

PALLIATIVE CARE GRANTMAKING SNAPSHOT REPORT



COMMISSIONED BY

The Collaborative to Advance Funding for Palliative Care

December 2009

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PALLIATIVE CARE GRANTMAKING SNAPSHOT REPORT

EXECUTIVE SUMMARY

Appropriate and effective care can reduce suffering, yet there are increasing signs that too many people don't receive it. Growing bodies of research and literature document this, and recent national debate over healthcare reform has drawn further attention to the cost and effectiveness of care.

Palliative care prevents and relieves suffering and supports the best possible quality of life patients and their families, regardless of the stage of the disease or the need for other therapies. It expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision-making, and providing opportunities for personal growth. It is available across the life cycle from birth to older age.

This interdisciplinary form of care has emerged as a medical specialty. Today, 53 percent of hospitals in the United States that have 50 or more beds now have a palliative care program. In the last eight years there has been an increase in the number of hospitals providing palliative care in the US, from under 500 programs in 2000 to over 1,455 in 2008. However, it is still not available to the majority of the population.

The grantmakers who established the Collaborative to Advance Funding for Palliative Care commissioned the research described in this report to learn about private foundation support for this essential type of care and perceptions of related grantmaking. They wanted to identify ways to engage new funders and support those already involved in palliative care grantmaking.

The research revealed three major trends in palliative care grantmaking:

- The number of grants and foundations making them is growing, but palliative care still receives a very small percentage of philanthropic support for healthcare ¹
- The number of grants made in palliative care has risen and the range of types of palliative care that are supported has grown, with hospice the primary type of palliative care that receives support
- While the number of foundations making grants in palliative care has grown, a small number of foundations provide most of the funding in the category

Participants in the research believe contemporary medicine's focus on cures, a lack of understanding of palliative care by both healthcare professionals and the public, and insufficient funding from public and private sources are barriers to the field's expansion. They believe demand for palliative care will grow, and that grantmaking in the field should also increase.

The findings suggest ways private foundations can support the development of the field of palliative care grantmaking, and in doing so, help overcome the barriers to providing the high-quality palliative care people need:

- Encourage support for funding in the field and collaboration among private foundations
- Increase the resources available to inform effective palliative care grantmaking
- Demonstrate leadership through communication and sharing of best practices

Philanthropists now have an opportunity to build on other philanthropists' support for efforts around the country, including the more than \$200 million in grants that the Robert Wood Johnson Foundation and the Open Society Institute made to support the development and expansion of palliative care. By continuing to advance palliative care grantmaking, private foundations can increase the well-being of people with serious illnesses and contribute meaningfully to improving the delivery and impact of healthcare in the United States.

For additional information about palliative care and related grantmaking please visit the companion website to the Palliative Care Grantmaking Snapshot Report, www.FundPalCare.org. It includes an online version of the Snapshot Report, as well as an extensive listing of resources, and a Toolkit, which provides information about establishing a program in palliative care grantmaking.

PALLIATIVE CARE GRANTMAKING SNAPSHOT REPORT

This Snapshot Report provides an overview of the findings of research into the current state of palliative care grantmaking, as well as recommendations for engaging more private foundations in palliative care grantmaking, profiles of some of the funders who have been working in palliative care, and resources for those interested in learning more.

ABOUT PALLIATIVE CARE

*Dorothy, who has had both cancer and multiple sclerosis, was suffering from agonizing pain that disrupted her life. She was succumbing to hopelessness and depression. Then, she was referred to a palliative care team. Dorothy now sees a doctor on an outpatient basis and says, "Before I met Doctor S., I could not cope with the pain. I know I will not be cured of multiple sclerosis, but my pain is under control now, and I am able to go out of the house and enjoy time with my family."*²

"Palliative care emphasizes the relief of suffering, a truly noble cause."

— Rosemary Gibson, Co-chair,
The Collaborative to Advance Funding for Palliative Care

Since the early 1970s, palliative care has increasingly met the needs of people with serious illnesses, including those like Dorothy who must deal with chronic and terminal disease. This interdisciplinary form of care, first provided through hospice at the end of life, has emerged as a medical specialty that responds to the wider range of needs of patients at any stage of life. Palliative care helps people gain relief from pain and other symptoms of their illness, better understand their treatment options, and maintain the best possible quality of life. For the most vulnerable, such as a newborn infant or a person who is not able to express his or her needs, palliative medical advice enables caregivers to better understand the choices they must make to assure the best type of care.

Reducing Suffering

A growing body of literature documents that people in the United States suffer because the care they receive is not appropriate. In the last 15 years, research and demonstration projects in palliative care have shown that much of patients' suffering is unnecessary, and that providing more effective and appropriate care can reduce suffering. 53 percent of hospitals in the United States that have 50 or more beds now have a palliative care program. In the last eight years there has been an increase in the number of hospitals providing palliative care in the US, from under 500 programs in 2000 to over 1,455 in 2008.³ This achievement is celebrated by leaders in the field, but they caution that it falls far short of the goal of providing this care to all who need and would choose it. They also point to the national debate over healthcare reform, which has drawn further attention to ensuring high quality care. Palliative care is a way to do that.

Changing the Way Americans Deal with Serious Illness and Death

Hospice, which is one type of palliative care, laid the groundwork for the broader field of palliative care by establishing an interdisciplinary approach to relieving suffering and supporting quality of life at the end of life. Established in the United States in the 1970s, hospice is the only form of palliative care that has its own Medicare and Medicaid benefits. Through it, care is delivered in a variety of ways in public, private, and nonprofit settings. From the model established by hospice, palliative care has grown to encompass services that address the needs of patients confronting serious illness, not only at the end of life, but at *any* stage of life. Yet palliative care also covers the wider range of issues that patients, their families, and their caregivers must confront. Apart from hospice and other forms of palliative care, changes in medical technology and medical culture over the past 30 years have significantly altered the way Americans deal with serious illness and death.

**“People know that they are eventually going to die, but I know
of no one who is interested in suffering.”**

— Foundation Research Participant

Experts watching the evolution of both palliative care and medical practice indicate that aggressive medical treatment to prolong a life often has the negative repercussion of decreasing the quality of that life. They argue that Americans have lost sight of the balance between extending life and providing for quality of life. Furthermore, they believe too few medical professionals know how to deal with seriously ill or terminal patients and their families in appropriate ways, and too few organized systems exist to support patients at such a difficult time in their lives.

Many healthcare professionals, hospices, hospitals, and other organizations recognize the growing need for models that provide palliative care to a broader group of patients and in more flexible ways. For patients of all ages with a life-limiting or chronic debilitating illness, condition, or injury, palliative care is life changing.

Standardizing and Improving Palliative Care

“Additional financial incentives have to be found to really achieve integration. Now, it [palliative care] is done mostly as a ‘customer service’ and not as part of readily offered care.”

— Foundation Research Participant

Efforts are underway to ensure that the available palliative care is of the highest quality. A group of leading palliative care organizations formed the National Consensus Project (NCP) to standardize palliative care and improve its quality. Working with professionals, providers, and consumers involved in and affected by palliative care, the NCP created the Clinical Practice Guidelines for Quality Palliative Care ⁴ to promote the philosophy of palliative care, raise awareness of the need for quality palliative care, and recommend practices. These guidelines are also applicable in primary-care practices that incorporate palliative approaches.

The context for these guidelines comes from the eight domains of palliative care ⁵ the NCP established by working with the National Quality Forum, a private nonprofit membership organization involved in developing and implementing a national strategy to improve healthcare quality. These eight domains are:

- Structure and Process of Care
- Physical Aspects of Care
- Psychosocial and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious, and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care

Palliative care is now recognized as both a general approach to patient care that should be routinely integrated in treating disease and a growing specialty for appropriately trained physicians, nurses, social workers, chaplains, and others whose expertise can contribute to optimizing the quality of life for those with life-threatening or debilitating chronic illness.

THE RESEARCH

“Our hope is that in ten years we will not need to make specific palliative care grants, simply because palliative care will be—by that time—a natural part of how health services are delivered to all.”

— Lauren Weisenfeld, The Fan Fox and Leslie R. Samuels Foundation

To help ensure that foundation support for palliative care meets the needs of the field, a group of grantmakers established the Collaborative to Advance Funding for Palliative Care (CAFPAC). They wanted to share palliative care grantmaking concepts and success stories, as well as increase collaborative efforts to advance palliative care through grantmaking. The grantmakers also sought to learn about other private foundations’ palliative care funding efforts and better understand their peers’ perceptions of this grantmaking. In addition, they wanted to identify how they might engage new funders and support those already working in the field of palliative care grantmaking.

These goals prompted CAFPAC to commission the research highlighted in this report. The research has two components:

1. Recent Grantmaking, research into the current and recent levels and specific types of grantmaking in palliative care
2. Grantmaker Perceptions, research into grantmaker perceptions of palliative care and grantmaking in the field

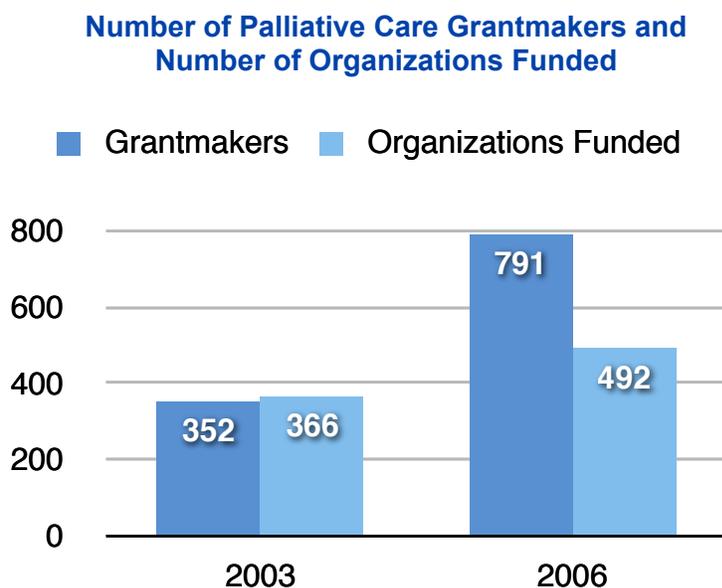
A total of 108 foundations participated in the primary research, which involved two surveys and one round of interviews. Participants represented foundations with assets ranging from \$2.2 million to \$10.3 billion and organizations identified as private foundations, independent foundations, public charities, community foundations, family foundations, corporate foundations, and operating foundations. Respondents included those who manage grant data and those directly responsible for grantmaking.

The research also incorporated Foundation Center grantmaking data for 2003–2006 to help determine foundations’ levels, types, and patterns of funding. Although the research was conducted during 2008, data for 2003–2006 was the most recent and complete available from the Foundation Center.⁶

RESEARCH FINDINGS: RECENT GRANTMAKING IN PALLIATIVE CARE

Based on the research, three major trends are evident in recent palliative care grantmaking:

1. The number of organizations funded and the number of palliative care grantmakers is growing, but palliative care continues to receive a very small percentage of the philanthropic support going to healthcare.



In 2006, 5 percent of foundations making grants in healthcare funded palliative care, an increase from 2 percent in 2003. However, palliative care grantmaking represents only around 1 percent of all 2006 foundation grants related to healthcare (Based on available statistics from the Foundation Center, which represents trends in funding).⁷

2. The number of grants made in palliative care has risen and the range of types of palliative care that are supported has grown, with hospice the primary type of palliative care that receives support. Foundation Center data on palliative care grantmaking indicate that hospices represent 65 percent of all organizations receiving funds for work in palliative care. The data also show that funds going to hospices are widely distributed in small amounts to local organizations.

Although hospice care has been and continues to be the leading beneficiary of palliative care grants, the number of grants for other types of palliative care—hospital-based programs, pediatric palliative care, and others—has also grown.

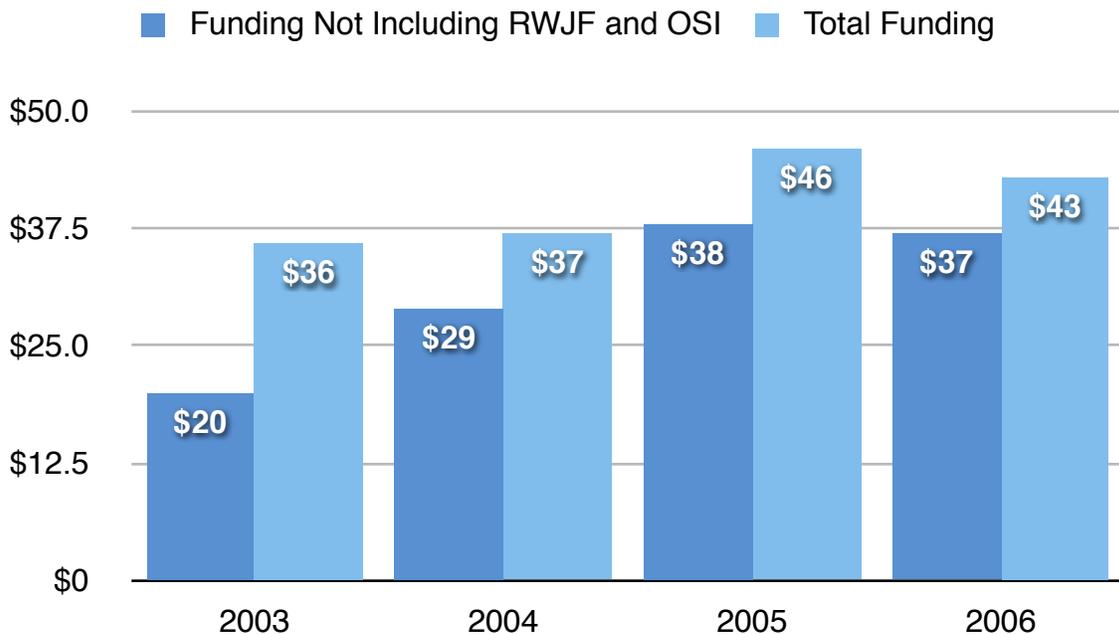
Of those participating in the research survey, 68 percent had made grants in palliative care in the past five years.

3. While the number of foundations making grants in palliative care has grown, a small number of foundations provide most of the funding in the category. The research suggests that palliative care is being funded by a wider range of foundations in terms of endowment size, grantmaking and geographic focus, and number and size of grants awarded. Their average annual giving ranged from \$675,000 to \$407 million, with palliative care receiving an average ranging from \$7,000 to \$6.7 million.

Approximately 110 funders provide 67 percent of palliative care funding. 11 out of the 29 grantmakers with assets over \$100 million that fund palliative care allocate more than 1 percent of their annual giving for this purpose. At the time this research was conducted (2008), the assets of these 29 grantmakers ranged from \$132 million to \$10 billion (2007 data).

The figure Palliative Care Funding Totals, 2003–2006, below, includes totals with and without amounts from the Robert Wood Johnson Foundation and Open Society Institute. Given the two foundations’ large grantmaking efforts, it is of interest to note growth in the field apart from their significant contributions.⁸

Palliative Care Funding Totals, 2003-2006 (in millions)



RESEARCH FINDINGS: GRANTMAKER PERCEPTIONS

Both the survey of grantmakers and the follow-up interview questions were designed to help determine what grantmakers know about palliative care. Their responses focus on their views of healthcare practices, the field of palliative care, the demand for services, and how these influence grantmaking.

Almost all of the survey participants believe there are some or a significant number of barriers to expanding the field of palliative care. Among the top reasons they gave were:

- Contemporary medicine's focus on cures
- A lack of understanding of palliative care by both healthcare professionals and the public
- Insufficient funding from public and private sources, including private foundations

Perceptions of Healthcare

Management of pain and emotional stress is widely viewed as inadequate. Many (45 percent) of the grantmakers participating in the research believe that healthcare does not fully address the pain, symptoms, and stress of serious illness. Although a large majority (66 percent) of participating grantmakers indicated healthcare for serious illness always or almost always provides care and treatment focused on a cure, only about half (49 percent) believe that it relieves pain and symptoms. Nearly two-thirds (65 percent) of the respondents believe that care for emotional stress is never or almost never provided.

“Physician education needs to emphasize that while cure of disease is a noble goal, death is natural, inevitable, and not a failure.”

— Foundation Research Participant

Training is considered an issue. The respondents expressed strong opinions about the training of healthcare professionals. Most (73 percent) felt healthcare professionals receive only some or very little training in pain and symptom management, and that this is far less than is needed.

Whether or not palliative care is provided is dependent on the setting in which care is provided. Most participants (75 percent) feel the extent to which palliative care is provided largely depends on the setting (hospital, intensive care unit, emergency room, long-term care facility, hospice, etc.).

Access to key professionals is considered limited. The majority of participants (56 percent) indicated that patients with serious illnesses almost never or never have access to psychologists or

psychotherapists. About half (45 percent) believe that patients sometimes have access to social workers, and the majority (58 percent) believes that patients sometimes or almost always have access to spiritual counselors or religious ministers. A significant number of the participants felt patients are never or almost never encouraged to contact psychologists or psychotherapists (44 percent), social workers (39 percent), spiritual counselors or religious ministers (31 percent).

Perceptions of Palliative Care

Most participants were familiar with the term palliative care. In part, the research provides a sense of how often, if ever, grantmakers hear the term “palliative care” and what they believe it involves. Results indicate that just under half (43 percent) hear the term often or very often, just over a third (37 percent) sometimes hear it, and a quarter of the participants (25 percent) never or almost never hear it.

Of the respondents, the majority (58 percent) believe palliative care is never or almost never provided at the same time as treatment meant to cure an illness or disease. The large majority (71 percent) believe palliative care should be provided at any point it is needed but especially when a terminal illness is diagnosed (62 percent) or in its final stages (51 percent); during or after a serious injury (57 percent); and when someone experiences emotional distress associated with a serious illness (48 percent).

Asked what they believe palliative care involves, almost all responded that it involves controlling pain and symptoms (98 percent), providing emotional support (82 percent), supporting family members and other caregivers (81 percent), and communicating about and coordinating care (79 percent). Asked about the relationship between palliative care and hospice, a large majority (76 percent) indicated they believe hospice is a type of palliative care.

Others’ lack of understanding is seen as limiting palliative care’s growth. Although the survey participants largely are aware of the term “palliative care” and understand what palliative care involves, they believe lack of understanding on the part of healthcare professionals (74 percent) and the public (68 percent) is a major barrier to wider provision of this type of care.

Perceptions of the Demand for Palliative Care and Grantmaking in the Field

Demand for palliative care will increase. The research participants (72 percent) believe that there will be a big or very big increase in demand for palliative care. The majority of respondents (80 percent) indicated, however, that society should work to increase palliative care. Almost half (47 percent) believe society's ability to care for those with serious illness is growing, but about one-third (28 percent) think this ability is decreasing. Almost half (46 percent) believe palliative care will likely be integrated into standard healthcare practices, and half (50 percent) consider this to be only somewhat likely or not likely.

“The public does not demand the service. People view chronic disease and death as their own personal family experience. It is not seen as a movement for better care, like childbirth has been.”

— Foundation Research Participant

Lack of funding is a barrier to the expansion of palliative care. The survey participants believe both public (68 percent) and private (48 percent) funding for palliative care is insufficient. Many respondents (44 percent) indicated that palliative care is a low or very low priority for their foundations. However, over half of the participants (51 percent) indicated palliative care is a priority. Many of the interview participants expressed a desire for leadership in palliative care grantmaking, as well as for information and connections to other funders working in the field.

RECOMMENDATIONS: ADVANCING PALLIATIVE CARE PHILANTHROPY

“We have dedicated staff—philosophically and in our budget—to do this work. We fund others where there are good partners. We do not keep our focus or willingness to partner a secret.”

— Nancy Zions, Jewish Healthcare Foundation

This research on palliative care grantmaking and perceptions of grantmakers suggests several ways private foundations can advance the field of palliative care grantmaking and help overcome the barriers to increasing the availability of high-quality palliative care services.

Encourage and Support Collaboration

- Assist other foundations by providing the access to information, connections to other funders, and leadership in palliative care funding that grantmakers say they need
- Reach out to the increased numbers of foundations supporting palliative care to encourage collaborations and strategic grantmaking
- Bring together hospice and other palliative care groups—and those advocating for this care—to address best practices, challenges, opportunities, and funding needs in the field of palliative care

Increase Resources to Inform Grantmaking

- Participate in efforts by the Foundation Center, Grantmakers In Aging, the Grant Managers Network, and foundations across the country to improve palliative care grantmaking data collection and reporting, to make it possible to better understand how individual foundations are supporting palliative care
- Share crucial information with other foundations, including strategy documents and grant recommendations related to palliative care

Demonstrate Leadership

- Advocate for palliative care grantmaking by communicating with foundations that currently fund or have indicated an interest in palliative care grantmaking
- Participate in affinity groups, develop networks, share best practices and case studies, and help establish richer resources for other foundations

Expand Understanding of Palliative Care and Grantmaking in the Field

- Fund marketing efforts to increase understanding of the term “palliative care”
- Educate foundations about the barriers to grantmaking in palliative care
- Promote understanding of the fact that palliative care can measurably improve healthcare

By advancing palliative care grantmaking and understanding of the field, private foundations can have a substantial influence on the well-being of people with serious illnesses and contribute meaningfully to improving the delivery and impact of healthcare in the United States.

VIEWS FROM THE FIELD OF PALLIATIVE CARE GRANTMAKING

Several foundations that participated in the research offered more details about their palliative care grantmaking. These foundations vary in their endowment size, geographic and grantmaking focus, and level of involvement in palliative care funding.

Representatives of the foundations described specific challenges they have sought to address, the ways they have chosen to accomplish their goals, and the results of their grantmaking. In most cases, more extensive information about this grantmaking is available at each funder's website.

It is of interest to note that their grantmaking in palliative care is considered by some of these funders to be among their most important (see Views from the Field: The Fan Fox and Leslie R. Samuels Foundation, page 28) and that it has been chosen from the broad range of possibilities—in front of other types—for creating impact through health-related grantmaking (see Views from the Field: The Regence Foundation, page 26).

The experiences of these foundations with palliative care grantmaking offer ideas and lessons for others interested in beginning or expanding their own support for the field. They showcase specific opportunities private foundations have identified to make it possible for them to have a meaningful impact on clinical care, the economics of healthcare, and the quality of life for patients and their caregivers.

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VIEWS FROM THE FIELD: ARCHSTONE FOUNDATION

Long Beach, California
Geographic Focus: California
www.archstone.org

Improving End-of-Life Care for Older Adults

The Challenge

Archstone Foundation Program Officer Elyse Salend, MSW, explains that although palliative care has made great progress, the limited number of trained and skilled palliative care professionals, particularly nurses and social workers, is a barrier to further expansion. She says another key challenge is that chaplains often are not considered members of the palliative care team; consequently, patients' spiritual needs go unaddressed. She also believes there is a need to document the quality of care and to identify metrics to measure the impact of palliative care, and notes that public policy related to palliative care needs to change as well.

“Through growing leadership and shared community learning, the foundation’s projects are working toward improving the quality of palliative care for California’s older adult population.”

— Elyse Salend, Archstone Foundation

The Foundation’s Approach

The Archstone Foundation has developed its End-of-Life Initiative to promote improved end-of-life care for all older adults in California by 1) training current and future healthcare professionals; 2) supporting high-quality palliative care and expansion of these services; and 3) promoting spiritual care at the end of life. Launched in 2006, the End-of-Life Initiative builds on the foundation’s \$4.2 million investment in palliative care from 1998 through 2005.

The Archstone Foundation subsequently has invested over \$5 million in such efforts as:

Training Healthcare Professionals The foundation has awarded 18 grants to educate and train physicians, nurses, and social workers. Most of the funding supports a five-year investment in the End-Of-Life Nursing Education Consortium (ELNEC) training program for nurses. The program uses a train-the-trainer model and will track participants over five years to understand the impact of providing palliative care in hospitals and long-term care facilities.

Palliative Care Expansion and Quality The foundation has supported developing, expanding, and improving the quality of palliative care in hospitals, initially by providing funding for five palliative care teams. Specific efforts include:

- Supporting the Palliative Care Leadership Center at the University of California, San Francisco, which is providing training and technical assistance to California hospitals seeking to develop and expand their palliative care services
- Supporting a three-year project in ten San Diego County long-term care facilities to demonstrate that training certified nursing assistants in fundamental palliative care skills helps avoid unnecessary transfers to hospitals as patients approach the end of their lives
- Contributing funds to help develop a national benchmarking tool

Promoting End-of-Life Spiritual Care The foundation supported a February 2009 national meeting of 40 thought leaders to address how to improve the quality of spiritual care as a part of palliative care.

Salend notes, “Archstone’s investments support leadership development as well as foster interdisciplinary learning communities.”

The Results

Accomplishments related to Archstone’s palliative care grantmaking to date include:

Training Healthcare Professionals The End-Of-Life Nursing Education Consortium (ELNEC) has directly trained 901 California-based critical care and geriatric care nurses in palliative care, and these nurses have collectively educated an additional 27,000 nurses at their work sites. The nurses ELNEC trained have developed a grief program in an emergency department; prompted adoption of a core palliative care curriculum in a new nursing graduate education program; and helped establish palliative care teams in seven of eight of one organization’s long-term-care facilities.

Palliative Care Expansion and Quality The foundation’s support led to five hospitals’ developing palliative care teams and/or establishing an inpatient unit, as well as to increasing palliative care referrals and consultations with palliative care teams. In a two-year period, the five hospitals served over 4,000 older adults. In addition, the hospitals improved clinical care, honored patients’ wishes more frequently, saved money, and improved their patient and family satisfaction scores. During this time, one hospital was able to leverage the Archstone Foundation’s support to obtain an additional \$3.1 million to expand its program. Another hospital received a Circle of Life citation award from the American Hospital Association in July 2009.

In addition, the foundation's palliative care pilot project at long-term care facilities in San Diego County has led to the development and testing of training modules for nursing directors and certified nursing assistants. The curriculum provides basic training in three palliative care clinical skills and teaches nurse supervisors effective methods to train and mentor certified nursing assistants.

Promoting End-of-Life Spiritual Care The convening of experts on spiritual care led to recommendations and activities to improve the quality of spiritual care at the end of life. The recommendations are published in the October 2009 issue of the *Journal of Palliative Medicine*.

Based on its experience to date, the Archstone Foundation suggests that other foundations might consider supporting the development and refinement of benchmarking tools; ongoing efforts to improve and standardize palliative care; and the development and expansion of evidence-based care and best practices for the field.

VIEWS FROM THE FIELD: CALIFORNIA HEALTHCARE FOUNDATION

Oakland, California
Geographic Focus: California
www.chcf.org

Promoting Appropriate End-of-Life Care

The Challenge

Promoting appropriate care toward the end of life is one of the California HealthCare Foundation's (CHCF) ten program objectives. A 2008 CHCF survey of service quality at California hospitals noted that these hospitals increasingly recognize the need for palliative care in acute-care settings. The study found that about 43 percent of California hospitals now offer some form of palliative care, which represents a sharp increase over the past eight years.

Despite this increase, CHCF Program Officer Kate O'Malley says a lot of work remains to be done and "identifying the highest leverage opportunities is a challenge, especially with shrinking philanthropic dollars."

“Given the diversity of people that receive services in the public hospital setting, we are focusing specifically on cultural humility as palliative care services are developed or expanded.”

— Kate O'Malley, California HealthCare Foundation

The Foundation's Approach

CHCF is supporting its goal of providing appropriate end-of-life care in three areas, the first focused on public hospitals, the second on dissemination of information about end-of-life issues, and the third on end-of-life care in nursing homes.

Public Hospitals In June 2008, the CHCF board approved a \$2.5 million grant to spread palliative care in public hospitals. The three-and-one-half-year project incorporates planning, implementation, and expansion grants.

"For sustainability, we will look at the business case in the public hospital setting. We have an external evaluation to look at how well we achieve the objectives of the project," says O'Malley.

Dissemination CHCF is also providing multi-year support for efforts to disseminate the Physician's Orders for Life Sustaining Treatment (POLST) in California. The foundation is working on this effort with a state task force and 17 community coalitions.

Nursing Home Guidelines CHCF grantees are also working with stakeholders to develop guidelines and practical approaches to improve end-of-life care in nursing homes.

The Results

Public Hospitals All of the planning and expansion grants, as well as three implementation grants, have been awarded. The goal is that two-thirds of California's 17 public hospitals will have a palliative care program by the end of the grant period.

Dissemination Extensive educational materials and programs are being used throughout the state to improve providers' skill in "having the conversation" around end-of-life choices and POLST.

Nursing Home Guidelines Once the guidelines are completed, the CHCF grantees will work with California's survey agency to ensure that state surveyors are aware of these guidelines. In addition, the impact of the guidelines on reducing hospital transfers will be tested in 90 nursing homes.

O'Malley notes, "I am fortunate to work in a foundation with a specific objective around end-of-life care, so the road is already paved for this work. This means that great grantee partnerships can be developed and sustained over a longer period. Working with other foundations is also an important strategy."

VIEWS FROM THE FIELD: HEALTHCARE FOUNDATION OF NEW JERSEY

Milburn, New Jersey

Geographic Focus: Greater Newark and Metro West, New Jersey

www.hfnj.org

Supporting Children and Families

The Challenge

Palliative care is not a core focus area for the Healthcare Foundation of New Jersey (HFNJ), but the foundation recognizes that grantmaking in palliative care can help in achieving its grantmaking goals of reducing disparities in healthcare delivery and improving service to vulnerable, underserved populations. As a result, HFNJ has dedicated more than \$1.2 million over the past few years to palliative care initiatives, providing seed funding and support for efforts focused on children and families.

“Sustainability of palliative care programs is definitely an issue.”

— Marsha Atkind, Healthcare Foundation of New Jersey

The Foundation’s Approach

HFNJ has made grants to a variety of organizations and initiatives the foundation believed would be successful in supporting the specific populations they serve and could provide replicable models. The grant recipients include:

- *Circle of Life Children’s Center*, Newark – Seed funding for a new organization that helps terminally ill children live life as fully as possible, for as long as possible, by providing comprehensive palliative care and end-of-life care
- *Palliative Care Team, Newark Beth Israel Medical Center*, Newark – Seed funding and support for the palliative care team to meet with families and set up a care plan within 48 hours of admission; educating families about their options; reducing unnecessary tests and procedures; and moving people out of the emergency room or ICU and into the palliative care unit
- *Palliative Care Suite*, Broadway House, Newark – Capital funding to establish a special suite, specialized care, and end-of-life treatment for those suffering with AIDS, and to provide support for their families
- *Trinitas Regional Medical Center*, Elizabeth – Funding for a pediatric palliative care program supporting children with HIV/AIDS

The Results

Executive Director Marsha Atkind notes that the programs funded by HFNJ face several challenges in providing palliative care, including:

- Overcoming the desire of some doctors and families to provide life-prolonging procedures that may, in fact, increase patients' suffering rather than help them
- Overcoming some doctors' resistance to "turn their patients over to palliative care" rather than control treatment themselves
- Overcoming the difficulty of coordinating care for patients who have numerous doctors and a variety of ailments

Atkind believes all of the palliative care programs the foundation has funded nonetheless have been extremely successful and represent replicable models. In particular, she points to the Circle of Life and the Newark Beth Israel programs. These, she believes, attend to families in a very timely and compassionate fashion; reduce unnecessary procedures; and move patients into palliative care sooner, thereby reducing hospital costs.

She acknowledges, however, that sustainability of palliative care programs will likely continue to be an issue without modification of reimbursement and billing procedures.

VIEWS FROM THE FIELD: JEWISH HEALTHCARE FOUNDATION

Pittsburgh, PA
Geographic Focus: Pittsburgh, PA
www.jhf.org

Prompting Discussion of End-of-Life Care

The Challenge

The Jewish Healthcare Foundation (JHF) sees a variety of challenges in addressing end-of-life care needs: a lack of understanding of the impacts on patients and families; reimbursement and other policies that work against change; and physician behaviors it considers “entrenched.”

Nancy Zions, Chief Program Officer at JHF, says grantmakers and their boards, healthcare administrators, and policymakers are also part of the general public, and their reluctance to address palliative care and end-of-life issues is much like that of the general public.

“This issue is very personal, and when you can engage people in looking at and listening to the patient experience, there is a chance to shift their views and thinking.”

— Nancy Zions, Jewish Healthcare Foundation

The Foundation’s Approach

JHF aims to address these challenges and promote change by shining a light on the issues and creating a palliative care social movement. Its current efforts focus on the following areas:

- Developing educational materials to help patients and their families understand and plan for the end of life. These materials address palliative care, hospice, advance planning, prognosis, and grief and bereavement resources
- Initiating or catalyzing community conversations about the end of life, focusing on systems surrounding the end-of-life experience
- Building community coalitions to “change the culture” around the end of life in a region where people typically don’t access the hospice and palliative care they need and are reluctant to discuss the end of life openly
- Advocating for better state and federal policies, and for systematic and financial support for quality end-of-life care by legal and medical professional organizations

As part of this effort, JHF has funded a series of discussions titled “Closure” to bring community leaders together to discuss different facets of the end of life. The six-month program draws on the expertise of leaders in medicine, nursing, law, and social services to address healthcare systems, religious, and cultural issues surrounding the end of life. The program culminates in a call to action, in which participants are asked to commit to concrete actions to improve the end-of-life experience in the region.

The Results

Zionts says, “The window of opportunity to discuss end of life publicly is opening—not wide yet, but opening. The time seems right to gear up with willing partners to set the stage for a successful social movement. To be successful we need to engage consumers at all levels and think broadly. This is a public health imperative that will impact everyone and that crosses clinical lines.” She notes that JHF’s success in palliative care grantmaking results from its commitment to and long-term presence in the field, supported by the foundation’s board. She says, “Where there was no one to move the agenda forward, we did it ourselves!”

VIEWS FROM THE FIELD: THE EMILY DAVIE AND JOSEPH S. KORNFELD FOUNDATION

New York, New York
Geographic Focus: National
www.kornfelddn.org

Enhancing Understanding of Palliative Care

The Challenge

Boby List, Executive Director of the Kornfeld Foundation, explains that the foundation's biggest challenge is the same as that of the field as a whole: getting funders, the public, and providers—especially doctors—to understand and demand palliative care. She says, “Everyone has a story about a difficult situation with a patient who may be elderly and experience a lack of physician-coordinated care that can result in aggravated and additional medical problems, or a family that is dealing with difficult medical decisions and feels abandoned in a nursing home situation where the attending physician is pushing for aggressive medical care at a point when the patient will suffer more with the care than without.”

“We value collaboration and believe that we, as a smaller foundation, can leverage our willingness to take risks with visionary thinkers, and help build leadership that will produce much larger support and results.”

— Bobye List, The Emily Davie and Joseph S. Kornfeld Foundation

These dilemmas were all too familiar to the woman the Kornfeld Foundation honors. Emily Davie Kornfeld's personal philanthropy was inspired by her own experience with chronic illness. During her lifetime, Mrs. Kornfeld supported medical research in pain control and treatment, as well as efforts to enhance individual choice in medical treatment and dying. Over the past 20 years, the foundation that bears her name has developed a medical grants program focused on three areas: amyotrophic lateral sclerosis (ALS), palliative care, and bioethics.

The Foundation's Approach

In 2005, Kornfeld made a grant of more than \$3 million to Mount Sinai School of Medicine to establish the National Palliative Care Research Center (NPCRC). The center's goal is to establish an evidence base for best practices in palliative care and to build a cadre of scholars. These scholars can then apply for larger, multi-year NIH grants to support major research that can help create, define, and have a positive impact on the field of palliative care.

NPCRC supports both pilot investigatory projects and junior faculty awards. It operates as a national research center without walls, providing grants to investigators around the nation and around the world. NPCRC research focuses on three areas: exploring the relationship of pain and other distressing symptoms with quality and quantity of life; improving communication among adults with serious illness, their families, and their health care providers; and evaluating current models and systems of care.

Referring to the importance of research, List says, “There is very impressive data for cost-savings with palliative care, and this information needs to be treated more seriously and used as a rationale for not just discussing but actually implementing active and widely recognized palliative care practices at hospitals.”

In addition to funding NPCRC, the Kornfeld Foundation has made grants to support the dissemination of information needed to establish palliative care more fully as a field, and to help coalesce funding for palliative care.

The Results

The efforts of NPCRC have been doubled by collaborating with the American Cancer Society, which has fully embraced palliative care as a focus. The American Cancer Society has created its own research grants program and structure modeled on NPCRC and now co-sponsors the annual palliative care symposium that NPCRC created.

Working with the American Cancer Society NPCRC has directed over \$5 million toward supporting 38 palliative care research projects since starting this initiative three years ago. Most significantly, three of the grantees have been awarded NIH grants. List says, “NPCRC has been more successful, more quickly than we imagined, and that is greatly due to the strong collaborative philosophy. The role of the Kornfeld Foundation has been to be very diligent in determining the funding plan and staying very involved in supporting the implementation and continuation of NPCRC.”

She concludes, “It is our hope that over the next ten years the practice of palliative care will be fully integrated into the healthcare system, such that patients and their families at their own homes, hospitals, nursing homes, and community health centers can have access to much-needed comprehensive care.”

List believes that working alone any funder can have an impact on a specific area of service, but that if palliative care is to become an essential part of medical teaching and practice in this country—and if it is to be an expected part of care—funders need to work together.

VIEWS FROM THE FIELD: THE REGENCE FOUNDATION

Portland, Oregon

Geographic Focus: Idaho, Oregon, Washington, and Utah

www.regencefoundation.org

Starting Hospital-Based Palliative Care Grantmaking

The Challenge

The Regence Foundation, which was incorporated in late 2007, started making its first grants in 2008. The foundation would like to see every person living in its four-state focus area gain access to palliative care.

“There has been a tension between wanting to be innovative and at the same time making grants that will likely lead to immediate results.”

— Michelle McClellan, The Regence Foundation

The Foundation’s Approach

The Regence Foundation first needed to establish a focused palliative care grantmaking strategy and have it approved by its staff and board. This proved challenging because the needs and opportunities in end-of-life and palliative care are enormous and diverse, and everyone brought his or her own experiences, expectations, and values to the discussion.

The foundation recognized that it had an opportunity to build on the model of Palliative Care Leadership Centers (that were established around the country by the Center to Advance Palliative Care and the Robert Wood Johnson Foundation) by taking advantage of what these centers learned about creating and maintaining high-quality palliative care programs.

The Regence Foundation decided to focus initially on hospitals—where the sickest patients seek treatment and the majority of Americans die regardless of their age or diagnosis—to achieve the greatest impact.

The Results

The Regence Foundation began accepting proposals in July 2009 under its Sojourns Pathway program, which focuses on advancing and expanding high-quality end-of-life and palliative care that meets the needs of patients and families across the care continuum. Grants are intended to support

planning, implementation, and innovation in hospital-based palliative care. Using data from the Center to Advance Palliative Care's (CAPC) hospital-based palliative care "scorecard," the foundation determined it would offer the three types of grants, because hospitals in the region are in different stages of developing palliative care programs.

The foundation plans to bring together teams from the hospitals that receive planning grants and program leaders who can provide training and mentoring. Hospitals also can apply for seed funding to implement palliative care programs, and those with existing programs can apply for funding to establish or deepen partnerships with hospice, community, and social service organizations to extend the reach of palliative care into local communities.

McClellan notes that hospital-based palliative care is likely to continue to face such challenges as workforce shortages and hospitals' ability to commit ongoing support when there are competing demands. She also advises other foundations new to palliative care grantmaking, "Palliative care is not well understood, so it's critical to be consistent in your communications with key audiences to ensure that misunderstandings are corrected and everyone is moving toward the same vision."

VIEWS FROM THE FIELD: THE FAN FOX AND LESLIE R. SAMUELS FOUNDATION

New York, NY
Geographic Focus: New York City
www.samuels.org

Supporting Cost-Effective, High-Quality Palliative Care

The Challenge

The mission of the Samuels Foundation's Healthy Aging program is to improve healthcare and the quality of life for the elderly in New York City. In focusing on the clinical component of palliative care, the foundation seeks to fund efforts consistent with a business model that considers cost savings and, to a lesser degree, the potential to generate revenue and increase service providers' capacity.

“Funding palliative care makes sense on so many levels. The people doing this work are extraordinary and are changing the culture in healthcare while being focused on what will make patients and families most comfortable.”

— Julio Urbina, The Fan Fox and Leslie R. Samuels Foundation

The Foundation's Approach

To meet its objectives, the Samuels Foundation has supported projects in three primary areas: palliative care consultation services, community and nursing home-based palliative care, and palliative care in emergency departments. Each year, the foundation typically funds five to seven projects that receive a total of \$1 million in support. The foundation's palliative care grants generally average \$200,000 and are distributed over a two-year period. The majority of the grants are for hospital-based palliative care programs.

The Samuels Foundation has supported work that uses the model created by the Center to Advance Palliative Care (CAPC) to develop and implement palliative care consultation services. In July 2009, foundation staff recommended expansion of a consultation service funded two years earlier. This expansion will create a palliative care fellowship position to help meet the growing demand for palliative care and make it possible for the grant recipient to respond to this demand while training a cohort of providers.

The foundation began funding palliative care in emergency departments more recently, believing that avoiding admission to an intensive care unit will enhance the quality of life for patients and their families. The foundation feels this can decrease expenses for each admission—although it can also decrease revenues, to a lesser degree—and help patients avoid unneeded procedures and tests. To further support this effort, in July 2009 foundation staff recommended funding the expansion of a palliative care team to provide better service to a public hospital’s emergency department. The staff also recommended funding another palliative care team expansion project for a public hospital that would increase case management and add a spiritual component.

The Results

Program Director Julio Urbina and Program Officer Lauren Weisenfeld believe their palliative care grants as a whole have been the most successful area of grantmaking for the Samuels Foundation. Weisenfeld explains, “They enhance the quality of care, reduce costs, and have shown enough cost savings for organizations to sustain them.” She emphasizes that the tools provided by CAPC have been invaluable to the foundation’s grant recipients.

Urbina and Weisenfeld note, however, that administrators can be reluctant to continue expanding palliative care after a foundation provides seed funding. They have observed that organizations will maintain the palliative care team made possible through the foundation’s grantmaking but rarely fund additional full-time employees—even when the need is evident and more cost savings can be realized. They also note that expanding palliative care programs in nursing homes continues to be difficult because the facilities often lack a financial incentive and sophisticated understanding of the role palliative care can play in this environment.

VIEWS FROM THE FIELD: HARRY G. AND CHARLOTTE H. SLATER FAMILY FUND

Milwaukee, WI
Geographic Focus: Milwaukee

Raising Awareness of Palliative Care

The Challenge

The Slater Family Fund is an advised fund of the Greater Milwaukee Foundation that describes itself as “a small fund that gives modest grants.” Marcia Slater Johnston and others at the fund consider their work successful when they raise public and foundation awareness of important issues, including palliative care. Slater Johnston notes, however, that getting grant proposals for palliative care funding is her greatest challenge. Over the past half-dozen years, the Slater Family Fund has contacted a dozen Milwaukee-area organizations in the Milwaukee area and received only two proposals.

“We've felt overall that we've gotten a good bang for our limited grantmaking bucks with both our end-of-life and palliative care grants.”

— Marcia Slater Johnston, Harry G. and Charlotte H. Slater Family Fund

The Foundation's Approach

The Slater Family Fund made grants in response to the two proposals it received to raise awareness of palliative care. The first palliative care grant supported an end-of-life lecture at the Marquette University College of Nursing. Physicians who are members of the Marquette Medical School faculty and other health professionals were invited to attend.

The second palliative care grant supported a public forum at the Milwaukee Jewish Home and Care Center (JHCC) on end-of-life care. The grant provided funds to bring an expert in end-of-life care to Milwaukee for a presentation that had two objectives: to provide information about end-of-life care and to recruit volunteers to assist terminally ill residents as a part of the Caring Partners program. A workshop for JHCC staff on end-of-life care was held the next day.

With funds from the grant, the JHCC also was able to send invitations to the program to hundreds of individuals in nearby neighborhoods.

The Results

Slater Johnston explains that the efforts the grants supported were effective in increasing awareness of palliative care. Although those invited to the lecture were not direct providers of end-of-life care, the Marquette Medical School faculty members and physicians, as well as other health professionals, could see that palliative care has stature at an academic institution—and that a foundation finds it worthy of support.

The JHCC public forum attracted 31 attendees, and several of them expressed interest in becoming Caring Partners volunteers. By promoting the forum, the JHCC also obtained coverage of its end-of-life care program in a widely-read publication for the Jewish community.

VIEWS FROM THE FIELD: ISAAC H. TUTTLE FUND

New York, NY
Geographic Focus: Manhattan, NY
www.tuttlefund.org

Enhancing Social Work Services

The Challenge

The Tuttle Fund seeks to enable older persons to continue living in their own homes as long as they are physically and mentally able to do so. Stephanie Raneri, Executive Director of the Tuttle Fund, explains that it became involved in several palliative care grants because of its desire to promote the integration of social work as a core component of in-home medical and nurse practitioner care for the elderly patients.

“We need to broaden the sector’s understanding of best practices, with regard to establishing appropriate pathways to integrate these services into a comprehensive health and social service care plan for homebound and frail clients.”

— Stephanie Raneri, The Isaac H. Tuttle Fund

The Foundation’s Approach

The Tuttle Fund has funded two palliative care programs, although it does not generally make grants in the field. It awarded its first grant in 2003, providing \$30,000 for social work services that are part of the Mount Sinai Visiting Doctors Program, which brings high-quality medical care to patients who have complex and serious illnesses but also have difficulty leaving their homes. It is the country’s largest academic primary care program for homebound patients, many of whom receive palliative care from the doctors, nurses, and social workers who come to their homes.

The Tuttle Fund also supported the Doula to Accompany and Comfort program, a nonsectarian program of New York’s Jewish Board of Family and Children’s Services that provides volunteers and professional social workers to clients nearing the end of life with only limited support from family and friends. A doula works with one person at a time to minimize the person’s sense of isolation, provide emotional comfort, assist with practical concerns, and advocate on behalf of the person with a life-limiting illness. The Tuttle Fund provided \$75,000 to the program over three years, awarding grants in 2003, 2004, and 2005.

The Results

The grant to the Mount Sinai Visiting Doctors Program enhanced the program's social work component, and the Tuttle Fund then made two subsequent grants in the amounts of \$23,000 and \$25,000 in 2004 and 2005.

Raneri says that, through this grantmaking, the Tuttle Fund has learned that palliative care should be part of the services available to patients in a visiting doctors program, along with social work. She considers it essential that hospitals sustain support for social work services as part of a comprehensive care plan for homebound patients.

PALLIATIVE CARE AND GRANTMAKING RESOURCES

This report is part of a larger effort by advocacy organizations and grantmakers to advance and support the field of palliative care and the patients it serves. The following list includes organizations and initiatives offering additional information and perspectives on palliative care and related grantmaking.

For additional information about palliative care and related grantmaking please visit the companion website to the Palliative Care Grantmaking Snapshot Report, www.FundPalCare.org. It includes an online version of the Snapshot Report, as well as an extensive listing of resources, and a Toolkit, which provides information about establishing a program in palliative care grantmaking.

Open Society Institute Project on Death in America

www.soros.org/resources/articles_publications/publications/report_20041122

The Open Society Institute's Project on Death in America issued a number of recommendations for those considering grantmaking in palliative care. These recommendations relate to how philanthropic support can improve hospital-based palliative care services and promote collaborations of hospice programs, hospitals, and academic medical centers; inform public policy that affects palliative care; support research on the science, ethics, and decision-making related to palliative care; and promote community outreach and education about death and dying, and advance-care planning. Complete details of the recommendations can be found at the Open Society Institute website.

America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals

www.capc.org/reportcard

Provided by the Center to Advance Palliative Care, this national and state-by-state report presents the most accurate estimates to date of the prevalence of hospital palliative care programs in the United States.

Center to Advance Palliative Care

www.capc.org

The Center to Advance Palliative Care (CAPC), a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness, provides healthcare professionals with the tools, training, and technical assistance they need to start and sustain successful palliative care programs in hospitals and other healthcare settings.

GetPalliativeCare.org

www.getpalliativecare.org

Provided by the Center to Advance Palliative Care, GetPalliativeCare.org offers information for people coping with serious, complex illness. Key components of the site include a palliative care directory of hospitals, a definition of palliative care, a definition of pediatric palliative care, and a detailed description of how palliative care differs from hospice care.

Grantmakers In Aging

www.GIAging.org

Grantmakers In Aging (GIA), the only international professional organization of grantmakers active in the field of aging, classifies palliative care as one of its members' focus areas. GIA has conducted issue discussion calls on the subject, featuring a palliative care expert and offering the opportunity for GIA members to ask questions and exchange information with those directly engaged in advancing the field. Palliative care is also covered in GIA's annual conference programming and is the topic of one of its Issue Briefs.

Institute of Medicine of the National Academies

www.iom.edu

The mission of the Institute of Medicine of the National Academies is “to serve as adviser to the nation to improve health. The Institute provides unbiased, evidence-based, and authoritative information and advice concerning health and science policy to policymakers, professionals, and leaders in every sector of society, and the public at large.” The Institute of Medicine website offers publications and recommendations about palliative care.

National Consensus Project for Quality Palliative Care

www.nationalconsensusproject.org

The National Consensus Project for Quality Palliative Care (NCP) works to further define and underscore the value of palliative care, and to improve the delivery of this care in the United States. The NCP seeks to heighten awareness of palliative care as a treatment option for those with a life-limiting or chronic debilitating illness, condition, or injury. It also seeks to raise public understanding of the growing need for palliative care.

National Hospice and Palliative Care Organization

www.nhpc.org

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization “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 and their loved ones.”

National Palliative Care Research Center

www.npcrc.org

The mission of the National Palliative Care Research Center (NPCRC) is to improve care for patients with serious illness and the needs of their families by promoting palliative care research. In partnership with the Center to Advance Palliative Care, the NPCRC will rapidly translate these findings into clinical practice. Specifically, the NPCRC is providing a mechanism to: establish priorities for palliative care research; develop a new generation of researchers in palliative care; and coordinate and support studies focused on improving care for patients and families living with serious illness.

Pediatric Palliative Care

www.getpalliativecare.org/whatis/4

Provided by the Center to Advance Palliative Care, this website is a good starting point to understand how palliative care is designed for children and their families as they make decisions about how best to care for a child with a life-threatening illness.

CREDITS

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SOURCES AND NOTES

¹ Of the almost \$4.4 billion made in Health Care Grants in 2006, about \$43.5 million, or less than 1 percent, were made for “palliative care,” “end-of-life,” or “hospice”. This percentage was determined by using the Foundation Center's report *Distribution of Foundation Grants by Subject Categories, circa 2006* (2008) to determine the total amount given in the field of Health Care. Please note that Foundation Center data does not represent all grant making, thus it is trends that are indicated rather than comprehensive amounts of grantmaking in any category. Since the particular areas of interest for this report – “palliative care,” “end-of-life,” and “hospice” – were not included as “subject” categories in the Foundation Center report, a separate search of the Foundation Center Grants Database was conducted to determine giving in these particular areas in 2006. That search yielded grants totaling about \$43.5 million given for “palliative care,” “end-of-life,” or “hospice.”

² The Fan Fox and Leslie R. Samuels Foundation. From grantee case studies. Unpublished.

³ Goldsmith BA, Dietrich J, Du Q, Morrison RS. Variability in access to hospital palliative care in the United States. *J Palliat Med.* 2008 Oct;11(1094-1102).

⁴ National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care.* 2009.

⁵ National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care.* 2009.

⁶ Note: The researchers used the Foundation Center's grants database, which includes 1,200 of the top grantmakers based on annual giving and 15 of the top foundations in each state, or a total of about 1,500 grantmakers. To augment the data obtained through the grants database, the researchers reviewed foundations' 990 forms (forms organizations use to report financial information to the United States Internal Revenue Service). The researchers conducted keyword searches within the grants database and studied individual 990s to find grant details and totals. The grants database can be searched for grants made in specific areas of interest; however, “palliative care” was introduced as a coding and search term only in 2008, making it necessary to also use the terms “end-of-life care” and “hospice.” Although it did not provide exhaustive information, this approach provided the most detailed information readily available.

⁷ Of the almost \$4.4 billion made in Health Care Grants in 2006, about \$43.5 million, or less than 1 percent, were made for “palliative care,” “end-of-life,” or “hospice”. This percentage was determined by using the Foundation Center's report *Distribution of Foundation Grants by Subject Categories, circa 2006* (2008) to determine the total amount given in the field of Health Care. Please note that Foundation Center data does not represent all grant making, thus it is trends that are indicated rather than comprehensive amounts of grantmaking in any category. Since the particular areas of interest for this report – “palliative care,” “end-of-life,” and “hospice” – were not included as “subject” categories in the Foundation Center report, a separate search of the Foundation Center Grants Database was conducted to determine giving in these particular areas in 2006. That search yielded grants totaling about \$43.5 million given for “palliative care,” “end-of-life,” or “hospice.”

⁸ Note: The Open Society Institute's Project on Death in America, through which it made palliative care grants in the United States, completed its grantmaking in 2003. The Robert Wood Johnson Foundation also completed its large-scale grantmaking efforts in the field in the years following 2003.