

Center to Advance Palliative Care

An RWJF national program

The Robert Wood Johnson Foundation (RWJF) established the Center to Advance Palliative Care (CAPC) in October 1999 at Mount Sinai School of Medicine in New York City to:

- Increase the number of hospitals with the capability to provide quality palliative care¹
- Create momentum to make hospital-based palliative care standard practice in comprehensive patient care
- Provide leadership in the development of standards for palliative care programs

In order to maximize the reach of CAPC and engage different kinds of hospitals, staff from CAPC and from RWJF developed a model of technical assistance delivered through six Palliative Care Leadership CentersTM (PCLC) throughout the country. Three other hospitals, not funded by RWJF, later also joined as Leadership Centers.

Authorizations by the RWJF Board of Trustees for the Center to Advance Palliative Care and related projects totaled up to \$22.2 million from October 1999 through June 2006. In July 2006, RWJF President and Chief Executive Officer Risa Lavizzo-Mourey, MD, MBA, authorized a \$5 million challenge grant to CAPC, with funds contingent upon CAPC raising \$5 million in matching funds from other sources.

¹ Palliative care is specialized care for people with serious illnesses, focused on providing patients with relief from the symptoms, pain and stress of their illness.

CONTEXT

Medical Advances Lead to a Changed Demographic Environment

Advances in public health, preventive medicine and medical technology have led to dramatic increases in the number of Americans living longer. The federal Administration on Aging estimates that the percent of Americans age 65 or older will increase from 12.4 percent in 2000 to 19 percent by 2030.²

Many people over age 65 enjoy good health and an independent lifestyle for some time. Yet, according to researchers from Mount Sinai School of Medicine, "eventually, most adults will have one or more chronic illnesses with which they will live for years before they die. These years are often characterized by physical and psychological distress, progressive functional dependence and frailty and increased needs for family and external support." About 90 million Americans are living with serious medical conditions and life-threatening illness, according to data from the Center to Advance Palliative Care. By 2020, some 157 million people will be living with at least one chronic illness.

Health Policies and Systems Are Not Equipped to Address Changing Patient Characteristics and Care Needs

The nation's health care system is not well suited to address the array of medical, social, emotional and other needs of patients living for long periods with serious but not immediately terminal conditions.

A 1997 report of the Institute of Medicine, entitled "Approaching Death: Improving Care at the End of Life," identified four deficiencies in care of people with life-threatening illnesses:

- Needless suffering, in which people live with serious pain and receive aggressive care that involves ineffectual and intrusive interventions
- Legal, organizational and economic obstacles such as flawed laws governing drug
 prescriptions, disconnected systems of care and payment systems that reimburse only
 short-term hospice care and favor medical procedures over supportive services

² "Aging Statistics" from Administration on Aging, Department of Health and Human Services. Available online.

³ Morrison RS and Meier DE. "Palliative Care." *New England Journal of Medicine*, 350: 2582–2590, 2004. The first 100 words are available online.

⁴ "Palliative Care FACTS AND STATS," Available online.

⁵ Committee on Care at the End of Life, Institute of Medicine "Approaching Death: Improving Care at the End of Life." Field MJ and Cassel CK (eds). Washington: National Academy Press, Washington, 1997. Available online.

- Shortcomings in the education and training of physicians and other providers, leaving them without the attitudes, knowledge and skills required to care well for dying patients or patients with long-term serious conditions
- Insufficient knowledge and understanding regarding what constitutes evidence-based practice at the end of life

In 2000, only 658 of the nation's approximately 5,000 hospitals had palliative care programs. See the section of this report, "Palliative Care Defined."

High-Profile Cases and Laws Prompt Public Interest and Attention

By the early 1990s, widespread debate was emerging over caring for patients at the end of their lives. Controversies arose over the roles of patient choice, medical technology, hospital and physician opinions and public policy in determining care delivered towards the end of life.

Despite this attention, only a small proportion of Americans had prepared advance directives to guide their care. Medicare financing for hospice became permanent in 1986, but relatively few people received hospice services.

Events prompting increased attention to patient rights included the 1990 Supreme Court decision in the case of Nancy Cruzan, which affirmed the right of patients to reject medical treatment and the report of Dr. Jack Kevorkian's first assisted suicide, also in 1990. The Patient Self-Determination Act of 1990 required hospitals to inform patients of their rights to make treatment choices regarding resuscitation and other life-saving technology. In 1994, Oregon residents approved the "Death with Dignity Act" that legalized physician-assisted suicide.

Diane E. Meier, MD, director of CAPC at Mount Sinai School of Medicine and a pioneer in promoting ways to improve care for seriously ill patients, has noted, "All surveys show that no one wants to die tethered to machinery. People want their pain controlled, they want to strengthen their relationships with family and loved ones, they want to reduce the burden on their families and they want to complete tasks. We may steal these opportunities with technology."

The confluence of changing demographics, availability of high-tech interventions and emerging patient rights created a perfect storm surrounding medical care for very ill patients and a unique opportunity to introduce changes.

⁶ Meier was quoted by Ethan Bronner in a chapter entitled "The Foundation's End-of-Life Programs: Changing the American Way of Death," In the Robert Wood Johnson Foundation Anthology: *To Improve Health and Health Care, Volume VI*, Isaacs SL and Knickman JR (eds). San Francisco: Jossey-Bass, 2003. Chapter is available online.

RWJF's Interest in This Area

RWJF has a long and deep involvement in end-of-life care: between 1977 and 2011, the Foundation issued 485 grants and invested more than \$212 million in this area.

SUPPORT: The First Investment

RWJF's first major investment in end-of-life care was its \$29 million, five-year program SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment). SUPPORT was the largest study of dying ever undertaken in America; it began in 1985.

Since more than half of Americans died in hospitals, hospitals were an important focus for end-of-life efforts. During the first phase of SUPPORT, from 1985 to 1991, researchers interviewed 4,301 critically ill patients in five hospitals, their families and the staff who cared for them. Phase I yielded high-quality data and valid models to predict survival time and functional disability, the first data and models of their kind.

After analyzing the interviews, researchers reported "Decision making was often far short of ideal. Physicians did not know what patients wanted with regard to resuscitation.... Orders against resuscitation were written in the last few days of life. Most patients who died in the hospital spent most of their last days on ventilators in intensive care. We had not expected to find the high levels of pain that were reported, especially in noncancer illnesses."

RWJF funded a second phase of SUPPORT in an attempt to address these problems. During Phase II, from 1991 to 1994, 2,652 critically ill patients in the five hospitals received an intervention that included intensive counseling for patients and families, frequent meetings with physicians, elicitations of preferences, planning for contingencies and providing the care team with the best information about prognosis and preferences. The team compared patient outcomes with outcomes of a similar number of patients in similar circumstances at the same hospitals who did not receive the intervention.

In November 1995, SUPPORT researchers reported that the intervention had "no effects" on reducing the problems identified during Phase I.⁸ "Hospital bed supply alone is a stronger explanation than all the demographic and physiologic information put together" for whether a person died in a hospital.⁹

⁷ Lynn J. "Unexpected Returns: Insights from SUPPORT," In *To Improve Health and Health Care*, Isaacs SL and Knickman JR (eds). San Francisco: Jossey-Bass, 1997 (p.4). Available online.

⁸ Ibid. (See "Unexpected Returns: Insights from SUPPORT" for more information about SUPPORT.)

⁹ Ibid. p. 172.

Leveraging SUPPORT Findings

Although surprised by the SUPPORT findings, RWJF staff was determined to use the disappointing results to mobilize families, health care professionals, funders, policy-makers and others to address the needs of dying people. The Foundation mounted a major media campaign featuring SUPPORT findings, followed by a number of projects and programs funded over many years.

RWJF's programs fall into three strategies:

- Train nurses, doctors and other health professionals to deliver better end-of-life care. Projects under this strategy include:
 - A grant to the National Board of Medical Examiners to add questions about endof-life to medical licensing examinations¹⁰ (see Program Results Report)
 - Five grants to the Medical College of Wisconsin to train faculty in how to incorporate end-of-life content into their curricula¹¹ (see Program Results Report)
 - A grant to the American Board of Hospice and Palliative Medicine to implement accreditation for fellowship training programs¹² (see Program Results Report)
 - End-of-Life Nursing Education Consortium, a national education initiative that
 provides training about palliative care to undergraduate and graduate nursing
 faculty, continuing education providers, staff development educators, specialty
 nurses in pediatrics, oncology, critical care, geriatrics and other nurses.
- Educate and empower the public, including building public awareness. Projects include:
 - Last Acts: A Vision for Better Care at the End of Life, a communications campaign to improve end-of-life care through coalitions of professional and consumer organizations. More than 800 coalitions participated (see Program Results Report)
 - Community-State Partnerships to Improve End-of-Life Care, a national program in which 21 states received grants to promote policy change (see Program Results Report)
 - Development of the "Five Wishes" easy advance directive that promoted dialogue on end-of-life care, by the Florida Commission on Aging with Dignity (see Program Results Report)

¹⁰ ID# 33887.

¹¹ ID#s 32598, 36669, 41481, 44826, 46547.

¹² ID# 39835.

- "On Our Own Terms: Moyers on Dying," a four-part PBS TV program on the cultural, medical, ethical and spiritual aspects of death and dying¹³ (see Program Results Report)
- Make high quality end-of-life care available in health care institutions. Projects include:
 - Promoting Excellence in End-of-Life Care, a national program supporting
 innovative models of palliative and hospice care for people and in settings where
 they were underutilized or unavailable and to support initiatives to provide quality
 palliative care earlier in the course of illness, concurrent with life-extending care
 (see Program Results Report)
 - Pursuing Perfection: Raising the Bar for Health Care Performance, a national program that supported efforts by seven health care organizations to improve their care processes and patient outcomes. Its purpose was to both improve the performance of the participating institutions and to demonstrate to the broader provider community that ideal care is attainable (see Program Results Report).

For more information on RWJF's funding in this area see:

- Retrospective Series report, *Improving Care at the End of Life*¹⁴
- End-of-Life & Palliative Care section of RWJF's website
- RWJF Anthology chapter entitled "The Foundation's *End-of-Life* Programs: Changing the American Way of Death"

THE PROGRAM

RWJF established the Center to Advance Palliative Care (CAPC), originally called the National Resource Center for Palliative Care, in October 1999 to:

- Increase the number of hospitals with the capability to provide quality palliative care
- Create momentum to make hospital-based palliative care standard practice in comprehensive patient care
- Provide leadership in the development of standards for palliative care programs

Funding

The RWJF Board of Trustees authorized CAPC in October 1999. Total authorizations for CAPC and related projects were \$22.2 million through June 2006.

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¹³ ID# 38858.

¹⁴ Patrizi P, Thompson E and Spector A. *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field*, Princeton, NJ: Robert Wood Johnson Foundation, March 2011. Available online.

In July 2006, RWJF President and Chief Executive Officer Risa Lavizzo-Mourey, MD, MBA, authorized a \$5 million challenge grant to CAPC, with funds contingent upon CAPCE securing matching funds from other sources. According to Lavizzo-Mourey, "The goal was to stimulate investments in the center and in the field as a whole. We wanted to encourage new investments that would provide not only money, but would also support the work of an ambassador who could describe this new field and advocate for it."

CAPC more than met the challenge, raising \$19,275,000 from several private foundations, the American Cancer Society and the U.S. Department of Veterans Affairs.

One of the earliest and closest partners with RWJF was the New York-based Open Society Foundations' Project on Death in America. Project Director Kathleen Foley, MD, credits the first SUPPORT study as part of the rationale for the Open Society Foundations' nine-year multimillion dollar project.

The Open Society Foundations provided fellowships to emerging leaders in end-of-life care, an effective complement to RWJF investments in the substantive components of end-of-life care services.

See Appendix 1 for a list of other funders of CAPC.

Palliative Care Defined

CAPC defines palliative care as follows: 15

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and is available together with curative treatment.

Program Design

According to Rosemary Gibson, RWJF program officer for CAPC and most of RWJFs programmatic work on end-of-life care, "We designed the program based on extensive discussions with physicians who were working on end-of-life care in their hospitals. These doctors were getting requests from colleagues across the country who wanted to learn what they were doing. We responded to nascent demands emerging from doctors

¹⁵ 2011 Public Opinion Research on Palliative Care. New York: Center to Advance Palliative Care, 2011, p. 8. Available online.

and hospitals about how to develop palliative care. CAPC was a culmination of RWJF's strategy on end-of-life care. The few physicians who were providing this care were showing us what we needed to do."

RWJF's overarching strategy was to identify hospitals that were early adopters of palliative care, create a critical mass of palliative care programs and communicate the message to influential audiences. To do this, RWJF authorized the establishment of CAPC, which this report addresses.

The authorization also included funding to assist organizations such as the American Hospital Association and the U.S. Veterans Health Administration to build palliative care capability among their members and also to support the establishment of palliative care capability in other settings. Those projects took place in collaboration with CAPC staff. This report does not address their results.

A Productive Synergy

Eleven months after CAPC was authorized, in September 2000, PBS aired a series called "On Our Own Terms: Moyers on Dying," also funded by RWJF. 16 "This turned out to be an incredibly important driver of CAPC's work," remembers Gibson. "Richard Davidson, head of the American Hospital Association, sent a letter to every hospital telling them about the airing of the program *and* that if they wanted to do what was featured in the documentary—that is, make palliative care available—they should contact CAPC as a resource to set up a palliative care program. As I recall, CAPC received requests from nearly 20 percent of U.S. hospitals."

Management

To house CAPC and guide its development, RWJF selected Mount Sinai School of Medicine in New York City, where Christine K. Cassel, MD and Diane E. Meier, MD, both regarded as leaders in the field of palliative care, ran a well-respected palliative care center. Moreover, Meier had been in the first cohort (1995) of the Open Society Project on Death in America fellows and had established Mount Sinai's clinical palliative care program in 1997. According to Gibson, "We went to Mount Sinai because of Christine and Diane."

¹⁶ For more information on the program, see Program Results Report.

National Program Office

Cassel and Meier, working closely with RWJF staff, created CAPC in November 1999. Cassel left Mount Sinai in 2002.¹⁷ Carol Sieger, JD, is deputy director of CAPC and Lisa Morgan is its communications director.

Expert Consultants

RWJF's Gibson realized that CAPC would need outside expertise to complement Cassel's and Meier's clinical background as geriatricians. Meier recalls, "Rosemary is a strategic thinker. She told me to make a substantial investment in social marketing. The other thing she encouraged me to do was to hire and retain someone who understood how to make the business case for palliative care."

Meier recruited three expert consultants for her management team:

- James A. Block, MD, a Baltimore-based health care consultant and a strong advocate for the development of palliative care in the United States. Block brought with him understanding of and access to leading health care clinicians and the associations that represent them. Block is a former president and chief executive officer of Johns Hopkins Health Care System and the Johns Hopkins Hospital.
- Lynn Hill Spragens, MBA, a Durham, North Carolina-based consultant with extensive experience on the business side of health care. Before beginning her work as a consultant in 1998, Spragens held senior business positions at Kaiser Permanente in North Carolina.
- Sharyn Sutton, PhD, a Washington-based consultant with a track record in marketing social interventions, including some related to end-of-life care. Sutton also conducted focus groups of physicians for the 1996 RWJF-funded project "Education for Physicians on End-of-Life Care."

Program Strategy Emerges

Meier credited a presentation by Sutton for prompting a fundamental shift in program strategy. By asking three questions, Sutton identified both a challenge and a potential for palliative care in the understanding of its market:

- Who was interested in palliative care?
- What motivated that interest?
- What would prompt more people to provide palliative care?

Therefore, rather than focusing on the inherent good in providing care, Meier began to invest in learning what was important to hospital physicians, patients and families.

¹⁷ As of 2011, Cassel is president and chief executive officer of the American Board of Internal Medicine.

"We started out with an end-of-life framework," she says. "Almost by definition, that put us into a model of offering *either* care aimed at curing illness *or* care aimed at providing comfort during the last days of life. The patients we were seeing were not in that place. They were appropriately pursuing life-prolonging care, but they were also in great pain. The real need was for 'upstream' palliative care to be delivered along with curative care.

"We realized that the more we focused on end-of-life care, the more we were driving away the people we wanted to reach. If our goal is to see that the most seriously ill people get the best palliative care, identifying our services with dying does not work. Most patients, their family members and their physicians don't see their conditions that way."

This insight framed CAPC's mission and drove its work. In its writings, technical assistance, conference presentations and public opinion efforts, staff and consultants:

- Distinguished palliative care from hospice and end-of-life care, thus expanding its target population and making it more acceptable to patients, families and doctors
- Promoted palliative care centers as a benefit to physicians who were overwhelmed by distraught family members or who needed pain management expertise, or both
- Provided marketing, business modeling and financial expertise needed to make a business case to hospital leadership that demonstrated the value of palliative care

According to Patricia Patrizi, a consultant to RWJF who prepared a retrospective analysis¹⁸ of the Foundation's role in creating the field of palliative care, "This understanding evolved into a substantial reframing of the problem and CAPC's evolution. It may also be one of the most significant strategy shifts in this work and instrumental to what has become CAPC's enduring success."

Guided by this perspective, CAPC staff and consultants undertook a variety of activities to promote palliative care.

Key Program Activities

Palliative Care Leadership Centers (PCLC)

RWJF wanted to maximize CAPC's reach and to engage different kinds of hospitals. According to Gibson, "We knew that we needed to be in different parts of the country and should not restrict ourselves to academic medical centers. We had to reflect the differences in hospitals across the country. Also, with a decentralized approach, we could create an infrastructure that would endure." To do that, says Meier, "We developed a model in which our center would create a system of technical assistance to be delivered through the Palliative Care Leadership Centers."

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¹⁸ Patrizi P, op. cit.

The Centers

In 2003, CAPC selected promising leaders in hospital-based palliative care programs and provided them with resources to build the capacity of other hospitals to create their own programs. Six institutions received grants of about \$750,000 each for three years:

- Fairview Health Services, Minneapolis.¹⁹ The PCLC provides guidance in using the
 consult team care model and in providing services in hospitals without a dedicated
 palliative care unit.
- Massey Cancer Center of Virginia Commonwealth University, Richmond.²⁰ The PCLC particularly provides assistance to academic medical centers, cancer centers and hospitals serving low-income and medically underserved people.
- Medical College of Wisconsin.²¹ As of April 2010, the Medical College was no longer an active PCLC.
- Mount Carmel Health System, Columbus, Ohio. ²² The PCLC grew out of a hospice-hospital partnership. It offers expertise in promoting collaborations among palliative care, hospice services and long-term-care facilities.
- Palliative Care Center of the Bluegrass, Lexington, Ky.²³ The program of this PCLC is especially relevant for hospitals with community partners, hospice programs, home or community-based long-term care agencies and rural hospitals in general.
- University of California, San Francisco.²⁴ The PCLC provides assistance that is
 particularly helpful to university- and community-based medical centers and
 hospitalist programs.

See Appendix 2 for grant and contact information for the Palliative Care Leadership Centers.

Within three months of announcing the formation of the Leadership Centers, some 200 institutions were on a waiting list to participate.

¹⁹ Fairview Health Services is a nonprofit, academic health system that works in partnership with the University of Minnesota and provides a wide spectrum of health care services (ID# 049043).

²⁰ VCU Massey Cancer Center is a nonprofit organization within Virginia Commonwealth University. It is one of the two cancer centers in Virginia designated by the National Cancer Institute (ID# 049037).

²¹ At the Medical College of Wisconsin, established in 1893, more than 1,700 physicians and other health practitioners provide adult and pediatric care to more than 400,000 patients each year (ID #049036).

²² Mount Carmel is a community hospital with 8,000 employees and 1,500 physicians who provide a range of health care services throughout central Ohio (ID# 049044).

²³ Palliative Care Center of the Bluegrass is a subsidiary of Hospice of the Bluegrass, which serves more than 1,000 Kentucky patients every day (ID# 049040).

²⁴ The University of California, San Francisco, dedicated exclusively to the health sciences, promotes health through biomedical research, graduate-level education and patient care (ID# 049043).

In 2008, CAPC added three Palliative Care Leadership Centers, not funded by RWJF. These Leadership Centers are supported by tuition from visiting hospital teams and from funds secured from other sources.

- Akron Children's Hospital, Ohio. ²⁵ The PCLC assists academic and freestanding pediatric, community, or rural hospitals; hospitals considering educational initiatives such as fellowships; and others.
- Children's Hospitals and Clinics of Minnesota, St. Paul-Minneapolis. ²⁶ This PCLC program is especially relevant for hospitals wanting to develop or grow their pediatric palliative care programs and those wanting to develop relationships beyond the hospital.
- University of Alabama at Birmingham.²⁷ The PCLC is the only one located in the Deep South. Hospitals experiencing institutional barriers to palliative care or needing to build the case for care within the institution and the community find the program here to be a good model.

Services Provided by the Leadership Centers

The Leadership Centers:

- Host two-day site visits from interdisciplinary teams from other hospitals interested in building or improving their palliative care programs
- Provide structured training during the site visits in topics such as organization, finance and business planning; hospital-hospice partnerships; staffing; and tracking systems
- Provide distance mentoring to visitors for one year
- Follow-up on planning, implementation and long-term management of palliative care programs attending the site visits

CAPC staff, consultants and staff from the Leadership Centers created an eight-module curriculum covering topics such as marketing, finance and management. The curriculum includes tools, worksheets, a "Site Visitor Workbook," and lesson plans to guide Leadership Center staff in delivering the curriculum.

Hospitals interested in establishing or growing their palliative care capacity form teams and apply to CAPC for a visit to a Leadership Center. Teams include, for example, a senior administrator, physician, nurse, social worker and finance person. The teams

²⁵ Akron Children's Hospital provides care to infants, children, burn victims of all ages and adults with congenital, genetic and maternal/fetal conditions.

²⁶ Children's Hospitals and Clinics of Minnesota is an independent nonprofit health care system, with more than 12,000 inpatient visits and more than 200,000 emergency room and outpatient visits each year.

²⁷ The University of Alabama at Birmingham is a research university and medical center.

choose the Leadership Center they prefer, often based on hospital type (for example, faith based hospitals tend to visit Mount Carmel Health System and cancer centers tend to visit Virginia Commonwealth University), geographic proximity, or specialization. They pay a fee to attend.

Before the site visit, teams complete a pre-training questionnaire that requires them to gather finance, utilization and administrative data to analyze during the visit. Site visits include presentations from Leadership Center staff, small group sessions that guide the team through the steps involved in creating a palliative care program and walk-throughs of the host institution's palliative care program. They leave the visit with an action plan to be executed when they return home.

Leadership Center staff convenes follow-up telephone mentoring sessions for one year after the visit. As the Leadership Centers evolved, some began "reverse site visits" in which Leadership Center staff visit the hospital team to help them on their home turf.

Leadership Center directors describe their work with the client hospitals:

- According to Lori Yosick, MSW, executive director of the Mount Carmel Health System PCLC, "We had been providing palliative care as a result of our hospice work. We were getting requests from other hospitals that wanted to come here for training but we needed support to accommodate them. CAPC was getting started at about this time and we became a Leadership Center."
 - Yosick's colleague Sharol Herr, MSEd, says, "We are now doing more custom training than we did initially. For example, we had a group come for a second site visit. They came originally for our core curriculum but wanted additional consultation to address some specific needs. So, they spent a full day with our clinical team."
- Sarah Friebert, MD, Akron Children's Hospital PCLC director and a pediatric
 oncologist/hematologist, notes the importance of having a Leadership Center with a
 pediatric focus. She says "When we joined the Leadership Centers, we rewrote the
 CAPC pediatric curriculum for ourselves and we have updated it twice since. CAPC
 has supported us in creating a pediatric track at its national seminars."
- Christine Ritchie, MD, director of the University of Alabama at Birmingham
 Palliative Care Leadership Center says, "Before I came to the university, a team from
 here received training from the Virginia Commonwealth Palliative Care Leadership
 Center. That training helped our program grow quickly. We were a seed that became
 a plant."

National Consensus Project on Quality Palliative Care

At the time the Center to Advance Palliative Care began its work, palliative care was a poorly understood concept, lacking measures of quality and standards of practice commonly found in medical specialties.

In December 2001, Meier organized a meeting of palliative care leaders to begin to develop definitions, essential elements and best practices for palliative care. This meeting led to the National Consensus Project on Quality Palliative Care: Essential Elements and Best Practices. A 19-person Steering Committee drafted standards, raised money to support the work and oversaw a consortium of five palliative care organizations²⁸ that disseminated draft consensus documents to their members for review and feedback.²⁹ Subsequent to release of the National Consensus Project (NCP) Guidelines, RWJF supported development of the National Quality Forum's *Framework and Preferred Practices for Quality Hospice and Palliative Care*, published in 2007. This document built directly on the NCP Guidelines—with the added imprimatur of the forum, known as NQF.

Building on these accomplishments and based on several years of CAPC advocacy, The Joint Commission for Accreditation of Healthcare Organizations (JCAHO, now called the Joint Commission³⁰) agreed to establish and release a quality certification mechanism for hospitals with established palliative care programs. The criteria for certification are directly from the NCP Guidelines and the NQF Framework and their existence was prerequisite to the Joint Commission's decision to develop the certification process.

The Advanced Palliative Care Certification (released in September 2011) has received more response and attention than any prior Joint Commission certificate (such as for heart failure and stroke). The first five awardees were announced in February 2012.³¹

LiveSTRONG, of the Lance Armstrong Foundation, released a call for proposals (CFP) to provide financial and technical assistance support to cancer centers within hospitals interested in pursuing certification. Again, the response to this CFP exceeded all prior LiveSTRONG initiatives. CAPC's goal is to leverage the high response to the certification program into a case for requiring palliative care teams to meet the certification guidelines as a condition of hospital accreditation. ³²

²⁸ American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership, National Hospice and Palliative Care Organization.

²⁹ The Washington-based Partnership for Caring housed The National Consensus Project shortly after it started. In 2007, the project became a formal subcommittee of the Hospice and Palliative Care Coalition. The Hospice and Palliative Nurses Association is its administrative home.

³⁰ The Joint Commission regulates the quality, structures and processes of most hospitals in the United States.

³¹ The hospitals receiving the award were Regions Hospital in St. Paul, Minn.; Strong Memorial Hospital in Rochester, N.Y.; Mt. Sinai Medical Center in New York City; St. Joseph Mercy Oakland in Pontiac, Mich.; and the Connecticut Hospice in Branford, Conn.

³² Consultant Block introduced Meier to key Joint Commission leadership and staff. His experience and credibility with health care leaders was essential both in helping consortium members come to consensus and in moving the certification process along.

Making the Business Case for Palliative Care

CAPC's management team realized that, in order for palliative care to expand and take hold in hospitals, hospital administrators and finance directors would have to see its effects on their bottom line. Under Spragens' leadership, staff at CAPC researched models and outcomes of hospital-based palliative care in different clinical settings.

CAPC staff and consultants also analyzed administrative data for 2002 through 2004 from eight hospitals with established palliative care programs to better understand the effect of palliative care teams on hospital costs. In an article published in the *Archives of Internal Medicine* in 2008, they concluded, "Hospital palliative care consultation teams are associated with significant hospital cost savings." ³³

Spragens developed several financial and strategic planning tools (available online, with email sign up), including templates and sample business plans, to guide hospital administrators in analyzing the business aspects of palliative care programs within their institutions.

Spragens, Meier and Sutton marketed both the business case strategy and the specific tools at CAPC meetings, with the Leadership Centers and in journal articles.^{34,35}

Support for Hospitals

In addition to the work of the Leadership Centers, CAPC supports hospitals in planning, developing, operating and evaluating palliative care programs through a wide range of activities and products.

National Seminars

From 2002 through 2011, CAPC convened 20 national meetings that addressed planning, funding, building and sustaining palliative care programs. Information about the upcoming 2012 seminar is featured on the CAPC website. CAPC does not publish the seminar proceedings.

³³ Morrison RS, Penrod JD, Cassel B, Caust-Ellenbogen M, Litke A, Spragens L and Meier DE for the Palliative Care Leadership Centers' Outcomes Group. "Cost Savings Associated With U.S. Hospital Palliative Care Consultation Programs." *Archives of Internal Medicine*, 167 (16):1783–1790, 2008. Available online.

³⁴ Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J and Meier DE. "Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries." *Health Affairs*, 30(3): 454–463, 2011. Available with subscription online.

³⁵ Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L and Meier DE. "Cost Savings Associated With U.S. Hospital Palliative Care Consultation Programs." *Archives of Internal Medicine*, 168(16): 1783–1790, 2008. Available online.

Audio Grand Rounds

CAPC hosts a monthly "Palliative Care Grand Rounds" series, during which registered callers listen to leaders in the field of palliative care present on management, operational and clinical issues. Topics include billing for palliative care, the role of nurses and data collection.

The center has hosted 88 audio grand round conferences between 2001 and March 2012, with 39,447 participants. CAPC Audio Conferences on the website provides information on registering for upcoming grand round conferences. A complete list of past audio conference offerings available for purchase is also available at the CAPC website.

Tools and Guides

In addition to financial and strategic planning tools to support the business case for palliative care, Center staff has produced several tools to help hospital staff design and manage their palliative care programs. The tools offer templates that can be adapted to the circumstances of each hospital and address clinical, measurement, billing and marketing needs. Sign up on the CAPC website for access to all tools (many of which are available at no cost) and to receive news about the palliative care field.

Among the publications are two palliative care primers by CAPC staff and consultants that take health care professionals through the steps involved in establishing a palliative care program:

- "The Case for Hospital Palliative Care" helps professionals demonstrate the rationale for establishing a successful, lasting program.
- "The Guide to Building a Hospital-Based Palliative Care Program" features sample forms, policies and procedures that palliative care professionals can adapt to their hospital. The guide can be purchased from the CAPC website.

Partnerships

CAPC has promoted the development of partnerships between hospitals and hospice programs in order to ensure that patients and families would receive a continuum of palliative and hospice care throughout their illness. CAPC's Web page "Palliative Care and Hospice Care Across the Continuum" includes articles, reports and guides that address collaboration and partnerships in several settings, including intensive care, long-term care and pediatrics.

In cooperation with the National Hospice and Palliative Care Organization, the center published a monograph in December 2001 entitled *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service.*³⁶

³⁶ The monograph is available online.

IPAL Project

The center established the IPAL (Improving Palliative Care) Project as a venue for sharing expertise, tools and resources to advance palliative care in specific components of the health care system. For each component, the IPAL process involves convening an oversight board, preparing a catalog of most-needed resources, identifying existing tools and resources, developing new peer-reviewed tools and updating the tools as new ones are available. Two IPAL projects have been created and one is underway:

- IPAL-ICU: Improving Palliative Care in the ICU launched 2010
- IPAL-EM: Improving Palliative Care in Emergency Medicine launched 2011
- IPAL-Outpatient Clinics under development as of January 2012, launch fall 2012

Information about the IPAL projects is available online.

Systems to Track Progress

State Report Card. CAPC researchers examined variation in access to palliative care state-by-state. They published findings in a "report card" in 2008, which they updated in 2011. In the 2011 report, "America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," CAPC gave eight jurisdictions an "A" grade (at least 81% of hospitals had palliative care programs): District of Columbia, Maryland, Minnesota, Nebraska, Oregon, Rhode Island, Vermont and Washington.

They mailed copies of the report card to all members of Congress and took out a full-page advertisement in *Politico*, congratulating the states that received an 'A.'

The report card is available online.

Palliative Care Registry. The National Palliative Care RegistryTM, launched in 2008, is a repository for national data on the structures and processes of hospital palliative care programs. Its goals are to help palliative care programs track their development and to standardize palliative care structures and processes.

Hospitals are asked to enter operational data annually. Participating hospitals will have access to Palliative Care COMPARE, a Web-based system allowing them to compare their operational data to aggregate data of other programs. (COMPARE will launch in 2012). As of December, 2011, 893 palliative care programs had registered.

Hospitals can register and access their registered information online.

CAPC Website

CAPC's website (*www.capc.org*) receives about 275,000 visits per year. It is a central vehicle for providing technical assistance and for engaging clinicians, researchers and the general public. The website houses the National Palliative Care Registry, tools and guidebooks, the IPAL Project, State Report Cards and several publications. It also includes access to the Palliative Care Leadership Centers, audio grand rounds and seminars.

In addition, visitors to the website can take courses online or join an online forum:

- CAPCconnect[™] Forum, a free resource for health professionals to share information, exchange ideas and receive advice about operating their palliative care programs.
 More than 3,493 people registered with the forum as of April 2012.
- CAPC Campus Online[™], an e-learning program offering courses about structural, operational and financial aspects of palliative care programs. The courses have been approved for continuing medical education and continuing education credits. Some 1,179 people have enrolled in 11 e-learning courses as of April 2012.

The center provides an affiliated website, "GetPalliativeCare.org," directed toward consumers of palliative care. It includes a directory of hospitals and an interactive questionnaire to help visitors to the site determine whether palliative care is appropriate for them. GetPalliativeCare.org receives an average of 215,000 visits per year.

OVERALL PROGRAM RESULTS

Increases in Palliative Care Programs

CAPC has been a key factor influencing significant increases in the number of hospital-based palliative care programs:

- By 2009, more than 1,568 hospitals had palliative care programs, a 138 percent increase from the 658 programs in 2000.
- Since 2004, the Palliative Care Leadership Centers trained 1,095 teams from hospitals interested in establishing or improving palliative care programs, including 171 palliative care teams from VA hospitals. The Leadership Centers continued providing services via tuition and other funds, after RWJF funds ended.
 - Some 67 percent of teams that were trained had established programs at their home institutions 12 months after training and 80 percent had programs 24 months after training.
 - The Leadership Centers each trained between 80 and 111 teams, from 20 to 30 states.

Newly established palliative care programs grew rapidly. Within two years of startup, these new programs were receiving referrals at the same rate that mature programs had achieved five years earlier, about 2 percent of overall hospital admissions.
 Leading programs were close to reaching 4 to 6 percent of hospital admissions, or double to triple the national rate.

In reflecting on the successes of the Leadership Centers, Meier notes, "We wanted to grow leaders. We chose the Leadership Centers based on their track record in leadership and asked them to continue leading using what we believed was a powerful tool—peer-to-peer mentoring. This is an apprenticeship model—the old model of training."

Recognition and Awards

- In September 2006, the American Board of Medical Specialties approved Hospice and Palliative Medicine as a sub-specialty of 10 specialty boards: Anesthesiology, Emergency Medicine, Family Medicine, Internal Medicine, Obstetrics and Gynecology, Pediatrics, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Radiology and Surgery. As of August 2011, 2,995 physicians had received this certification.
- The National Quality Forum, the nation's leading organization focused on taking pragmatic action to ensure access to quality care, endorsed a framework and preferred practices for palliative and hospice care. In December 2006, NQF published *A National Framework and Preferred Practices for Palliative and Hospice Care Quality* A National Framework and Preferred Practices for Palliative and Hospice Care Quality, ³⁷ a report putting forward the consensus standards.
- In September 2011, the Joint Commission launched its Palliative Care Advanced Certification Program. ³⁸ Through its accreditation authority, decisions of the Joint Commission have important influences on the priorities of hospitals. CAPC created an online technical assistance tool to facilitate hospitals' participation in the certification program.
- Insurers, including at least five states' (Hawaii, Michigan, New York, Pennsylvania and South Carolina), Blue Cross Blue Shield affiliates, included palliative care initiatives in their pay-for-performance or benefit options.
- Meier was one of 25 people selected for the 2008 MacArthur Fellowship. ³⁹ The MacArthur Fellowship provides \$500,000 "no strings attached" awards to people chosen for their "creativity, originality and potential to make important contributions in the future."

³⁷ National Quality Forum, "A National Framework and Preferred Practices for Palliative and Hospice Care Quality." NQF: Washington, 2006. Available online.

³⁸ Advanced Certification for Palliative Care Programs. Available online.

³⁹ Details about the MacArthur Fellows Program are available online.

• Meier was awarded a one-year Health and Aging Policy Fellowship⁴⁰ in 2009. The fellowship program is funded by the Atlantic Philanthropies and administered by Columbia University. Meier's fellowship placement involved stints on the U.S. Senate Committee on Health, Education, Labor and Pensions and at the Office of the Health and Human Services Assistant Secretary for Planning and Evaluation.

Research

- CAPC worked closely with the National Palliative Care Research Center, established by Sean Morrison, MD, at Mount Sinai School of Medicine, to translate research into practical technical assistance aimed at improving palliative care. The research center funds projects in the following categories:
 - Pilot and Exploratory Projects
 - Junior Faculty Career Development Awards
 - Infrastructure Support for Collaborative Studies
 - Support for Research Design and for Statistical Analyses

Publications

Many CAPC endeavors resulted in written products for practitioners, researchers and policy-makers. Staff and consultants wrote several book chapters and articles published in peer-reviewed journals including the *Journal of Palliative Medicine*, *Health Affairs and* the *New England Journal of Medicine*.

CAPC reports include, among others:

- Improving Palliative Care in Nursing Homes
- Policies and Tools for Hospital Palliative Care Programs: A Crosswalk of National Quality Forum Preferred Practice
- Top Tools for Palliative Care Programs: A CAPC Toolkit. Sign up for tools online.

See the Bibliography for more information about publications. Virtually all CAPC publications are available on the CAPC website.

SIGNIFICANCE OF THE PROGRAM

In 2000, when CAPC began operating, palliative care in the United States was, at best, a poorly defined, amorphous concept. It lacked standards of care, consensus on best practices and specialty status within the medical community. Few hospitals offered palliative care programs.

⁴⁰ More information about the Health and Aging Policy Fellows program is available online.

By 2011, when the last RWJF grant to CAPC ended, this picture had changed significantly:

- Hospitals were creating palliative care programs faster than CAPC and the Palliative Care Leadership Centers could accommodate.
- The National Quality Forum endorsed preferred practices of care.
- Ten specialty medical fields had adopted palliative care subspecialties.
- The Joint Commission established its Palliative Care Advanced Certification Program.

In addition to these objective indications that a new field of palliative care had emerged and was taking hold, several key stakeholders summarized CAPC's significance:

- Lavizzo-Mourey notes, "The center has been a shining success. Diane Meier has been a strong voice throughout and she has been consistent in explaining the importance of this field. As a result, people know that these choices they have now will not go away. To see Diane and the center continue so effectively, even after our funds ended, is a great measure of success."
- Gibson says, "RWJF built this field. There was no field of palliative care before RWJF became involved and CAPC has been a fundamental part of building the field. CAPC created access to a kind of care for people that would not otherwise be available to them."
- Spragens agrees: "This is now a robust field. At the start, the field didn't have a workforce and those who worked in palliative care didn't have a power base. The growth in the number, size and quality of palliative care programs is mind-boggling. Moreover, for a new field, the level of institutional awareness is huge. The fact that NQF and the Joint Commission believe palliative care is important is a tremendous credit to a decade of deliberate efforts by CAPC to instigate social change."

LESSONS LEARNED

Lessons Related to Overall Program Management

- 1. Employ both "push" and "pull" strategies to effect change. Program Director Meier realized CAPC had to both promote new demand for palliative care services and address the needs of the providers who supplied those services. If either component—supply or demand—outpaced the other, the program would have less impact.
- 2. Think through the dimensions of providing quality technical assistance.

First, high-quality technical assistance is expensive, involving design work by experts, rollout in multiple venues and format and feedback from end-users. (Program Director/Meier)

Second, when developing technical assistance material, focus on practical tools and resources. For example, providing samples and templates for common protocols reduces fear of the unknown and accelerates adoption. (Program Director/Meier)

Third, there is a need for technical assistance regarding operational and leadership activities such as budgeting, marketing, hiring, etc. This lack of support for implementation is a major barrier to the uptake of proven clinical improvements. (Program Director/Meier)

Fourth, develop technical assistance products based on audience needs. According to Sutton (consultant), "CAPC significantly adjusted its early seminars to meet audience demand, created a guide for building palliative care programs based on needs identified by seminar attendees and shaped its Leadership Centers to meet the mentoring needs of early-stage programs."

Fifth, develop simple tools that allow clinicians to "see" their activities in a programmatic way and that support the translation of clinical impact into likely financial impact. (Business Consultant/Spragens)

- 3. When building a field, do not rely only on a core group of experts disseminating information from a central place. CAPC developed credible leaders outside of the national program office in New York, such as the directors of the Palliative Care Leadership Centers. It also fostered peer-to-peer and apprenticeship opportunities such as the site visits and follow-up mentoring led by the Leadership Centers, the national seminars and the CAPCconnect Forum. (Program Director/Meier)
- **4.** When using clinicians to spread clinical innovations, include financial people in the mix so that they become partners in the innovation. For example, CAPC offered a discount to teams that included a finance officer at the site visit. In this way, Meier notes, "the clinical team had a hospital finance partner who could help them get the administrative and financial data necessary to make the case for initial and ongoing financial support."
- **5.** Direct substantial attention to managing relationships with other health care organizations. Managing these critical partnerships is not an *incidental* activity but requires consistent attention from senior managers, clarity about goals and a significant investment of time. (Program Director/Meier)
- 6. Bring principal actors of complex change initiatives together at least quarterly. While a lot of work can be accomplished without face-to-face meetings, regular inperson discussions improve synergy, reduce the risk of diverging priorities and improve strategic and entrepreneurial thinking. (Program Director/Meier)

- 7. Collect and use measurement data to increase adoption, standardization and dissemination. CAPC's National Registry of Palliative Care Programs and its articles regarding costs and savings of palliative care are examples of effective use of data to improve uptake of programs and inform policies about them. (Program Director/Meier)
- 8. To effect changes in practice, familiarize yourself with business principles and surround yourself with good people. "My academic training helped me with writing and speaking persuasively and with conducting research," says Meier. "But, more important, I had to understand how health care works from a financial perspective and realize that anything I do with palliative care has to align with money."
- **9. Identify people with leadership skills and attributes.** Spragens says, "Leadership here mattered. Diane is a great leader, she has grown as a leader and she has built other leaders around her."

Lessons Related to Marketing and Communication

Marketing consultant Sutton offered lessons regarding how to market and communicate change efforts:

- 10. Root systems-change initiatives in issues that are compelling and relate to quality of care and then reach out to all key people involved in bringing about change. At the time CAPC began, there was significant evidence and great concern about the unacceptably high levels of pain and distress experienced by people with advanced illness. CAPC positioned palliative care as a solution to this problem and developed strategies to reach policy-makers, hospital leaders, physicians and other clinicians, patients and others.
- **11.** Link change efforts to broadly perceived, underlying problems in hospitals. Hospitals adopted palliative care because it addressed problems they understood: poor coordination among providers, inadequate communication between physicians and patients and poor staff morale.
- **12. Develop a business case for a cause and teach professionals how to make that case.** CAPC demonstrated to hospitals, health systems and policy-makers that palliative care improves the bottom line by reducing hospital and ICU stays and spending on testing and pharmaceuticals. By including the economic dimension of palliative care in all outreach activities aimed at a variety of audiences, it taught others how to make the business case for their programs.
- **13. Develop an audience-based marketing plan for each player essential to diffusing innovation.** For example, CAPC showed physicians how palliative care gives them more time to focus on their clinical practice; it showed administrators how palliative care improves staff retention and profit; and it showed patients how palliative care helps them get relief from distress and negotiate a complex health care system.

Lessons Related to Running a Leadership Center to Help Create Institutional Change

Directors of Palliative Care Leadership Centers offered lessons from their experiences:

- **14. Identify a catalyst when promoting institutional change.** Vision and resolve are essential for change, but they are not sufficient. Change requires a catalyst such as the Palliative Care Learning Center, to organize, instruct, remind and mentor programs. (Former Project Director/Mary Ann Gill, Mount Carmel Health System)
- 15. "Don't ignore your little voice that says 'I can make a change' or 'We can do that better." says Mount Carmel's Executive Director Lori Yosick. Even when working in an established institution with well-defined rules, it is possible to make improvements.
- 16. "A mix of people is needed," says Mount Carmel's Sharol Herr, MSEd, "the visionaries who challenge us to reach to a new level and the people who can take that vision and make it real."
- 17. "Practice what you preach," says Sarah Friebert, MD, director of the Akron Children's Hospital Palliative Care Leadership Center. "Being a Leadership Center made us focus on our own processes and metrics. It has also made us more flexible. Many of the hospital teams that visit us aren't exactly like us, so we have had to generalize so that what we do works for others."
- **18.** Being a Leadership Center can improve not only the programs of the "students" but that of the "teacher." The University of California, San Francisco's Project Director Steven Z. Pantilat, MD, offers a similar lesson. He says, "By helping others develop and strengthen their palliative care services, we were able to greatly improve our own program. Over the course of the three project years, our service volume increased by 60 percent and the support we receive from our medical center tripled."
- 19. "Invest in an administrative person with strong interpersonal skills who can engage callers and comfortably assist visiting teams," says Christine Ritchie, MD, director of the Center for Palliative and Supportive Care at the University of Alabama at Birmingham.
- **20.** Be prepared to spend significant time helping hospitals institute palliative care programs. Follow-up and mentoring calls to help hospitals sustain their new programs were essential but time-consuming.(Project Director/David E. Weissman, MD, Medical College of Wisconsin)
- **21. Take full advantage of infrastructure support.** In a report to RWJF, Lyn Ceronsky, APRN, MS, project director of the Fairview Health Services Leadership Center writes, "CAPC staff coordinated the application process and sent communications about new developments in the field of palliative care. This led to a smooth and efficient process and allowed ongoing measurement of our ability to attract site visitors."

AFTERWARD

CAPC, so far, has survived the end of RWJF support—something rare for national program offices. But Meier and Sutton both are concerned about how CAPC will fare without continued foundation support. Meier says, "The growth of the field of palliative care was entirely due to private philanthropy and strategic investments by people who knew the health care system. Private philanthropy—especially RWJF and the Open Society Foundations—allowed me to bridge the gap between what health care offered and what patients needed.

According to Sutton, "There will be backsliding. I don't think CAPC is at a place where it could be self-sufficient through charging for its services. And, when you don't have sound financial support, you spend so much of your time looking for money."

A Plan for the Future

Despite her worries about funding, Meier has an ambitious agenda for CAPC in the future, put forth in a 10-year strategic plan completed in 2010. The plan focuses on continuing technical assistance, informing public policy—a major focus for Meier—and developing leaders. Selected activities include:

- Preparing communication strategies targeted to reach legislators, other policy-makers and consumers
- Working with the Joint Commission towards adoption of accreditation requirements for palliative care, with a goal of engaging at least 10 percent of hospital palliative care programs over five years
- Creating specialty-specific approaches in areas such as cardiology or surgery
- Developing technical assistance to support palliative care initiatives in other settings such as outpatient clinics
- Producing and disseminating tools to support generalist-level palliative care skills across the health system to help meet broad population needs

Select outcome goals include:

- Support the establishment of at least 300 new palliative care programs
- Support established programs, currently serving 2 percent of hospital admissions, in achieving the capacity to serve 4 percent to 6 percent of each hospital's annual admissions, as the Leadership Centers did
- Ensure that at least 1,000 palliative care programs register with and provide data to the National Palliative Care Registry by 2014
- Implement the Palliative Care COMPARE, a Web-based reporting tool by mid-2012

Health Care Reform, an Evolving Field and a New Focus

Meier believes that passage of health care reform, combined with steady growth and maturity of palliative care as a field of health care, has important implications for CAPC and for her work in the years ahead. She says "I think CAPC will end up as a palliative care policy institute. After the Joint Commission accredits palliative care [the next step after certification], the field will not need the kind of technical assistance CAPC has provided. In addition, health care reform emphasizes quality of care, which is what palliative care promotes and provides.

"There is now a strong evidence base for the quality of palliative care and there is good data about cost savings from it. Health care reform will fail if it does not integrate palliative care into medical practice.

"I am planning to focus the next 10 years of my career trying to influence policy around palliative care. I want to be a content-expert who can translate policy-relevant research into policy-relevant recommendations for this field."

Prepared by: Mary Nakashian

Reviewed by: Mary B. Geisz and Molly McKaughan Program Officers: Rosemary Gibson and Michelle Larkin

Program ID: HBP

Program area: Quality/Equality

APPENDIX 1

Other Funders

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

Archstone Foundation New York Community Trust

Altman Foundation New York State Health Foundation

Atlantic Philanthropies Olive Branch Fund

Brookdale Foundation Open Society Institute

Donaghue Foundation Partnership for Palliative Care

John A. Hartford Foundation Y.C. Ho/Helen and Michael Chiang Foundation

Mill Park Foundation

APPENDIX 2

Leadership Centers

University of California, San Francisco, School of Medicine, San Francisco

Palliative Care Leadership Center

ID# 0049042 (August 2003–January 2007) \$749,999

Project Director

Steven Z. Pantilat, MD

(415) 476-9019

stevep@medicine.ucsf.edu

Palliative Care of the Bluegrass, Lexington, Ky.

Palliative Care Leadership Center

ID# 049040 (August 2003–July 2006) \$750,000

Project Director

Gretchen M. Brown

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Project Director

Terence L. Gutgsell, MD

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Fairview Foundation, Minneapolis

Palliative Care Leadership Center ID# 049043 (August 2003–January 2007) \$750,000

Project Director

Lyn Ceronsky (612) 672-6456 Lcerons1@fairview.org

Mount Carmel Health System, Columbus, Ohio

Palliative Care Leadership Center ID# 049044 (August 2003–July 2006) \$750,000

Project Director

Philip Santa-Emma (614) 234-3750 Psanta-emma@mchs.com

Virginia Commonwealth University, Massey Cancer Center, Richmond, Va.

Palliative Care Leadership Center

ID# 049037 (August 2003-July 2006) \$733,128

Project Director

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Medical College of Wisconsin, Inc., Milwaukee

Palliative Care Leadership Center ID# 049036 (August 2003–July 2008), \$749,284

Project Director

David E. Weissman, MD (414) 805-4607 dweissma@mcw.edu

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