

TRANSFORMING THE CULTURE OF DYING

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PDIA Advisory Board

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

THIS second three-year report describes the Project on Death in America's continuing effort to foster change in the culture and experience of dying in America. Responding to the public's increasing concern with care at the end of life, our funding initiatives identify barriers to humane, compassionate end-of-life care and propose patient and family-centered solutions. A national discourse — "death talk" — has ensued, opening doors to a broad public conversation on the needs of dying patients, caregivers, families, and the institutions providing care.

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

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

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

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

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

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

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

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

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

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

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