competence, from onset of serious illness through to death. We need home care, doctors, hospitals, pharmacies, hospices, nursing homes, and caregivers to work as one system."

Joanne Lynn, M.D., Americans for Better Care of the Dying, Washington Home Center for Palliative Care Studies, and RAND Health

# PDIA's Grantmaking Strategies







# and Recommendations to Funders

Based on PDIA's nine years of grantmaking and the suggestions of the many grantees interviewed for this report, we have compiled the following recommendations to help other funders. These recommendations focus on areas of maximum leverage, where even modest philanthropic investment will yield significant impact.

# Professional Education >

## RECOMMENDATIONS TO FUNDERS

### Grantmaking to Improve Professional Education

Every grant made to support palliative care education for health professionals has a direct and immediate impact on care for dying patients and their loved ones. Philanthropic support at every level—whether a one-time grant that facilitates pain management training for a rural community doctor or multiyear grants that establish new palliative care training programs—will have a lasting impact on communities across the country.

- ▶ Of the more than 100,000 medical school faculty members in the United States today, fewer than 100 specialize in palliative care. Support the development of palliative care faculty in the nation's medical schools. Clinical role models and academic faculty are both crucial in teaching medical, nursing, and social work students essential palliative care knowledge and skills.
- ▶ Support the establishment of a university chair in palliative medicine.
- ▶ Support continuing education opportunities in palliative care for practicing physicians, nurses, and social workers.
- ▶ Fund faculty development programs to foster leadership in palliative medicine. Grantmakers may support existing programs, develop new ones, or fund individual practitioners to attend these programs and bring new skills and leadership back to their communities.
- ▶ Fund palliative care training sites where practicing doctors, nurses, and social workers can gain clinical experience and mentoring.
- ▶ Give grants that enable medical, social work, and nursing schools to use hospital-based palliative care programs and hospices as student training sites.
- ▶ Fund existing palliative care fellowship programs or support the creation of new programs.
- ▶ Fund palliative care educational initiatives in different clinical settings, such as nursing homes, cancer centers, emergency rooms, dialysis centers, large managed-care organizations, rural communities, and prisons.
- ▶ Support professional and public education programs in symptom control, pain relief, and palliative care specifically for children.
- ▶ Support the development of new models for training other medical specialists who care for seriously ill patients, including cardiologists, geriatricians, surgeons, nephrologists, pulmonologists, oncologists, and hospitalists.
- ▶ Fund communication training for doctors, nurses, and social workers.
- ▶ Support palliative care education programs for clergy members of all faiths.

# Professional Education >

## PDIA'S GRANTMAKING STRATEGIES

### Supporting Professional Education

Education, skill, and experience are just as essential to mastering the intricacies of palliative care as they are to becoming competent in the traditional areas of diagnosis, treatment, and cure. Mentors, role models, and peer respect and support are essential to the educational process. PDIA invested in the academic faculty and clinician leaders who would spearhead change. PDIA also supported the development of innovative curricular materials, educational methods, patient-centered clinical teaching, and system-level quality-improvement activities at all levels of professional health care education.

The following are key examples of PDIA grants and funding initiatives.

## Faculty Scholars Program

The Project on Death in America's Faculty Scholars Program, led by PDIA board member Susan Block, M.D., was established to identify outstanding faculty and clinicians committed to improving care for dying patients. Five to eight scholars were chosen each year to receive two-year awards of up to \$76,500 per year. All scholars conducted a clinical, research, educational, or advocacy project for the period of their award. They also participated in individualized professional development and a collaborative faculty development program with other PDIA scholars. The program enhanced the professional visibility of the faculty scholars, enabling them to become more effective leaders and moving them into more influential positions within their institutions.

The 87 faculty scholars selected during the program's nine years are today among the most prominent and active leaders of palliative care. They have expertise in a variety of disciplines—including medical ethics, medical education, economics, nursing, geriatrics, psychiatry, critical care medicine, neurology, pediatrics, oncology, and general medicine. Through their clinical excellence, research, scholarly publications, and activism, these scholars are institutionalizing change in their own hospitals, medical schools, and professional organizations.

PDIA has conducted ongoing evaluations of the Faculty Scholars Program and found that its investment of \$13.4 million in the program had a major impact on the field. Among the faculty scholars' collective accomplishments are awards of more than \$113 million to support research, education, and program development in hospice and palliative care. Faculty scholars have also made more than 2,000 published contributions to books and journals. Each of the medical schools where a scholar is affiliated has major projects under way to improve end-of-life care, whether in research, clinical care, or professional education.

The Faculty Scholars Program has fostered an intellectually vibrant, mutually supportive, and cross-fertilizing network of colleagues and has helped retain many talented practitioners in a difficult and neglected area of medicine. Perhaps most important, these talented individuals are mentoring the next generation of practitioners who will care for seriously ill patients and families.

## The Social Work Leadership Development Awards

Social workers provide essential psychological, social, and practical support to terminally ill patients and their families. They also provide case management, counseling, and advocacy services for the dying. Social workers themselves,

however, have reported gaps in graduate and postgraduate training in end-of-life care. PDIA recognized the need for leaders in the field to develop a national social work curriculum on end-of-life care, addressing both the theoretical and practical aspects of the practice of social work.

In 2000, PDIA launched the Social Work Leadership Development Awards program under the direction of Grace Christ, D.S.W., professor at Columbia University School of Social Work. The program was designed to develop the profession's capacity and commitment to meet the needs of dying people and their loved ones.

The leadership awards have promoted innovative research and training projects that reflect collaboration between schools of social work and practice sites. Forty-two social work leaders in academic and clinical settings received two-year awards and achieved national recognition for specific projects aimed at advancing the field. Projects have included research, fellowship training, development of assessment and intervention tools, curriculum design, and the creation of communications networks.

PDIA's social work leaders work at a national level to focus professional attention on the role of social work in end-of-life care, a process that began in March 2002 with the Social Work Summit on End-of-Life and Palliative Care at Duke University, co-sponsored by PDIA, the Robert Wood Johnson Foundation, and the Duke Institute on Care at the End of Life. The summit brought together 40 leaders in the field, including many PDIA grantees, and led to an informal consortium that has continued to advance the priorities defined at the summit.

## 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 partnered with national nursing organizations to encourage cooperative leadership. At a focus group convened by PDIA, nursing experts recommended holding a national summit meeting where nursing subspecialty groups could gather to develop organizational priorities to address end-of-life care.

In June 1999, PDIA funded the Nursing Leadership Consortium on End-of-Life Care, which brought together national nursing organizations to develop a coordinated and collaborative nursing agenda within the areas of practice, policy, research, and education. The goal of the conference was to increase the leadership capacity of nurses and to elevate nursing practice in the field of end-of-life care.

The conference generated the document "Designing an Agenda for the Nursing Profession in End-of-Life Care," which led to the formation of a National Nursing Leadership Academy based at Johns Hopkins University. The academy's role is to increase the leadership capacity of nurses in end-of-life care, building on the prior-

**"PDIA helped me do this work by giving me institutional support. Would I have done it anyway? Only after hours. PDIA altered my work identity and changed its focus. It altered a generation's professional identity—changing careers and creating a cadre of young, dynamic, clinical researchers and academicians who were necessary to the building of palliative care in this country."**

William Breitbart, M.D., Memorial Sloan-Kettering Cancer Center, New York City

**"Palliative care is a growing area of practice, and many social workers are unprepared to deal with the complex medical, legal, ethical, and practical problems faced by dying patients. Social work as a field benefits from PDIA's support of new social work leaders who will teach state-of-the-art palliative care in social work schools and practice sites."**

Grace Christ, D.S.W., Columbia University School of Social Work

**"PDIA supported nursing with funding for a nursing leadership conference, convened to define the profession's priorities for palliative and end-of-life care. PDIA's willingness to fund projects to acknowledge nursing's importance in end-of-life care and to stimulate its advancement was unprecedented. It was a bold step on their part."**

Cynda Hylton Rushton, D.N.Sc., Johns Hopkins University

ities developed by the consortium. Nursing academy members have published journal articles, incorporated palliative care into national nursing conferences, and developed core educational curriculums. Within their respective organizations, they have developed projects designed to give palliative and end-of-life care a higher priority within the profession.

An important complement to PDIA's support of nursing in end-of-life care was the development of the End-of-Life Nursing Education Consortium (ELNEC), a national nursing continuing-education program, funded by the Robert Wood Johnson Foundation. ELNEC is a comprehensive education program to improve end-of-life care by nurses through the development of a core curriculum, a core group of expert nursing educators, and national coordination of nursing education efforts in end-of-life care.

## **Funders Consortium to Advance Palliative Medicine**

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 care. The Funders Consortium to Advance Palliative Medicine was designed to support professional education and increase the number of physicians trained in palliative care. Support for palliative care fellowship programs is critical for palliative care to become widely recognized as an essential component of medical education and clinical practice, and for palliative medicine to achieve formal recognition as a medical subspecialty by the Accreditation Council for Graduate Medical Education and the American Board of Medical Specialties.

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 and 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 the Kornfeld Foundation committed a total of \$1.95 million for 13 grant awards to support fellowship training from 2003 to 2006. PDIA committed a total of \$1.35 million, and the Kornfeld Foundation committed a total of \$600,000. Each selected fellowship program received \$150,000 over the course of two years to support the training of one or more palliative care fellows.



**"There's no hope of changing care at the bedside without trained medical faculty in the medical schools—not just for the scientific content but also the attitudes, the way of being. If new doctors don't learn it from experts in palliative medicine, they won't learn it."**

Diane Meier, M.D., Center to Advance Palliative Care, Mount Sinai School of Medicine

**"Those of us who live to the age of eighty-five will have a fifty percent chance of spending some time in a nursing home. Now is the time for research and demonstration programs to make sure that nursing home residents receive competent, coordinated, and compassionate end-of-life care."**

Joan Teno, M.D., M.S., Brown University

# Research >

## RECOMMENDATIONS TO FUNDERS

### Grantmaking to Support Research

A strong and diverse research base is essential for palliative care to become the recognized model of good clinical practice and for palliative medicine to become an accredited medical subspecialty. Current research is limited, however. With increasing support, palliative care research will change the way in which individuals and institutions deliver care to patients and families. By funding research—from basic science to ethics and decision making—grantmakers can help improve the quality of care for people facing the end of life and for those with chronic illness who endure years of treatment-related pain, fatigue, nausea, depression, and other debilitating symptoms.

- ▶ Fund research in all disciplines, for adults and children, concerning:
  - Pain and symptom management
  - Molecular biology of symptoms
  - Quality-of-life measures
  - Cultural competency
  - Interdisciplinary team care
  - Psychiatry and end-of-life care
  - Service-delivery models
  - Quality improvement
  - Communication
  - Grief and bereavement
  - Religion and spirituality
  - Ethics and decision making
  - Health and legal policy
  - Economics, reimbursement, and Medicare
  
- ▶ Support networks of researchers who are collaborating on measurement and evaluation efforts.
  
- ▶ Fund conferences and working groups that enable experts in the field to share research findings.
  
- ▶ Support research in health economics on end-of-life care.
  
- ▶ Fund centers of excellence for the development of research, clinical care, and education.
  
- ▶ Support demonstration projects of all sizes that test different models of care delivery in a range of settings and communities.

# Research >

## PDIA'S GRANTMAKING STRATEGIES

### Building the Palliative Care Evidence Base

The Project on Death in America supported research and analyses of the social forces that affect the process of dying: where and how death occurs and under what social and medical conditions; the services that are delivered to dying persons and their families, at what expense, and according to what types of legal and ethical guidelines; how different communities and different cultural, religious, and socioeconomic groups respond to the process of dying and grieving; how healthcare professionals predict outcomes, including death and suffering; and how the plan of care develops.

The following are key examples of PDIA grants and funding initiatives.

## The Institute of Medicine

The Institute of Medicine (IOM) is a private, nonprofit organization that provides advice on health policy concerns under a congressional charter to the National Academy of Sciences. One of PDIA's first major grants helped support a comprehensive public-private study of end-of-life care by the IOM. The 1997 report, *Approaching Death: Improving Care at the End of Life*, strongly indicted the medical system's deficiencies in the care of the dying. It provided an unprecedented, thorough examination of what is known and what is still unknown about the experience of dying, including how best to help people retain their dignity and find comfort and meaning throughout the process. The report found that consistently good and compassionate care at the end of life is an attainable and urgently needed goal. It offered a series of recommendations to governmental, nongovernmental, educational, and public groups to encourage the development of policies and procedures to address the unique needs of dying patients.

IOM's report had tremendous impact in encouraging the academic medical establishment to take notice of deficiencies in end-of-life care. PDIA, a major catalyst for and sponsor of the study, distributed more than 4,000 copies of the published report to diverse constituencies.

In 2003, IOM released a report on pediatric palliative care, *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The study was sponsored by PDIA, the National Institute for Nursing Research, the National Cancer Institute, the Greenwall Foundation, and the Robert Wood Johnson Foundation, among others.

According to this report, the American healthcare system is poorly equipped to care for the more than 53,000 children who die each year and the 400,000 children who are likely to die from their life-threatening conditions before they reach adulthood. Few healthcare professionals are trained in palliative and end-of-life care, but even fewer are equipped to handle the specialized needs of pediatric patients.

The IOM report outlines recommendations to improve care for children and their families, recognizing the physical and emotional suffering caused by illness, the difficulty of making treatment decisions, the complexities of health and financial systems, and the pain of grieving. The report also highlights several local and national initiatives that could serve as models for improving coordination and delivery of care.

## Improving Textbooks on End-of-Life Care

Medical and nursing textbooks are critical tools for improving patient care. Medical and nursing students learn from textbooks and are tested on their content. Physicians and nurses rely on these books for guidance when faced with unfamiliar clinical situations. Material that is not included in textbooks is not included on tests or in practice, and vice versa. In this way, medical and nursing textbooks mirror medical culture.

In 1999, PDIA funded a review of widely used general medical textbooks for information about care of the dying. The study, conducted by the Center to Improve Care of the Dying and George Washington University, found that general medical textbooks provide little information that would help a physician care for a dying patient. The PDIA-supported textbook review concurred with two other studies of end-of-life content, funded by the Robert Wood Johnson Foundation—one a study of medical specialty textbooks, the other of nursing education texts. All three studies found that end-of-life content was generally absent or inadequate. PDIA and the Robert Wood Johnson Foundation co-sponsored a conference for doctors, nurses, textbook writers, editors, publishers, and healthcare advocates to discuss strategies for change. As a result of these efforts, end-of-life deficiencies in textbooks have largely been identified and addressed, and clear guidelines for end-of-life care content have been instituted. In 2001, PDIA Social Work Leader Betty Kramer developed end-of-life content guidelines and conducted a similar review of social work textbooks.

## Grief Research: Gaps, Needs and Actions

The inadequacy of support for grieving people is a significant cause of needless suffering. Death is impersonalized in the move from home to hospital, and geographic mobility and age-segregated living arrangements have eroded the personal bonds of family and the other social connections that once served to support those who are grieved. Grief does not just affect individuals and communities; it is a significant public health issue of concern to employers, policymakers, healthcare providers, and managed-care administrators.

PDIA committed funds to the Center for the Advancement of Health to conduct a comprehensive review of the existing research and create an authoritative white paper reporting on the current state of the grief and bereavement field—what services exist, which ones work, how they are paid for, who utilizes them, and what is missing. PDIA's goal for this project was to improve the ability of professionals and lay counselors to effectively diagnose, treat, and support grieving individuals and families. This work requires improved scientific understanding of the phenomenon of normal and complex grief; development and testing of treatment interventions; and broad dissemination of the results of these scientific explorations to medical and

## Recommendations from the Institute of Medicine

The Institute of Medicine (IOM) of the National Academy of Sciences is an important source of evidence-based information about medicine and public health. As an independent nonprofit organization, IOM works outside the framework of government and private interest and is wholly focused on improving public health. With financial and/or technical support from the Project on Death in America, the Institute of Medicine developed four comprehensive national reports on end-of-life care, published by National Academies Press in Washington, D.C.:

1997: *Approaching Death: Improving Care at the End of Life*

2001: *Improving Palliative Care for Cancer*

2003: *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*

2003: *Describing Death in America: What We Need to Know*

Collectively, these reports represent a thorough review and synthesis of the evidence found in the medical literature and provide evidence-based recommendations for guiding national policy on end-of-life care. Together, they stand as a detailed agenda for a national healthcare policy that could restructure the system to better respond to the needs of all Americans approaching the end of life, and to the needs of their families.

These recommendations for improving end-of-life care provide a roadmap for the future. Other funders and the public have the opportunity to convert the recommendations into actual practice and policy. For more information about the reports, visit the National Academies Press website, [www.nap.edu](http://www.nap.edu), or call 202-334-3313.

mental health professionals and to lay- and faith-based counselors. PDIA recognized that, without a strategic plan, efforts to fund grief and bereavement programs throughout the country would not profoundly institutionalize or build capacity in the field.

The resulting report, *Grief Research: Gaps, Needs and Actions*, made recommendations for building capacity in the field, developing and supporting leaders in research and practice, and building effective partnerships of researchers, participants, and policymakers.

# Clinical Care >

## RECOMMENDATIONS TO FUNDERS

### Grantmaking to Improve Direct Service Delivery and Clinical Care

Ultimately, improving services—one patient, one hospital, one region at a time—may make the most difference to seriously ill people and their families.



- ▶ Support new hospital-based palliative care services.
- ▶ Fund inpatient palliative care consultation teams to support physicians from other disciplines who care for seriously ill patients.
- ▶ Support collaborations of hospice programs, hospitals, and academic medical centers.
- ▶ Fund initiatives to introduce or expand palliative care services in nursing homes and assisted living facilities to help avoid hospitalization and enable residents to be cared for in comfortable and familiar surroundings.
- ▶ Support palliative care services aimed at underserved groups, such as non-English speaking families or the residents of rural communities or inner-city neighborhoods.
- ▶ Support palliative care programs for indigent patients, patients without family caregiving support, or patients without health insurance.
- ▶ Support nurse care coordinators to assist patients transferring between the hospital, home, and nursing home during the course of a serious illness.
- ▶ Fund pediatric palliative care within routine healthcare settings rather than in hospice settings only. Many parents won't consider palliative care if it means foregoing potentially curative therapies.
- ▶ Support bereavement counseling programs that specialize in a range of circumstances, including sudden and violent death or the death of a child.
- ▶ Fund initiatives in telemedicine to allow rural communities to expand professional educational opportunities and gain access to consultations with palliative care specialists.
- ▶ Fund support services for family and informal caregivers, including respite programs, home modifications or assistive devices, support and advocacy groups, and family counseling.
- ▶ Give grants that help meet the daily needs of seriously ill patients and their families, including assistance in locating and accessing home health services, nutrition support, and transportation.

# Clinical Care >

## PDIA'S GRANTMAKING STRATEGIES

### Improving Direct Service Delivery and Clinical Care

The Project on Death in America promoted measures to assess existing systems of care for the dying and to develop appropriate new systems of care. PDIA provided funding for programs that examined various settings for death, identified barriers to essential services, and designed strategies to overcome them. PDIA was also concerned with improving continuity of care for patients, stimulating ongoing quality improvement, and replicating promising models of patient care.

The following are key examples of PDIA grants and funding initiatives.

## United Hospital Fund

In 1996, with funds from PDIA, the Greenwall Foundation, and the JM Foundation, the United Hospital Fund of New York City launched a major three-year palliative care initiative to analyze and improve the quality of hospital care for dying patients. Twelve New York City hospitals received planning grants to review patterns of care for terminally ill patients and to design improvements. Five of the most promising innovators received subsequent implementation grants. A 1998 report on the initiative, *The Challenge of Caring for Patients Near the End of Life*, identified specific areas needing improvement, such as clinical education about pain management and palliative care techniques; communication among hospital staff, patients, and families; and coordination of care across settings.

In 2000, PDIA also supported the United Hospital Fund as it launched the Community-Oriented Palliative Care Initiative. A three-year effort to develop new approaches to comprehensive end-of-life care, the initiative will fill in the gaps in services for families and patients by drawing on the strengths of diverse organizations working in collaborative networks. The six groundbreaking community palliative care networks created under the initiative—collaborations among a broad range of hospitals and long-term care, social service, and other community organizations—were designed to provide coordinated, compassionate care in a timely and comprehensive manner. The networks were also intended to serve as models of how to more effectively reach the thousands of New Yorkers who are likely to die each year from such common progressive illnesses as congestive heart failure, Alzheimer's disease, and AIDS. A 2004 assessment of the initiative found that these networks can provide comprehensive and flexible end-of-life care that improves the quality of life for people with terminal illness.

## Pediatric Palliative Care

Many factors unique to children can complicate efforts to prevent and relieve their suffering. Physically and emotionally, children cannot be treated like small adults. Infants, young children, and adolescents each may react differently to drugs and other therapies. About 15 percent of children lack health insurance, and the rest are covered by a multitude of private and public insurers that vary in their coverage of palliative and end-of-life care.

In 2001, PDIA awarded a grant to the Education Development Center, Inc., to create a national laboratory for quality improvement in family-centered pediatric care and to prepare educational resources for the country's 240 children's hospitals.

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, the center developed a curriculum and video series. These materials were designed to help children’s hospitals and similar institutions develop effective, interdisciplinary, palliative care teams made up of doctors, nurses, social workers, chaplains, and allied healthcare professionals.

## The Initiative to Improve Palliative Care in the African American Community

Even when they have full access, African Americans and other members of medically underserved communities use relatively few palliative and hospice services. Little data exists to explain this phenomenon, although the historical denial of these groups’ access to healthcare and past abuses in medical research have contributed to a general mistrust of the healthcare system. From this perspective, patients may perceive palliative and hospice care as a less valuable form of care compared to aggressive, curative treatment. Compounding the problem is the relative scarcity of physicians trained to deliver culturally competent end-of-life care.

PDIA supported the creation of the Initiative to Improve Palliative Care for African Americans (IIPCA), led by Richard Payne, chief of the pain and palliative care service of Memorial Sloan-Kettering Cancer Center. IIPCA’s goal is to define and promote a research, education, and policy agenda and to build coalitions among mainstream organizations, stakeholders in the African American community, and palliative care groups.

## Care of the Dying in Prisons and Jails

In 1998, more than 2,500 of the 1.83 million men and women incarcerated in the United States died of natural causes in state and federal correctional facilities. Longer sentences and fewer paroles, coupled with the increasing age of prisoners, contribute to the increasing numbers of terminally ill inmates. In 1998, in order to define the issues and explore possible solutions, PDIA and the Center on Crime, Communities, and Culture—another Open Society Institute program—co-sponsored the first meeting ever devoted to the growing problem of caring for the dying in prisons and jails.

PDIA also supported the production of a compelling video documentary about one of the nation’s first prison hospice programs at Angola Prison in Louisiana, in which inmate volunteers are trained to care for fellow inmates who are dying.

As a result of these efforts, a series of ongoing initiatives has advanced the care of dying prisoners through the development of guidelines, educational

**"Pediatric palliative care is almost like an orphan cause, without many people willing to advocate for the intensive support needs of a relatively small number of patients and their families. Supporting pediatric palliative care was very forward-thinking of PDIA, and as a result, we've seen tremendous progress in national recognition that children need to be included in considerations of palliative care."**

Joanne Wolfe, M.D., M.P.H., Dana-Farber Cancer Institute, Children's Hospital Boston

**"There is much that we can do for patients and their families. We can provide pain management, emotional and psychological support, and offer opportunities for spiritual growth and counseling. Yet I have witnessed much ambivalence, sometimes outright hostility, and certainly difficulty in discussing the pertinent issues about personal choices and preferences for care when terminally ill with many of my patients, particularly African American patients and families."**

Richard Payne, M.D., Memorial Sloan-Kettering Cancer Center

**"We were concerned about the issue of people growing old and dying in prisons—but we couldn't figure out what to do about it. With PDIA's help, we pulled in other partners in order to raise the awareness of those who administer correctional medical programs about end-of-life care and promote quality standards for such care."**

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

initiatives for prison healthcare professionals, and policy changes. In collaboration with the Robert Wood Johnson Foundation, PDIA supported the development of national guidelines for palliative care in prisons and jails.

# Public Policy >

## RECOMMENDATIONS TO FUNDERS

### Grantmaking to Inform Public Policy

Grantmakers have an important role to play in informing and improving public policies that affect end-of-life care, including pain management, regulation of professional practice, reimbursement, Medicare benefits, and patient care. Because appropriate pain relief is essential to quality palliative and end-of-life care, PDIA has paid particular attention to the impact that regulations designed to prevent illegal prescription drug abuse have on patient access to appropriate pain medication.

- ▶ Fund programs that evaluate prescription drug regulation to help legislatures, professional licensing boards, and healthcare organizations reconsider and modify policies that impede appropriate pain management.
- ▶ Fund health services research to collect data and analyze end-of-life care policy. Foundation-supported studies can give local, state, and federal public officials the information they need to make sound and politically viable decisions regarding end-of-life care.
- ▶ Create opportunities for policymakers at all levels to learn from palliative care clinicians and researchers.
- ▶ Support partnerships among disability rights groups, caregiver groups, mental health organizations, advocates for senior citizens, and others who have a stake in improving end-of-life care for their members.
- ▶ Support community coalitions of hospitals, churches, citizen associations, local businesses, and others that are working to improve end-of-life care.
- ▶ Support grassroots coalitions to educate policymakers about:
  - the importance of adequate reimbursement for palliative care treatment and prescription medications;
  - the limitations of the Medicare Hospice Benefit and suggested improvements;
  - the experiences and needs of family caregivers; and
  - ways to revise existing state policies and create new policies to improve end-of-life care.
- ▶ Fund opportunities to give policymakers the chance to hear from bereaved family members about the quality of care their loved ones received—whether inept and unacceptable or skilled and compassionate.
- ▶ Support national organizations that are already working to examine and transform public policy affecting end-of-life care.

# Public Policy >

## PDIA'S GRANTMAKING STRATEGIES

### Informing Public Policy

Many of the issues crucial to the improved care of the dying raise important public policy questions. How do federal regulations and state licensure affect practicing end-of-life care providers? What care is covered by health benefits, and how much must providers fight to obtain adequate and timely reimbursement? What new models, benefits, or demonstration projects might lead to improvements? What does the federal research establishment recognize as worthy of funding, and how much of a priority do the National Institutes of Health, the Health Research and Services Administration, and other federal agencies place on the challenges of improving end-of-life care? PDIA recognized the importance of addressing these questions and made grants to support improved public policy.

The following are key examples of PDIA grants and funding initiatives.



## Barriers to Pain Medicine

Pain management is affected by a complicated tangle of federal and state policies. Highly regulated prescription and practice policies can prevent patients from getting the medications they need to alleviate acute and chronic pain.

In 1997, PDIA awarded the first of several grants to the University of Wisconsin Medical School to address the barriers to availability of opioids for pain relief. The university's Pain & Policy Studies Group promotes policies for the increased availability of opioid analgesics for pain patients. It has undertaken the only systematic analysis of the international, national, and state drug regulations that impact pain management. This analysis can serve as a valuable resource for grantmakers who want to ensure that people who suffer from cancer, AIDS, surgery, accidents, and chronic conditions have relief from their pain and a better quality of life, and that caregivers will know when and how to use opioid analgesics without fear of excessive regulatory scrutiny.

## Palliative Care Academic Career Awards

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. PDIA supported the promotion and distribution of a policy report that details the need for the federal government to create a modest academic career awards program in palliative care, which would support the career development of medical school faculty as palliative care academicians. The ultimate goal is to establish at least three permanent faculty members in all 144 U.S. medical schools. These individuals will conduct the research needed to advance the science of the field and will disseminate this information to new generations of physicians in medical schools, residencies, and fellowship programs.

## Americans for Better Care of the Dying

In 1997, PDIA made one of its largest grants to date in support of the work of Americans for Better Care of the Dying (ABCD), a nonprofit organization dedicated to social, professional, and policy reform. ABCD focuses its efforts on fundamental reforms, such as improved pain management, better financial reimbursement systems, enhanced continuity of care, support for family caregivers, and changes in public policy. It also helps organizations and individuals improve their community care systems and assists healthcare organizations in implementing rapid-cycle quality-improvement methods.

# Public Engagement >

## RECOMMENDATIONS TO FUNDERS

### Grantmaking to Broaden Public Engagement

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. Patients and their families from all cultures should expect and receive skilled, dependable, and compassionate care at the end of life. Foundations can play an important role in helping people understand that such care is possible right now and that they must demand quality care at every stage of illness.

- ▶ Support community outreach and education about advance-care planning. Living wills, advance directives, and healthcare proxies are essential tools that enable people to make informed choices about end-of-life care.
- ▶ Fund culturally appropriate translations of patient education and advance-care planning materials for non-English speakers.
- ▶ Enable local school districts to offer grief training programs for teachers, school psychologists, nurses, counselors, and social workers.
- ▶ Fund public education campaigns tailored to the needs of specific cultural, religious, geographic, or ethnic communities.
- ▶ Make information available to help people understand and access the Medicare Home Health Benefit and the Medicare Hospice Benefit.
- ▶ Enable local hospitals to develop and distribute high-quality patient education materials about palliative care, pain management, and decision making.
- ▶ Make sure that hospital pediatrics departments have a range of support services available to help parents cope with their child's illness and make informed decisions about treatment.
- ▶ Fund hospital and community workshops that teach people strategies for effectively communicating with their healthcare providers.
- ▶ Support documentary films, radio, photography, poetry, dance, performing arts, and literature that explore the diverse human experiences of illness, dying, and bereavement.

# Public Engagement >

## PDIA'S GRANTMAKING STRATEGIES

### Broadening Public Engagement

PDIA promoted the effective use of education and the media to increase discussion of dying, death, and bereavement. It supported strategies for informing the public about programs available to provide a range of support services at the end of life. PDIA also advanced strategies to address the needs of special populations.

The following are key examples of PDIA grants and funding initiatives.

## Medicare Rights Center

Lack of information about payment options for end-of-life care is a substantial barrier to obtaining quality end-stage care. In 1996 and 2000, PDIA awarded grants to the Medicare Rights Center (MRC), the largest independent source of Medicare information and assistance in the United States.

MRC maintains a website to educate consumers, families, caregivers, professional counselors, and clinicians about Medicare hospice and home health benefits for the terminally ill in both the fee-for-service and HMO programs. The Home Care Channel ([www.medicarerights.org/homecare.html](http://www.medicarerights.org/homecare.html)) provides an online consumer booklet on home health and hospice benefits, a technical guide for professionals, and fliers for consumers on the specific topics of home healthcare, hospice care, and skilled nursing care.

The center also provides telephone hotline services for consumers and medical professionals. Its education department teaches patients, healthcare providers, social service workers, family members, and others about Medicare benefits and rights.

## American Pain Foundation

Pain experienced by the chronically, seriously, or terminally ill is vastly under-treated in the United States, especially among underserved populations. The American Pain Foundation (APF) is a national nonprofit organization dedicated solely to meeting the needs of people in pain. In 2001, APF received a PDIA grant to increase the information and assistance provided to pain sufferers, their caregivers, and the public. APF expanded its website ([www.painfoundation.org](http://www.painfoundation.org)) and increased its materials and resources for consumers and professionals.

## PDIA Media Resource Center

To realize its mission to “transform the culture and experience of dying and bereavement in America,” PDIA recognized that it must help change existing ways of thinking and encourage public discussion. PDIA worked to introduce “death talk” into the culture—to let people know what is right and wrong with the current methods of end-of-life care, what might be hoped for, and what they, as consumers, have a right to expect from healthcare providers and policymakers. Through the years, PDIA often worked with Last Acts, a national communications campaign created by the Robert Wood Johnson Foundation in 1996. Last Acts is

both a public communications campaign and a coalition of organizations representing professionals and the public.

Through its media resource center, PDIA has worked with newspaper journalists, book authors, magazine writers, investigative reporters, documentarians, television and radio producers, and newsletter and industry-publication editors to encourage their participation in addressing the culture and experience of dying in America. PDIA also provided content, technical assistance, and other support for the PBS documentary series *On Our Own Terms: Moyers on Dying*, which aired in the fall of 2000 and drew an audience of more than 20 million viewers. The Robert Wood Johnson Foundation, a major funder of the series, supported a complementary community action campaign to encourage national discourse about the complex issues that families face as they care for family members dying at home or in the hospital.

## Grief at School

In 1999, PDIA awarded a grant to the American Hospice Foundation (AHF) in Washington, D.C., for a Grief at School Program. The grant supported a three-city pilot program that offers workshops to prepare schoolteachers, counselors, psychologists, nurses, and social workers to help grieving children in the classroom and in after-school programs. Through these workshops, participants learn to identify grieving children, conduct age-appropriate classroom lessons on loss and grief, establish school-based grief support groups, and use hospices as local resources for grief expertise.

In 2000, PDIA awarded the foundation another grant to expand the program nationally. Working with the initial Grief at School Program as a model, AHF began to provide training to school-based professionals across the country through workshops conducted at national and state conferences of the National Association of School Psychologists. The program's goal is to quickly and broadly expand the influence of these train-the-trainer workshops to reach both school psychologists and graduate students.

## The Arts and Humanities Initiative

Through a special funding initiative, PDIA recognized the importance of the arts and humanities in cultural transformation. This initiative was met with an outpouring of interest and more than 262 proposals. The 15 grantees who were selected produced books, documentary films, performances, radio productions, and art exhibits. *Aging in America: The Years Ahead* is an award-winning exhibition,

**"The legacy of these efforts is that care at the bedside is improving. Not nearly enough, but your chances of getting good care at the end of life are better—particularly if you ask for it. Unfortunately, people are slow to ask."**

Victoria Weisfeld, M.P.H.,  
Robert Wood Johnson Foundation

**"We pay a lot of attention now to prenatal care and childbirth. We need to afford this last phase of life the same respect and careful attention we give to birth. We labor into life, and we labor out of life."**

Martha Henderson, M.S.N., Dr.Min., G.N.P.,  
University of North Carolina School of Nursing

book, and documentary film by photographer Ed Kashi and writer/producer Julie Winokur. This project has won awards from the National Press Club and the American Society on Aging and has been widely recognized as one of the most compelling and compassionate illustrations of what it means to grow old in today's society. The intricate fabric panels created by fiber artist Deidre Scherer, portraying the richness and complexity of our relationships at the end of life, have been exhibited throughout the country. PDIA could only make a small number of grants in this area, but found that there is no shortage of talented people exploring the experiences of illness, death, and mourning through the arts and humanities.





# The Years Ahead



**During its nine years** of grantmaking, PDIA has helped lay a strong foundation in the field of palliative care—but it did not work alone. Through their leadership, collegiality, and vision, many other foundations have contributed enormously to the development and progress of the field. The Robert Wood Johnson Foundation, the Nathan Cummings Foundation, the United Hospital Fund, the Fetzer Foundation, the Millbank Memorial Fund, the Commonwealth Fund, the Fan Fox and Leslie R. Samuels Foundation, the Emily Davie and Joseph S. Kornfeld Foundation, and many other private, corporate, family, and community foundations have emphasized the importance and effectiveness of philanthropic attention to end-of-life care.

How can we best assess PDIA's impact, achievements, and legacy as we reach the end of nine years of grantmaking? Has the quality of care significantly improved for dying patients and their loved ones? Will PDIA's targeted funding generate sustained, meaningful, self-replicating improvements?

PDIA may not have completely transformed the culture of dying in America, but we have helped shine a light on the people working throughout the United States to bring about such a transformation. We have seen modest demonstration projects yield extraordinary results and have identified areas of acute interest that make the field ready for the next round of funding.

We cannot control the fact that people die, but as a society, we certainly have the power to influence the experience of dying. We know that, for too many people, dying is still far more painful—emotionally and physically—than it should be. As individuals, we all have a vested interest in the future quality of end-of-life care. As grantmakers, we have the power to help transform the experience of dying in America—for ourselves, for our families, and for our communities.

"It is difficult to evaluate the ultimate legacy of PDIA, and I don't mean that negatively. I think we made medicine less phobic about end-of-life care, and we made palliative care seem worth doing. But death is such a powerful and frightening thing, it is going to take an ongoing, sustained effort to get people to keep addressing these issues."

Robert Butler, M.D., PDIA Advisory Board

"What strikes me today, ten years later, is that the issue isn't nebulous anymore. We've gotten ourselves a real field of palliative care and we are making things happen in that field. In some ways, we succeeded beyond our wildest dreams. In medicine today, our textbooks are different, teaching is different, the scientific literature is different. The field really is dramatically different than it was when we started."

Susan Block, M.D., PDIA Advisory Board

## SELECTED ONLINE RESOURCES

### Organizations

The American Academy of Hospice and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)

The American Board of Hospice and Palliative Medicine  
[www.abhpm.org](http://www.abhpm.org)

Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)

The Hospice and Palliative Nurses Association  
[www.hpna.org](http://www.hpna.org)

National Association of Social Workers  
[www.socialworkers.org](http://www.socialworkers.org)

United Hospital Fund  
[www.uhfnyc.org](http://www.uhfnyc.org)

### Professional Education

Education for Physicians on End-of-Life Care  
[www.epec.net](http://www.epec.net)

End-of-Life Nursing Education Consortium Project  
[www.aacn.nche.edu/el nec](http://www.aacn.nche.edu/el nec)

End-of-Life Physician Education Resource Center  
[www.eperc.mcw.edu](http://www.eperc.mcw.edu)

Harvard Medical School Program in Palliative Care Education and Practice  
[www.hms.harvard.edu/cdi/pallcare](http://www.hms.harvard.edu/cdi/pallcare)

Initiative for Pediatric Palliative Care  
[www.ippcweb.org](http://www.ippcweb.org)

Nursing Leadership Academy on End-of-Life Care  
[www.palliativecarenursing.net](http://www.palliativecarenursing.net)

Smith College School of Social Work: End-of-life Care Certificate Program  
[www.smith.edu/ssw/endofcert.htm](http://www.smith.edu/ssw/endofcert.htm)

Social Work Summit on Palliative and End-of-Life Care  
[www.swlda.org](http://www.swlda.org)

### Research

The Brown University Center for Gerontology and Health Care Research  
[www.chcr.brown.edu/dying/factsondying.htm](http://www.chcr.brown.edu/dying/factsondying.htm)

Center for the Advancement of Health  
[www.cfah.org](http://www.cfah.org)

Duke Institute on Care at the End of Life  
[www.iceol.duke.edu](http://www.iceol.duke.edu)

Life's End Institute: Missoula Demonstration Project  
[www.missoulademonstration.org](http://www.missoulademonstration.org)

National Alliance for Children with Life-Threatening Conditions  
[www.nacwltc.org](http://www.nacwltc.org)

## Policy

The American Alliance of Cancer Pain Initiatives  
[www.aacpi.org](http://www.aacpi.org)

The American Pain Foundation  
[www.painfoundation.org](http://www.painfoundation.org)

Americans for Better Care of the Dying  
[www.abcd-caring.org](http://www.abcd-caring.org)

The GRACE Project: Guiding Responsive Action in Corrections at End-of-Life  
[www.graceproject.org](http://www.graceproject.org)

Initiative to Improve Palliative Care for African-Americans  
[www.iipca.org](http://www.iipca.org)

The National Hospice and Palliative Care Organization  
[www.nhpco.org](http://www.nhpco.org)

Pain & Policy Studies Group at the University of Wisconsin  
[www.medsch.wisc.edu/painpolicy](http://www.medsch.wisc.edu/painpolicy)

Promoting Excellence in End-of-Life Care  
[www.promotingexcellence.org](http://www.promotingexcellence.org)

The Washington Home Center for Palliative Care Studies  
[www.medicaring.org](http://www.medicaring.org)

## Public Education

Aging with Dignity  
[www.agingwithdignity.org](http://www.agingwithdignity.org)

American Hospice Foundation  
[www.americanhospice.org](http://www.americanhospice.org)

Children's Hospice International  
[www.chionline.org](http://www.chionline.org)

Family Caregiver Alliance  
[www.caregiver.org](http://www.caregiver.org)

Growth House: End-of-Life Internet Resources  
[www.growthhouse.org](http://www.growthhouse.org)

Last Acts  
[www.lastacts.org](http://www.lastacts.org)

Last Acts Partnership  
[www.lastactspartnership.org](http://www.lastactspartnership.org)

Medicare Rights Center  
[www.medicarerights.org](http://www.medicarerights.org)

Midwest Bioethics Center: Community-State Partnerships to Improve End-of-Life Care  
[www.midbio.org](http://www.midbio.org)

Pain Medicine and Palliative Care at Beth Israel  
[www.stoppain.org](http://www.stoppain.org)

Partnership for Caring  
[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

Rallying Points  
[www.rallyingpoints.org](http://www.rallyingpoints.org)

## ADVISORY BOARD AND STAFF

### PDIA ADVISORY BOARD

Susan Block, M.D., *Dana-Farber Cancer Institute, Harvard Medical School*

Robert A. Burt, J.D., *Yale Law School*

Robert N. Butler, M.D., *International Longevity Center-USA., Ltd.*

Ana O. Dumois, Ph.D., D.S.W.

Kathleen M. Foley, M.D., *Memorial Sloan-Kettering Cancer Center,  
Weill Medical College of Cornell University*

Patricia Prem, M.S.W.

### PDIA STAFF

Kathleen M. Foley, M.D., *Director*

Mary V. Callaway, M.E., *Associate Director*

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

Grace Christ, D.S.W., *Social Work Leadership Development Awards Project Director*

Lori McGlinchey, *Program Officer*

Nina Gadmer, *Faculty Scholars Program Officer*

### OPEN SOCIETY INSTITUTE

George Soros, *Chairman*

Aryeh Neier, *President*

Gara LaMarche, *Vice President and Director of U.S. Programs*

*Editor:* Lori McGlinchey

*Designer:* Jeanne Criscola/Criscola Design

*Printer:* Gist and Herlin Press, Inc.

*Photography*

Ed Kashi: pages 6, 12, 22, 63

Bastienne Schmidt: page 30

Death is inevitable, but severe suffering is not. We must all look toward the day when compassionate and skilled end-of-life care becomes such a part of the fabric of American communities and the American healthcare system that we won't need to request it—it will simply be offered when needed. As grantmakers, we have the opportunities and resources to help bring us all closer to that day.

The Open Society Institute (OSI) is 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.



OPEN SOCIETY INSTITUTE

[www.soros.org](http://www.soros.org)