

GRANTS PROGRAM



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

Strengthening Organizational Capacity

**American Board of Hospice and
Palliative Medicine**
Silver Spring, MD
Dale Ellen Lupu, Ph.D.

\$219,380

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

American Pain Foundation
Baltimore, MD
John D. Giglio, J.D.

\$100,000

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

The Cicely Saunders Foundation

London, England

Irene J. Higginson, Ph.D.

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

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

National Hospice and Palliative Care Organization

Alexandria, VA

Stephen Connor, Ph.D.

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

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

University of Alabama at Birmingham

Birmingham, AL

John Shuster, M.D.

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

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

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

Judge David L. Bazelon Center for Mental Health Law

Washington, DC
Mary Baluss, J.D.

\$233,866

Palliative Care Law Project

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

International Longevity Center

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

\$19,075

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

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

University of Wisconsin-Madison Medical School

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

\$105,362

Institutionalizing Pain Management through Practice Change Programs

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



Three Men by Deidre Scherer

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

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

\$399,947

The Initiative to Improve Palliative Care for African Americans

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

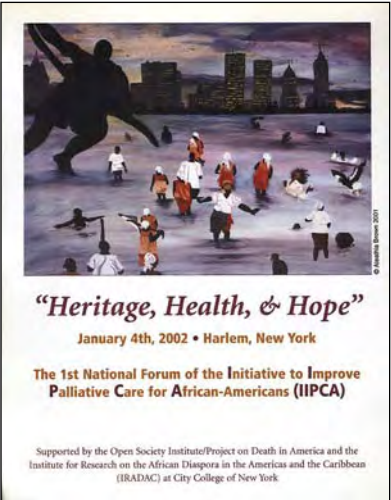
North General Hospital
New York, NY
Richard Payne, M.D.

\$75,000

The Initiative to Improve Palliative Care for African Americans National Conference

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

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



Increasing Access to Palliative Care for Vulnerable Populations

New Jersey Health Decisions

Verona, NJ

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

\$169,738

Health Decisions for People with Disabilities

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

Radio Bilingue

Fresno, CA

Hugo Morales

\$102,025

Últimos Cuidados, Cuidados para los Desahuciados y sus Familias

Final Care, Care for the Dying and their Families

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

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

\$47,611

*Improving the Quality of Clinician-Family
Communication in the Intensive Care Unit for
Non-English-Speaking Families*

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

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

\$66,666

*Last Passages: Transforming the Experience
of Death for Individuals with Developmental
Disabilities and their Families*

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

Improving Palliative Care for Children and Families

The Life Institute

Albany, NY

Daniel Tobin, M.D.

\$18,650

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

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

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

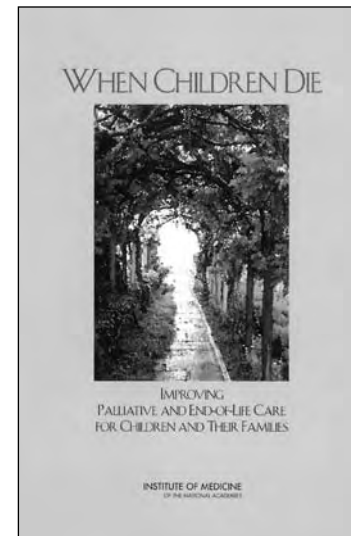
Newton, MA

Mildred Z. Solomon, Ed.D.

\$500,000

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

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



National Academy of Sciences

Washington, DC

Marilyn Field, Ph.D.

\$12,193

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

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



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

Other Grants

2001 - 2003

Meryl Levin
New York, NY

\$23,000

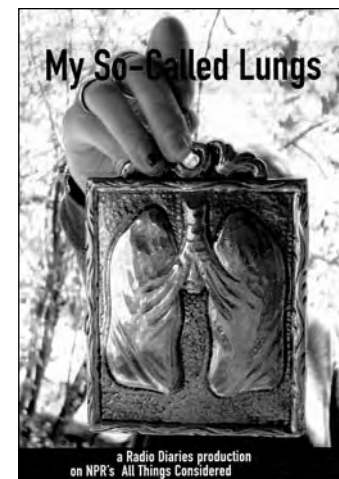
Anatomy of Anatomy: in words and images
This book and traveling exhibition combines photographs of a group of medical students during their dissection of cadavers in gross anatomy class with excerpts from journals they kept during the course. Initial support from PDIA made it possible to create *Anatomy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

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

\$67,407

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

Radio Diaries, Inc.
New York, NY
Joe Richman



\$1,250

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

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

\$10,000

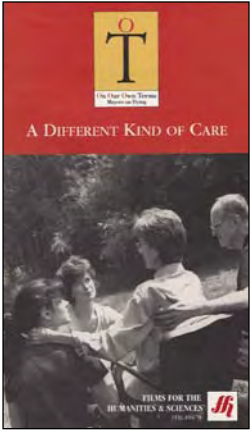
Still Life: The Humanity of Anatomy.
Support for Broadcast, Distribution, and
Medical Education

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

The Catticus Corporation
Berkeley, CA
Pierre Valette

\$10,000

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



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

\$25,000

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

American Hospice Foundation

Washington, DC

Naomi Naerman, M.P.A.

\$136,242

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

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

Center for the Advancement of Health

Washington, DC

Jessie C. Gruman, Ph.D.

\$9,000

Toward More Effective Responses to Grief

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

Hospice Foundation of America

Washington, DC

David Abrams

\$15,000

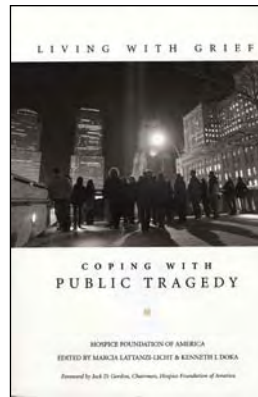
*2001 Living with Grief Teleconference:
Caregiving and Loss*

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



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

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



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

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

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

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

Making Peace with the Past

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