PDIA

Project on Death in America
Open Society Institute
888 Seventh Avenue
New York, New York 10106
Tel. 212/ 887-0150 Fax. 212/ 247-3890
http://www.soros.org/death.html

April 1997

Project Profile

History

On November 30, 1994 George Soros, chairman of the Open Society Institute, announced the Project on Death in America. In his speech, "Reflections of Death in America," Mr. Soros explained his interest in supporting a project aimed at transforming the culture of dying in America. Personal experience with the death of his parents increased his awareness of the American culture of death – a culture rife with denial and neglect. Death in our society is area in which misconceptions often act as barriers to quality of life at the end of life. Furthermore, lack of understanding or knowledge produces barriers to the resolution of grief among survivors. In the time since the project's introduction, the Project on Death in America has pursued its mission through the Grants and Faculty Scholars Programs, as well as through Special Initiatives.

Grants Program

Mission Statement

The experience of dying has changed over the past several decades, with many more people enduring prolonged deaths as a consequence of chronic and progressive disease. Needless suffering – physical, emotional, existential, and spiritual – too often accompanies these deaths, for both dying persons and survivors. The mission of the Project on Death in America's Grants Program is to understand and transform the culture and experience of dying in the America through initiatives in research, scholarship, the humanities, and the arts and to foster innovations in the provision of care, public education, professional education, and public policy. The following are the seven priority areas and examples of the 80 initiatives that have been funded through the Grants Program. For a complete list of the PDIA Grantees, please visit our Web site at http://www.soros.org/death/grants.html or call 212/887-0150.

- *The epidemiology, ethnography, and history of dying in the United States*
  Strong Museum
  Rochester, NY
  G. Rollie Adams, principal investigator
  $90,000 (July 1, 1995 - June 30, 1996)
  Memory and Mourning: American Expressions of Grief – a traveling exhibit that examines the cultural history of grief in America. Tel. 716/263-2700

Center for Ethics in Health Care
Oregon Health Sciences University, Portland, OR 97201-3098
Susan W. Tolle, M.D., principal investigator
$150, 000 (July 1, 1996 - June 30, 1998)
Research on End-of-life Care in Oregon
A study to compare end-of-life care in the three major settings where death occurs in Oregon: acute care hospital, nursing homes, and home/hospice. Tel. 503/494-4466

Staten Island University Hospital
Staten Island, NY
Barbara Malach, M.D., principal investigator
$25,000 (March 1, 1997 - February 28, 1999)
End-of-Life Issues Among the Elderly Russian Immigrant Population
Approximately 2,000 Russian patients over the age of 65 visit this not-for-profit, 633 bed, multi-site health care delivery system per month. The purpose of this project is to assess attitudes, beliefs and knowledge regarding end-of-life and bereavement issues among this population and to develop a culturally sensitive, educational program regarding these issues that will have a patient and health care professional component. Tel. 718/ 226-6347

- *The physical, emotional, spiritual, and existential components in dying and bereavement*

The Universalist Meeting House of Provincetown
Provincetown, MA
Reverend Jennifer Justice, principal investigator
$25,000 (August 15, 1996 - August 14, 1997)
Spiritual Support Programs for the Dying
In Provincetown, with the second highest AIDS population per capita in the country, The Universalist Meeting House provides programs to ease the suffering including: a support group for HIV-positive people and for partners and friends who are grieving the loss of loved ones; an eight-week course on "Living and Dying;" and a volunteer team that offers additional spiritual support to people who are dying. Tel. 508/349-7431

The Foundation for Interfaith Research & Ministry
Houston, TX
Ronald H. Sunderland, Ed.D, principal investigator
$126,826 (July 1, 1996 - June 30, 1998)
Grief Care Teams
Community-based programs to provide coordinated grief support and grief education programs for terminally ill child, adolescent, and adult populations. A team of volunteers, rather than a one-to-one "buddy" method, is used in order to pool resources and ease volunteer burden. Tel. 713/682-5995

Interfaith Neighbors, Inc
New York, NY
Eileen Lyons, CSW, principal investigator
$150,000 (July 1, 1996 - June 30, 1998)
Children's Bereavement Project will conduct outreach to educate students and teachers at ten schools regarding issues of grief and will do empirical research in order to identify the design considerations and ameliorative factors. Tel. 212/472-3567

$60,000 (January 1, 1997 - December 31, 1998)
On Death and Dying in America: A Photographic Exploration
Through photography and video, Bastienne Schmidt and Philippe Cheng will explore and document our evolving culture of death in America; how we emotionally, spiritually, and practically experience mourning, grief, and loss; and how our social and cultural environments impact and shape these responses. Tel. 718/447-5929

Tony Howarth
Hastings-on-Hudson, NY
$10,000 (December 15, 1996 - December 14, 1998)
Sundown
The ability of art to identify, create, and convey meaning in facing disability and death cannot be underestimated. This playwright will explore the dying process with a play about the experience of an elderly man whose living is complicated by the chaos of dementia. Tel. 914/478-0566

National Hospice Foundation
Arlington, VA
John J. Mahoney, principal investigator
$100,000 (July 1, 1995 - June 30, 1996)
An art exhibit, *Hospice: A Photographic Inquiry*, originating at the Corcoran Gallery of Art in Washington, DC and currently touring venues throughout the United States through the year 2000. Tel. 703/516-4928

- *New service delivery models for the dying and their family and friends*

The Hospice Foundation
Torrance, CA
Claire Tehan, principal investigator
$10,000 (January 1, 1997 - December 31, 1997)
Hospice Education & Outreach to Japanese Americans
A hospice will be created for Japanese nationals and Japanese Americans. Accompanying the hospice development, will be an education program for hospice and health care professionals caring for Japanese patients. Both approaches will enable health care professionals to overcome the language and cultural barriers that too often stand between the patient and quality end-of-life care. Tel. 310/530-3800

Providence Health System
Portland, OR
Alicia Super, RN, BSN, principal investigator
$100,000 (November 1, 1996 - October 31, 1998)
Supportive Care of the Dying: A Coalition for Compassionate Care is a collaborative effort of six health care systems that will 1) accurately assess the needs of those affected by life threatening illness, 2) use research findings to build community-based systems of care, information and education; and 3) disseminate this new care model through mentorship teams. Tel. 503/215-5033

United Hospital Fund
New York, NY
David A. Gould, Ph.D., principal investigator
$300,000 (July 1, 1995 - June 30, 1997)
The creation of a consortium of five New York City hospitals to design, implement, and evaluate a Palliative Care Initiative in order to fundamentally assess and change the

way hospitals provide care to persons at the end of life. Tel. 212/494-0700

- *Educational programs for the public about death and dying*

Medicare Rights Center
Medicare Beneficiaries Defense Fund, New York, NY
Diane Archer, principal investigator
$150,000 (January 1, 1997 - December 31, 1998)
Initiative for the Terminally Ill on Medicare
This initiative will educate consumers, their families, caregivers professional counselors and clinicians about Medicare hospice and home healthcare benefits for the terminally ill in both the fee-for-service and HMO settings. The initiative will include an aggressive public relations campaign and consumer guide. Tel. 212/869-3850

Hospice Foundation of America
Washington, DC
Jack D. Gordon, principal investigator
$50,000 (September 1, 1996 - August 31, 1997)
A video teleconference series for the public, health care professionals and social workers. This year's teleconference is "Living with Grief: When Illness is Prolonged." A resource book and video have been developed in conjunction with the teleconference. Tel. 202/638-5419

KPFA Radio/Pacifica Foundation
Berkeley, CA
Susan G. Stone, principal investigator
$40,000 (December 1, 1995 - November 30, 1996)
Public broadcaster KPFA Radio will produce, market, and distribute nationwide a five-part multi-cultural radio series on death and bereavement. The series will address the varied cultural traditions in the United States of experiencing, mourning and commemorating death. Tel. 510/848-6767

- *Educational programs for the health care professions*

Institute for the Study of Health and Illness
Bolinas, CA
Rachel Naomi Remen, M.D., principal investigator
$80,000 (January 1, 1997 - December 31, 1999)
"The Curriculum on Detoxifying Death for Physicians" is a multi-modal, continuing medical education curriculum aimed at physicians who care for patients living with a terminal illness. Goals include providing physicians with a different approach to caring for their patients as well as strategies for themselves for preventing burnout and for maintaining personal growth. Tel. 415/868-0970

Mount Sinai Medical Center
New York, NY
Christine K. Cassel, M.D., principal investigator
$75,000 (December 15, 1996 - December 14, 1997)
National Committee on Financing Care at the End of Life
This program is to create a Disease Related Group (DRG) for payment for terminal care services delivered to hospitalized patients and all palliative care. This new code will validate and legitimize the practice of palliative medicine by hospital professionals on behalf of their dying patients, since a reimbursed activity is much more likely to be viewed as an appropriate function for doctors and hospitals. Tel. 212/355-8400.

Educational Development Center, Inc.
Newton, MA
Mildred Z. Solomon, Ed.D., principal investigator
$149,951 (September 1, 1995 - August 31, 1997)
A program to educate health professionals in order to improve health care professionals' knowledge, attitudes, and practices in ethics, law, and pain management; help them to resolve conflicts between the goals of aggressive cancer treatment and palliative care; and address the impact of cultural diversity on treatment decision making.
Tel. 617/969-7100

- *The shaping of governmental and institutional policy*

University of Wisconsin Comprehensive Cancer Center- World Health Organization Center (WHO) - Pain and Policy Studies Group
Madison, WI
David E. Joranson, MSSW, principal investigator
$73,000 (January 1, 1997 - December 31, 1998)
A Resource Program to Address Barriers to Availability of Opioids for Pain Relief
A resource program will be developed to improve the capability of the Pain and Policy Studies Group to more fully respond to and provide expert assistance creating greater availability of opioid analgesics and policies in the US and to help develop a cancer pain and palliative care initiative for central and eastern Europe. The Center already provides expertise in the area of global pain and opioid availability policy studies and communications, including production of the WHO newsletter *Cancer Pain Release*. Tel. 608/263-7661

Alliance for Aging Research
Washington, DC
Daniel Perry, principal investigator
$93,959 (March 1, 1996 - February 28, 1997)
A study for release to the news media and policy makers which will provide reliable, up-to-date data on health care costs during the last year of life in the very old. The study is not intended to be an original research study, but will be an analysis of the most current literature and scientific data available on the topic. Tel. 202/293-2856

Institute of Medicine, National Academy of Sciences
Washington, DC
Marilyn Field, Ph.D.
$200,000 (July 1, 1995 - November 30, 1997)
Project: To examine: 1) the state of knowledge about clinical, behavioral, legal, economic and other important aspects of care for patients with life-threatening medical problems; 2) evaluate methods for measuring outcomes and predicting survival and functional status, determining patient and family preferences and assessing quality of care; 3) identify factors that impede or promote high quality care for patients approaching death; and 4) recommend steps that policymakers, practitioners and others could take to improve the organization, delivery, financing, assessment and quality of care for those with terminal illness and to increase agreement on what constitutes appropriate care. Tel. 202/334-2360

Faculty Scholars Program

Scholars Program Objective

We are hindered in our efforts to improve the experience of dying patients and their families by a number of factors: major inadequacies in our knowledge about the course, treatment, and outcomes of care of dying patients and their families; deficiencies in many of our current models of caring for dying patients and their families; and serious weaknesses in our education of health professional students about care near the end of life. Addressing these problems will require the development and sustenance of a cohort of clinicians, educators, and researchers who are committed to work in this area.

The Faculty Scholars Program of the Project on Death in America supports outstanding clinicians, educators, and researchers in disseminating existing models of good care, developing new models for improving the care of the dying, and creating new approaches to the education of health professionals. One of the goals of the scholars program is to promote the visibility and prestige of clinicians committed to this area of medicine and to enhance their effectiveness as academic leaders, role models, and mentors for future generations of health professionals. The individual work of the fellows and their collaborative efforts will foster new approaches to key problems and help transform the culture and care of the dying. Each year the program awards approximately 10 two-year fellowships (renewable for a third year) of up to $75,000 per year.

The following is a list of the 26 Faculty Scholars funded to date – three Canadians and 23 Americans. The 1997 cohort of ten Faculty Scholars will be announced soon. Please visit our Web Site http://www.soros.org/death/new.html for the announcement of the 1997 Cohort of Faculty Scholars. To obtain descriptions of the Faculty Scholars' projects, please call 212/887-0150 or visit http://www.soros.org/death/pdiaschol.html.

1995 Cohort

Nicholas A. Christakis, M.D., Ph.D., M.P.H.
University of Chicago Medical Center, Chicago, IL
Tel. 312-702-5300

Stuart Farber, M.D.
University of Washington School of Medicine, Tacoma, WA
Tel. 206-552-2900

Gerri Frager, R.N., M.D.
Dalhousie University and the Walton Killam-Grace Children's Hospital, Nova Scotia, Canada
pager: 902-428-8111 #1868

Carlos F. Gomez, M.D., Ph.D.
University of Virginia School of Medicine, Charlottesville, VA
Tel. 804-924-8146

Sarah J. Goodlin, M.D.
White River Junction VA Medical Ctr & Dartmouth Medical School, White River Junction, VT
Tel. 802-295-9363 ext. 5970

Steven H. Miles, M.D.
University of Minnesota Center for Biomedical Ethics, Minneapolis, MN
Tel. 612-626-9756

Thomas J. Smith, M.D., F.A.C.P.
Virginia Commonwealth University Massey Cancer Center, Richmond, VA
Tel. 804-828-8453

James A. Tulsky, M.D.
Duke University Medical Center and the Durham VA Medical Center, Durham, NC
Tel. 919-286-6963

Charles F. von Gunten, M.D., Ph.D.
Northwestern University Medical School, Chicago, IL
Tel. 312-908-9412

David E. Weissman, M.D.
Medical College of Wisconsin, Milwaukee, WI
Tel. 414-257-6117

1996 Cohort

Harvey Max Chochinov, M.D., F.R.C.P.C.
Manitoba Cancer Treatment and Research Foundation, University of Manitoba,
Winnipeg, Manitoba
Tel. 204-787-7949

Timothy J. Keay, M.D., M.A.-Th., C.A.Q.G.M., F.A.A.F.P.
University of Maryland School of Medicine, Baltimore, MD
Tel. 410-328-2651

David R. Kuhl, M.D.
University of British Columbia, Palliative Care Program, St. Paul's Hospital,
Vancouver, British Columbia
Tel. 604-682-2344

Marcia Levetown, M.D.
University of Texas Medical Branch at Galveston, Galveston, TX
Tel. 409-772-6101

Michael Lipson, Ph.D.
Columbia College of Physicians and Surgeons & Harlem Hospital, New York, NY
Tel. 212-939-2366

Susan J. McGarrity, M.D.
Pennsylvania State University Hospital, Milton S. Hershey Medical Center, Hershey, PA
Tel. 717-531-4290

Walter M. Robinson, M.D., M.P.H.
Harvard Medical School & Children's Hospital, Boston, MA
Tel. 617-355-7881

John Lee Shuster, Jr., M.D.
University of Alabama School of Medicine, Birmingham, AL
Tel. 205-934-5151

Daniel P. Sulmasy, O.F.M., M.D., Ph.D.
Georgetown University Medical Center, Washington, D.C.
Tel. 202-687-1122

Sharon M. Weinstein, M.D.
University of Texas M.D. Anderson Cancer Center, Houston, TX
Tel. 713-792-2824

OSI Soros Faculty Scholars

J. Andrew Billings, M.D.
Harvard Medical School, Massachusetts General Hospital, Boston, MA
Tel. 617-724-9196

William Breitbart, M.D.
Cornell University Medical College & Memorial Sloan-Kettering Cancer Center, New York, NY
Tel. 212-639-8704

Diane E. Meier, M.D., Judith C. Ahronheim, M.D., Jane Morris, R.N., and R. Sean Morrison, M.D.
Mt. Sinai Medical Center, New York, NY
Tel. 212-241-5561

PDIA Special Initiatives

Grantmakers Concerned with Care at the End of Life

The purpose of Grantmakers Concerned is to educate other foundations about what they can do to aid the research and development of new systems of care, help shape governmental and institutional policy, and provide broad public and professional education programs that focus on improved care for the dying, their families, and their caregivers. Grantmakers Concerned also aims to provide a forum for the rational debate of all end-of-life issues and to increase inter-foundation communications about projects funded and knowledge acquired. To accomplish its mission, the new funders group plans to organize conferences for foundations on the various issues of concern and disseminate information through a newsletter and over the Internet. A conference in November 1996 focused on physician-assisted suicide and America's culture of death.

Project to Improve How Textbooks for Medicine and Nursing Address Issues of Dying

At the turn of this century, medical textbooks described the course of a disease through to death. Today's medical textbooks have completely forgotten to develop -- or even retain -- this knowledge. The textbook project, directed by PDIA Advisory Board members Joanne Lynn, M.D., M.A., and Robert Butler, M.D., will review current textbooks for shortcomings and promote improvements by meeting with textbook editors to offer study findings and their recommendations and assistance. Follow-up efforts will include a review of new textbooks to evaluate changes in education on end-of-life care. The before and after studies will be published and disseminated. The expectation is that the project will increase the volume and improve the quality of texts addressing dying as well as create a demand for more information about specific dying situations where little is available.

A History of Death in America

As part of its mission to transform the culture of death, PDIA decided to undertake a multidisciplinary history of death in America in order to analyze the social, cultural, and intellectual forces that have shape American attitudes toward death, dying, and bereavement. Directed by board members David Rothman and Robert Butler, the history project draws upon the contributions of scholars in the fields of historical demography, epidemiology, social history, the history of medicine, legal history, economic history, and the arts. The resulting book will include essays on life expectancy and changing patterns of causes of death; the changing place of death in medical education and practice; the economics of death and dying; popular cultural ideas about; remembering the dead, including memorial photography and the wake; and class and ethnic differences in the attitudes and rituals surrounding death.

Conference on Medical Education for End-of-Life Care

The National Consensus Conference on Medical Education for Care Near the End of Life, which will take place in early 1997, will bring together a range of professional groups and individuals to share innovative educational methods, promote collaboration, and create a consensus statement on medical education for end-of-life care. PDIA Advisory Board member Susan Block, M.D., PDIA Grantee David Barnard, Ph.D., and Soros Faculty Scholar J. Andrew Billings, M.D. are the organizers. The consensus statement and conference proceedings and papers will be published in book form. Individual papers for medical educators and practitioners in particular clinical specialties will be prepared and published in appropriate professional journals.

Task Force on Human Experimentation on Persons Near Death

Persons near death have long served as subjects in medical experimentation. Although much of this research has been of high quality and of benefit to its human subjects, the practice has also been marked by numerous instances in which very sick patients were exposed to grave experimental risks without their consent or any realistic chance of therapeutic benefit to them. PDIA established the Task Force on Human Experimentation on Persons Near Death to explore the ethics of experimentation at the end of life in the context of the two different models for treating research subjects. In making policy recommendations, the task force will attempt to find ways to strengthen regulatory protection of terminally ill subjects – limiting the power of surrogate decisionmakers, for example – while increasing opportunities for gravely ill subjects to obtain promising experimental drugs as participants in clinical trials or as volunteers outside the bounds of formal research. The task force, which includes a number of PDIA Advisory Board members and faculty scholars, is co-chaired by Sherry Brandt-Rauf, J.D., of the College of Physicians & Surgeons of Columbia University and Neil MacDonald, M.D., director of the Center for Bioethics at the Clincial Research Institute of Montreal.

Supreme Court Amicus Brief on Physician-Assisted Suicide

In 1996, the Supreme Court agreed to hear arguments on whether terminally ill patients had a constitutional right to physician-assisted suicide. Two federal appellate courts, in cases involving the states of New York and Washington, had ruled that such a right did exist for people who are terminally ill, mentally competent, and acting voluntarily. The case has heightened debate over an issue that deeply divides the public and the medical profession. In an amicus brief written by Advisory Board member Robert Burt of Yale Law School, PDIA argued against a definitive ruling on physician-assisted suicide at this time, because the states have not had a chance to explore different solutions to a complex societal problem or, if physician-assisted suicide is an option, to fashion effective safeguards against abuses. The brief is available on-line at http://www.soros.org/death/amicusb.html

PDIA newsletter

The Project on Death in America publishes the ***PDIA newsletter*** to inform interested individuals and organizations about the project's activities and to help educate the public about issues surrounding death, dying, and bereavement. If you are interested in receiving future copies of the PDIA newsletter, you may contact PDIA. For up-to-the minute information on PDIA, visit our Web site at http://www.soros.org/death.html.

PDIA Advisory Board

Kathleen M. Foley, M.D.
Director, Project on Death in America
Memorial Sloan-Kettering Cancer Center
Cornell University Medical College

Susan Block, M.D.
Faculty Scholars Program Director
Harvard Medical School
Harvard Community Health Plan

Robert Burt, J.D.
Yale Law School

Robert Butler, M.D.
International Longevity Center
Mt. Sinai School of Medicine

Joanne Lynn, M.D., M.A.
Center to Improve Care of the Dying
The George Washington University

Patricia Prem, M.S.W.

David Rothman, Ph.D.
College of Physicians & Surgeons of
Columbia University

William D. Zabel, LL.B.
Schulte, Roth & Zabel

Open Society Institute

The Open Society Institute is a private operating and grantmaking foundation that promotes the development of open societies around the world, both by running its own programs and by awarding grants to others. The Open Society Institute-New York develops and implements a variety of U.S.-based and international programs in the areas of educational, social, and legal reform, and encourages public debate and policy alternatives in complex and often controversial fields. The Open Society Institute-New York is part of an informal network of more than 24 autonomous nonprofit foundations and other organizations created and funded by philanthropist George Soros in Central and Eastern Europe, the former Soviet Union, Haiti, and South Africa, as well as in the United States. Together with its Hungary-based sister organization, the Open Society Institute-Budapest, the Open Society Institute-New York assists these foundations and organizations by creating regional programs on common issues and by providing administrative, financial, and technical support. The Open Society Institute New York recently established information offices in Armenia, Azerbaijan, Mongolia, Tajikistan, and Uzbekistan. For more information on the Open Society Institute-New York, please visit our Web site at http://www.soros.org.

Open Society - A Definition

An open society is a society based on the recognition that nobody has a monopoly on the truth, that different people have different views and interests, and that there is a need for institutions to protect the rights of all people to allow them to live together in peace. The term "open society" was popularized by the philosopher Karl Popper in his 1945 book *Open Society and Its Enemies.* Broadly speaking, an open society is characterized by a reliance on the rule of law, the existence of a democratically elected government, a diverse and vigorous civil society, and respect for minorities and minority opinions.

If you would like further information about the Grants or Faculty Scholars Programs or Special Initiatives, please contact PDIA at 212/887-0150.