

TRANSFORMING THE CULTURE OF DYING

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PDIA Advisory Board

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

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

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

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

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

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

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

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

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

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

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

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

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

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