

CIRCLE OF LIFE AWARD



2018



CIRCLE of LIFE®

*Celebrating Innovation in Palliative and End-of-Life Care*

The 2018 awards are supported, in part, by the California Health Care Foundation, based in Oakland, California, and Cambia Health Foundation, based in Portland, Oregon.

Major sponsors of the 2018 awards are the American Hospital Association, the Catholic Health Association, and the National Hospice and Palliative Care Organization & National Hospice Foundation. The awards are cosponsored by the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, Hospice & Palliative Nurses Association/the Hospice & Palliative Credentialing Center/the Hospice & Palliative Nurses Foundation, and the National Association of Social Workers.

The Circle of Life Award is administered by the Health Research & Educational Trust.

This year's Circle of Life honorees embody a culture of "yes." They welcome the new, the unexpected, and the innovative, and whenever possible, they say yes — yes to providing advanced therapies at home, developing a dementia care and education center, and ensuring physicians and nurses throughout the system have the knowledge to provide primary palliative care and the access to a specialist team. They say yes to incorporating superheroes into social work, building palliative care into pathways, creating an app where patients rate their symptoms, and committing to social justice for patients, families, and communities. Perhaps most importantly, they say yes to adapting to the practices and standards of their parent organizations to more deeply embed palliative care throughout the continuum. Adopting a culture of yes, while not easy, has expanded the breadth and depth of comfort and support each honoree provides to patients and families, and it has made them models for the entire health care system. Please read their stories to learn more and be inspired.

The Circle of Life Award celebrates innovative palliative and end-of-life care programs that:

- Serve people with life-limiting illness, their families, and their communities.
- Demonstrate effective, patient/family-centered, timely, safe, efficient and equitable palliative and end-of-life care.
- Use innovative approaches to meeting critical needs and serve as sustainable, replicable models for a segment of the field.
- Pursue quality improvement consistent with the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care, NHPCO Standards of Practice for Hospice Programs or other widely-accepted standards, within their resources and capabilities.
- Address medical, psycho-social, spiritual and cultural needs throughout the disease trajectory.
- Use innovative approaches to reach traditionally marginalized populations.
- Actively partner with other health care organizations, education and training programs, the community, providers of care, and/or insurers.
- Use metrics that demonstrate significant impact and value for individuals, families and communities.

More information about the Circle of Life Award, complete award criteria, and past recipients is available at [www.aha.org/circleoflife](http://www.aha.org/circleoflife).

AWARD WINNER

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ARIZONA PALLIATIVE HOME CARE PROGRAM  
HOSPICE OF THE VALLEY

*Phoenix, Arizona*





Caring for a loved one who is declining into dementia is widely recognized as one of the toughest jobs around. It's painful, exhausting, and unrelenting, and there is little support for caregivers in the current health care system. That's why Hospice of the Valley (HOV), based in Phoenix, Ariz., has created innovative programs to care for both people with dementia and their caregivers. It is just one example of how the 40-year-old hospice is always open to new ideas even as it enjoys a long-standing reputation in the community as an organization with a comprehensive set of programs for seriously ill people and their families.

"As an agency, we're empowered to think 'yes,'" explains Rachel Behrendt, DNP, RN, senior vice president of operations for HOV. "An entrepreneurial spirit is a core belief for us." Even though the agency receives support philanthropically and through partnerships with the region's health care community, it recognizes that innovation must be sustainable.

HOV's unique innovations in dementia care include a specialized in-home palliative program, as well as a 10-bed hospice dementia inpatient unit dedicated to implementing best practices in everything from design to caregiving to volunteer experiences that enrich patients' and families' lives. "We noticed a lot of people were being diagnosed and didn't know what to do next," says Maribeth Gallagher, DNP, director of the Palliative Care for Dementia program. "Many felt adrift after diagnosis, as though it was 'diagnose and adios.' We help them make decisions about how their life will unfold while they still have the capacity."

Caregivers for people with dementia are supported early in the disease process and taught ways to cope and interact meaningfully with their loved one. "Things arise that they're not prepared for and our system doesn't have safety nets," says Gallagher. "Being able to pick up the phone knowing someone is on the other end sustains them longer." Caregivers also get opportunities for much-needed respite.

HOV is building a first-of-its-kind three-acre campus devoted to dementia care, with an education center and residence that will have 12 beds for assisted living and 10 beds for hospice patients. A 22-person adult day care will be integrated with a child care center, based on research that shows "children don't mind when folks can't remember things. They are much more accepting of people with dementia," notes Behrendt. The campus is near a high school, and HOV staff who are planning the campus activities believe student involvement will add vibrancy and energy to the mix.

HOV Medical Director Gillian Hamilton, MD, a geriatrician and palliative care physician, collaborated with staff from Arizona State University in creating several classes that allow undergraduate students to learn about dementia and gain real-life experience working with patients and families. These courses teach ways to comfort, support, and communicate when speech is no longer possible, and they are being taken by students with a variety of majors, from social work to engineering, who may apply their newfound skills in any number of ways, says Behrendt. "This has been transformative for these kids," she says. "Some came to the topic uncomfortable or unsure, and this course allowed them an opportunity to expand their thinking about people with dementia and look at this as a future career," she said. Two additional classes on hospice and palliative care will be offered by ASU and HOV starting in spring 2019.

Working to provide a complete continuum of care within the community, HOV provides a full spectrum of community-based care including hospice with 10 inpatient units for complex symptom management, a home palliative care

*Caring for a loved one who is declining into dementia is widely recognized as one of the toughest jobs around.*



## INNOVATION HIGHLIGHTS

### INTERWOVEN CARE CONTINUUM

### PROGRAMS FOR THOSE WITH DEMENTIA AND THEIR FAMILIES

### ARRAY OF ALTERNATIVE PAYMENT CONTRACTS

program that sees many chronically ill patients on a long-term basis, and home-based primary care practice for home-limited patients. Its home-based palliative care service has grown to be one of the biggest in the country, serving 950 patients each day.

“We call ourselves the ‘bridging department,’” says Jane Stern, RN, a team leader for the palliative home care program, which connects a variety of services (hospice, dementia care, primary care, and more) under one agency roof. “The ability to collaborate within the agency is pretty seamless,” she says.

The organization also provides transitional care to address another potential gap in the system: when patients at high risk of readmission leave the hospital. The program is designed to quickly connect patients to their primary care providers and specialists for continued care and partners with seven hospitals from three local health systems. Nurses visit within 24 hours of discharge, perform medication reconciliation, and return within 48 hours to update the medical care plan.

HOV’s Arizona Palliative Home Care program provides home-based and transitional care palliative care services to the community. A large number of the palliative home care patients are people with chronic diseases who can expect to live with these diseases for three to five years, explains Gobi Paramanandam, MD, who directs the palliative home care program. The interdisciplinary team spends time with these patients at home, identifying the patient’s unmet needs that, in some cases, keep them cycling into the hospital. The team also talks about goals of care. “We consider ourselves fortunate to have these conversations, and there’s no better place to do that than in someone’s living room or kitchen,” he says.

Patients and families of any program can reach knowledgeable support through an after-hours phone team that provides triage and sends appropriate staff (social workers, nurses, chaplains and others) to the home, if needed. The after-hours team takes about 10,000 calls each month, a testament to the tendency for crises to happen on evenings and weekends.

Hospice of the Valley works with local insurers to design reimbursement contracts that acknowledge the hospice and palliative care program’s ability to reduce avoidable hospitalizations for medically fragile, at-risk patients. It maintains palliative care contracts with eight health plans, some on a per-member, per-month basis. The idea is to move toward risk-based arrangements, but that requires data analysis. To that end, HOV is collecting both numbers and patient narratives describing how palliative care keeps patients out of the hospital to document savings.

Debbie Shumway, HOV’s executive director, feels the work is critical to meeting today’s health care needs. “We are continuing to innovate, to partner with hospitals, health systems, the community, and payers, developing unique services and ways of caring for people in our community. We feel privileged to do this work and are building on a 40-year legacy of caring and trust to provide what is needed now and in the future.” •

## HAND IN HAND PALLIATIVE CARE CHILDREN'S HOSPITAL AND MEDICAL CENTER OMAHA

*Omaha, Nebraska*

**A**t Hand in Hand Palliative Care, a team often works with families who have a child with a genetic disease that may drastically shorten their life or a chronic medical condition that may impact the child and family members' overall quality of life and lived experiences. The team supports such families from diagnosis through end of life and beyond. "We offer them a safe place to say whatever they need to say. The support of the team throughout their child's life and after death has made a huge difference for them," says Sheila Mee, cofounder of the program at Children's Hospital & Medical Center in Omaha, Neb.

Hand in Hand began twelve years ago in the pediatric ICU, driven by social work and chaplaincy, and is now an interdisciplinary team with strong relationships with medical specialties throughout the hospital. Many of the team members who started with the program are still there. Child life specialists, spiritual ministry, and nurse case managers are key team members.

"Once we got the backing of the hospital administration, because it was the right thing to do, it really couldn't stop," recalls social worker Sue Bace, another original team member. "We were charged with designing a program that fits our culture well."

That culture is family-focused, with the voice of the child guiding care choices, no matter what individual team members might think. "We want to help the family have the best quality of life possible and do what they think is best for their children, even when some of the medical team are not in agreement," explains Mee. "We have worked on



educating the medical staff about what palliative care really is. The family has to be the guide."

The Hand in Hand team is welcomed throughout the hospital, where clinicians are receptive to palliative care principles, said Meaghann Shaw Weaver, MD, MPH, who joined the team as division chief two years ago. Along with providing inpatient consults, Weaver also does home visits regularly to keep young patients comfortable and out of the hospital. Weaver attends subspecialty appointments with many palliative care patients and families to foster concurrent and partnered care. Andrew Macfadyen, MD, critical care and palliative care medical director, hosts an interdisciplinary palliative care outpatient clinic for children two mornings per month to focus on goals of care, symptom management, and family resiliency.

The team has a special focus on justice, a concept members remind one another of regularly and in many different ways, Weaver explains. "You have a right to pain management and respect and inclusion, we talk about that pretty often," she said. Justice comes

into play as well with the program's efforts to reach families throughout a multi-state, largely rural area; overcome economic disparities to access to care; obtain philanthropy funding to care for undocumented families; and participate in a global palliative care working group.

Hand in Hand maintains long-term collaborations with hospices and long-term care facilities in Nebraska and shares its pediatric palliative care expertise widely.

A small pilot study of Healing Touch among Omaha Children's patients found they almost universally became more relaxed as a result, so the modality became the first integrative method added to the team's service in 2012. Massage therapy, aromatherapy, and yoga and tai chi for both patients and their parents have subsequently been included. Mee retired as a chaplain and rejoined the team as a Healing Touch practitioner. "Many of our children are not verbal because of the nature of their illnesses, and you can tell by their heart rate that they are relaxing," Mee said.

The team also works to comfort one another and other staff members. "We do a lot for resiliency and moral distress," Weaver said. "PICU had a horrible week about a month ago and we set up a conference room where we did staff care and covered the nurses' shifts so they could get a 15-minute massage."



### INNOVATION HIGHLIGHTS

**LONG-TERM FAMILY-BASED INTERACTIONS**

**SOCIAL JUSTICE EMPHASIS**

**STRONG TEAM APPROACH MATCHED TO HOSPITAL CULTURE**



AWARD WINNER

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PENN WISSAHICKON HOSPICE AND CARING WAY  
PENN MEDICINE

*Bala Cynwyd/Philadelphia, Pennsylvania*







End-of-life care can be an awkward fit with a complex academic medical center, where the emphasis is on research, high-intensity care, and finding new ways to counter disease. But Penn Wissahickon Hospice and the community palliative care program Caring Way have been embedded into University of Pennsylvania Health System/Penn Medicine to build a meaningful continuum of care to support seriously ill patients, particularly in moving from hospital to home.

Nina O'Connor, MD, chief of hospice and palliative care for the system and chief medical officer for the hospice, is included in the system's leadership structure. "Being at those tables in a big academic health center has given us a lot of opportunities," says O'Connor. The fact that O'Connor oversees both hospice and palliative care is significant, she says. "I'm able to see the whole continuum of palliative care and make sure our strategies and care delivery models and philosophy are integrated throughout this huge academic health system."

A learning organization, the hospice and Caring Way share common approaches, language, and electronic health records with the health system and collaborate to improve continuity of care. The organization uses a systematic, evidence-based approach to improvement and to expanding end-of-life impact. Working as part of the system's innovation grants and rapid cycle improvement process, the hospice and palliative care service have taken on COPD, heart failure, and home care for frail elderly patients — with research integrity, precise and extensive use of data, and ability to explain how it ties to advancing the underlying academic mission.

For example, when the hospital was seeing advanced heart failure patients readmitted, Penn Wissahickon Hospice and Caring Way partnered with the system's innovation center to build a pathway for heart failure that incorporates elements of both the hospice's operations and those of the system as a whole, including inpatient palliative care, cardiovascular specialists, and home palliative care. "We've pushed the envelope a little," says O'Connor. "It means our patients aren't sent back to the hospital when they need IV diuretics, and our nurses take a lot of pride that they can offer these advanced therapies at home."

When end-of-life care was needed and complicated by increasing upstream technology use, team members quickly and thoroughly researched and wrote protocols that allowed them to care for those with ventricular assistance devices, a competency not provided by local hospices at that time.

Caring Way is a community-based palliative care program whose patients have a poor prognosis, are still getting aggressive treatment, and are having difficulty transitioning to hospice care. Others may have a long-term disease such as dementia and are showing decline, and their families need more support and education about disease progression. The program helps them clarify goals of care, set thresholds for medical intervention, and understand what doctors are telling them about their condition, explains Julia Schott, MSW, medical social worker for Caring Way.

"People are living longer with chronic and life-threatening illnesses, and they deserve to have expert symptom management, not only in the hospital setting but also at home," Schott says.

Penn Wissahickon Hospice and Caring Way are also focused on learning and education. Caring Way interdisciplinary teams meet every other week with the medical director and nurse practitioner; the group focuses on three to four patients that are particularly complex and invites all the disciplines involved to participate.

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INNOVATION HIGHLIGHTS  
 MATCHED TO A COMPLEX DELIVERY SYSTEM  
 A LEARNING ORGANIZATION  
 EMPHASIS ON SHORT-CYCLE INNOVATIONS

Patients and families sometimes listen in by conference call. “That is really helpful for us as a team to have a better understanding of what’s going on with the patient,” Schott says. “It also gives the patient and family the opportunity to talk with the team to vocalize what’s important to them, what their experience at home is, and to get their questions answered about what to expect.”

The organization seeks out populations that may not always get attention. For instance, Wissahickon maintains a comprehensive child bereavement program, whose counselors work with patients with children, initiating conversations soon after the parent’s condition becomes end-stage to help them talk with their children in an age-appropriate way about what to expect.

The program also supports bereaved children and families beyond the typical 13 months of bereavement support. “We saw a need in the second and third year [after a loss] for children to learn to have fun again and not just continue to process their grief,” explains Sarah Abramovitz, ATR-BC, child bereavement specialist. “We were getting calls in those years from surviving parents asking how to handle birthdays and holidays, saying they don’t connect the way they used to and it always turns into a sad conversation” about the person they miss.

Every three months the program hosts a get-together for families who have reached this point in their bereavement process. The event includes some element of fun — horseback riding, cooking, stand-up comedy — along with some emotional support. The get-togethers are supported by fundraising to allow about 35 to 40 participants to make positive memories together.

The hospice seeks out other groups of people who may typically be missed by the health care system. These include the so-called “live-alones” and the “left-alones,” chaplain David Stickley explains — frail elderly who want to stay at home but need assistance to do so. “We developed some protocols around that,” he explains. “They could stay at home alone as long as they were safe, comfortable, and clean.”

Stickley also checks in regularly at a center that cares for intellectually disabled people, some of whom have lived there for decades and are in failing health. “Nobody seems to want to talk about the fact that these people are aging and dying,” he says. “We’ve found that people who are intellectually disabled have a much faster trajectory of disease than people in the average population.”

Stickley’s duties with the residents can go beyond spiritual counseling; one day he noticed that one of the women he worked with was in bed all day, and it turned out that someone washed all the bed slings and they fell apart. Stickley contacted the hospice, and they sent someone right away to replace the slings so his patient could get out of bed and join the others in a common area.

It’s being willing to step in where needed, sometimes outside the usual lines of a hospice and home palliative care service, that sets Penn Wissahickon Hospice and Caring Way apart, Stickley says. “We have a culture of flexibility — a willingness to try things, to look at a situation and brainstorm about it.” •

DEPARTMENT OF SUPPORTIVE CARE MEDICINE  
MOFFITT CANCER CENTER

*Tampa, Florida*

**H**ow do you integrate comprehensive supportive and palliative care into the day-to-day care of patients at one of the world's major cancer centers in just five years? Moffitt Cancer Center in Tampa, Fla., baked it in, stirring in supportive care methods as its clinicians cooked up care pathways for dozens of diseases and conditions.

Diane Portman, MD, who heads the supportive care medicine department at Moffitt, wanted oncology and supportive care — both of which were undergoing tremendous expansion and fundamental change — to experience “intergrowth.” “The way I envision it is like beautiful crystals of different types that grow into each other,” explains Portman. “You still have two entities, but together they form a stronger, more functional whole.”

Supportive care team members are at the table when specialists sit down to update how they care for different kinds of patients. That way supportive care methods are incorporated into cancer care pathways as they are built or adjusted; these methods are now part of more than 30 clinical care pathways at Moffitt. “We thought it was much better to gain consensus up front on likely scenarios in which this care should be embraced,” Portman says.

Portman and Supportive Care Director Sarah Thirlwell, RN, are called on for their expertise when pathways need to be adjusted to adapt to new evidence or needs. “The growing evidence base for palliative and supportive care helps. So does the value that the team brings to everyday patient care,” she says.



The program earned a place at the table by providing a valuable service to their specialist colleagues — help with conversations, goals of care, and symptom control for the sickest patients. They also earned the support of hospital leadership, which installed supportive care as an integral part of the cancer center's plan for personalized care.

The supportive care medicine department maintains an outpatient clinic and two inpatient teams staffed by physicians, nurse practitioners, registered nurses, psychiatrists, psychologists, and a pharmacist. The social workers and chaplains of the cancer center's department of patient and family services integrate with the supportive care consultative teams.

Palliative care nurses are embedded into specific oncology clinics to help oncologists screen and refer patients to supportive care as needed. “Being in the clinics, in tandem with the pathways, has made the partnership with specialists pretty tight,” Portman says.

The team teaches oncologists primary palliative care skills, such as having difficult conversations around prognosis and progression of disease.

The team gives workshops based on the VitalTalk platform to medical fellows and nurse practitioners. A program nurse teaches the COMFORT curriculum to hospital nurses.

A welcome innovation by the team was its creation of a tablet-based app through which clinic patients can rate symptoms such as pain, nausea, sleep, breathing, and appetite. The app sends the information directly into the center's electronic health record, where it can be seen right away by a clinician at the start of a visit.

Another innovation resulted from recognizing that cancer patients often have trouble with appetite, weight loss, and weakness. Moffitt's supportive care program created a co-located, easily accessible, multidisciplinary Vitality Clinic to work with patients and family caregivers dealing with cancer anorexia cachexia syndrome.

To maintain the organizational support to make such changes, the team found it important to be integrated into leadership throughout the center, particularly in quality improvement. “We're always listening for opportunities for palliative care to provide that extra layer of support for anyone with serious illness,” Thirlwell says.



#### INNOVATION HIGHLIGHTS

##### PALLIATIVE CARE IN TREATMENT PATHWAYS

##### COORDINATED, CO-LOCATED PATIENT NUTRITION CLINIC

##### ROBUST SUPPORTIVE MEDICINE TEAM

AWARD WINNER

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PALLIATIVE CARE  
WESTERN CONNECTICUT HEALTH NETWORK  
*Danbury, Connecticut*





Fueled by the enthusiasm of its CEO and palliative care leaders, a small network of Connecticut community hospitals rapidly trained its hospital physicians and nurses in primary palliative care techniques. Western Connecticut Health Network spread palliative care throughout its continuum of care, from inpatient units to primary care offices, demonstrating that community hospitals can provide sophisticated care to seriously ill patients and their families. The system is now poised to use its expertise in caring for seriously ill patients to strengthen a forward-looking population health strategy.

Over less than a decade, Western Connecticut's palliative care program has grown from a small team serving Danbury Hospital to reaching patients across the system's continuum of care, including home care, nursing home, cancer center outpatient, and in the offices of primary care physicians and pulmonologists.

The rapid growth and spread of the concept has been encouraged by the organization's supportive leadership and efforts to educate staff and clinicians on the essentials of palliative care, says Damanjeet Chaubey, MD, MPH, endowed chair and medical director, WCHN Palliative Care. It also helps that the network cultivates an atmosphere in which bedside nurses feel empowered to call for a palliative care consult if it's appropriate, she said.

The fact that anyone can make a referral to palliative care, including chaplains, has empowered staff, says Lynn Crager, director of spiritual care for Danbury Hospital. "That's helpful on many different levels, including staff morale, when they feel their voice can be heard."

Crager has watched the acceptance of palliative care grow among hospital staff members. "When we started we'd have three patients on the list and now we go up to 25 or 30," Crager says. "There's a greater buy-in and understanding of its importance, and not equating it with hospice care, which was a big hurdle."

Educating hospital staff and physicians has been essential to the program's growth. More than 200 front-line nursing staff have been trained in ELNEC palliative care methods, says Karen Mulvihill, director of the palliative care program. In addition, all the hospitalists have been trained in generalist palliative care, as have about half of the network's primary care workforce. Training took place through conferences, modules, and online.

The biggest shift has come in the past couple of years as physicians are more routinely identifying patients appropriate for palliative care earlier in their illnesses. By training hospitalists at two of the hospitals in palliative care principles, the program can use a generalist-specialist model that maximizes limited resources. Hospitalists learn basic management of symptoms, goals of care discussion, and end-of-life care. The specialty palliative team manages refractory symptoms and more complex discussions.

Referrals are also prompted by a screening tool in the network's electronic health record system that nurses use at admission to flag high-risk patients and automatically refers for a palliative consult. The system also maintains a goals of care decision document that is completed for palliative care patients and remains accessible to care providers throughout the network.

When an analysis suggested a weak spot was lack of access to outpatient palliative care, program leaders set up clinic hours at oncology, pulmonary specialty, and primary care medical offices.

*By training hospitalists at two of the hospitals in palliative care principles, the program can use a generalist-specialist model that maximizes limited resources.*



#### INNOVATION HIGHLIGHTS

PALLIATIVE CARE ESSENTIAL VALUE IN  
POPULATION HEALTH

BROAD SCOPE EDUCATION FOR NURSES  
AND PHYSICIANS

LEADERSHIP AMONG REGIONAL  
COMMUNITY HOSPITALS

Western Connecticut's palliative care program gained The Joint Commission certification in 2014 and shares its expertise with other hospitals in Connecticut, also participating in a statewide initiative to promote patient-directed care strategies for people with serious illnesses.

Support from philanthropy and the network CEO John Murphy has been crucial to the spread of palliative care through the network's continuum. "The CEO has a personal commitment not only from the point of view that this is the right thing to do for patients and families, but that fits into the strategic planning of what we want to move into," Chaubey says. Western Connecticut is moving into value-based reimbursement arrangements with a few of its health plans and creating a population health management company whose goal is to get into risk sharing within a few years. Palliative care is a population health initiative in the network's 2020 vision strategic plan.

"The strategic plan is to move into population health management, and clearly palliative care adds a huge amount of value in that space," says Chaubey. A review of the Medicare Shared Savings Program in which the network participates found \$9,000 to \$10,000 in savings for patients who had palliative care. Data like that, along with stories from patients and families about how the care helped them, has influenced leadership to invest in the program.

Palliative care has expanded strategically, Chaubey says, to "impact where we could make the most difference." That included Medicare and cancer populations, with a focus on patients with multiple chronic conditions, those with lung and heart disease, and dementia.

Leadership also shows its esteem for palliative care by including program representatives in hospital initiatives on readmissions, accountable care, and quality.

Palliative care is provided in the home setting, where physicians make home visits, along with the network's home care staff. The palliative care team is responsive to their partners in home care. "Our staff can pick up the phone to reach them so we can make an immediate treatment change. It can make the difference for the patient being able to stay at home," says Alyson Blanck, executive director of Western Connecticut Home Care.

Home care staff have access to the electronic health record with notes from providers, Blanck says, keeping them informed on the latest information on the patients' care. Home care staff get training on palliative care from Chaubey and other team members, and they are participating in the Institute for Healthcare Improvement's Conversation Project.

Danbury Hospital created the Goldstone Caregiver Center, a space apart from where medical treatment takes place, where family members can take a break and seek out solace and spiritual care. "Sometimes family members feel they can be more open when they are away from the patient's bedside," says Crager. "This is a wonderful addition for families." •



RAINBOW KIDS  
INTERMOUNTAIN PRIMARY CHILDREN'S HOSPITAL  
*Salt Lake City, Utah*

Pediatric palliative care at Intermountain Primary Children's Hospital in Salt Lake City, Utah, provides comfort, support, and hope to sick children and their families but goes beyond that to build a sense of community among the families themselves. The Rainbow Kids program uses social media to bring families together for support and companionship on what can be a long and lonely journey.

"We'll have families who will post on the Facebook page, 'Hey we're inpatient in ICU Bed 6, is anybody else here and want to do dinner tonight?'" explains pediatric social worker Orley Bills, LCSW. "Other families respond and say, 'we're on the third floor, let's connect.'" Families also share their experiences with treatments, care planning, celebrations, and grief. In addition, the Rainbow Kids team holds free weekly lunches to connect families whose children are in the hospital.

The digital outreach that started with Facebook will soon be enhanced with a YouTube page featuring videos to educate both families and hospital clinicians about what palliative care is and how it can help children and families. Educating physicians and residents has been particularly helpful throughout Rainbow Kids' 11-year tenure, during which it has expanded its influence throughout the children's hospital by integrating with multiple specialties so more doctors can use the principles of palliative care.

Rainbow Kids consists of a multidisciplinary team that consults throughout the hospital providing inpatient pediatric palliative care. The team strives to build ongoing relationships with patients and families. "We become a stable point for these



families," explains David Pascoe, manager of Palliative Care, Chaplaincy & Bereavement Services. "We are the ones who remember their names, their social setting, their spiritual and religious preferences. We carry the story of that family from one acute episode to the next even if they are months or even years apart."

Though the team has grown over the years, its core makeup has barely changed from the start; the low turnover could be related to twice-monthly group therapy sessions. "We talk about the tough, hard issues at work," says Bills. "When you engage in that process with your teammates and allow yourself to be vulnerable with people you work with...we have grown together as a team immensely. We're basically a family; we watch out for each other."

The program, though affiliated with Intermountain Healthcare, has reached out to a competitor, University of Utah Hospital, to support the creation of the Utah Fetal Center and to collaborate in other areas of pediatric palliative care expertise. The Utah Fetal Center cares for women who are pregnant with a child expected to have major medical needs

after delivery. Kelly Kelso, APRN, who oversees the prenatal program, explains that by joining forces the hospitals can improve coordination for their patients. "We create a seamless pathway between systems," Kelso explains. "This helps us support families when they have a lot of difficult decision-making to do."

A theme running throughout the program is that the child's and family's needs come first. "We empower parents and coach them to be advocates for their children," says Kelso. Hearing their voices is essential. "When you get into people's worlds a little more, you understand better why they make the choices they do."

Rainbow Kids encourages innovation; a good example is Bills' incorporation of superheroes into his work with both children and clinicians. He uses multiple characters to represent emotions or values, such as anger, power, and responsibility. The messages are just as meaningful for clinicians as for children and families. He's seen some families put up in their child's hospital room a picture of the Green Lantern's blue power ring representing hope. "In the [superhero] universe the strongest weapon, which is almost undefeatable, is will power and hope," he explains. "In hospitals with critically ill children, hope can be a powerful message."



#### INNOVATION HIGHLIGHTS

**BUILDING FAMILY COMMUNITIES OF SUPPORT**

**COLLABORATION WITH HOSPITALS  
OUTSIDE SYSTEM**

**ONLINE OUTREACH TO PATIENT FAMILIES**



2017-2018 CIRCLE OF LIFE  
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*Toluca Lake, California*

Tina Picchi, MA, BCC  
Catholic Health Association  
of the United States  
*Camarillo, California*

Greg Vigdor  
Arizona Hospital and  
Healthcare Association  
*Phoenix, Arizona*

For more information on the Circle of Life Award program or to receive materials for future Circle of Life Awards, please e-mail [circleoflife@aha.org](mailto:circleoflife@aha.org), call the AHA Office of the Secretary at 312-422-2700, or write the Office of the Secretary, American Hospital Association, 155 North Wacker, Suite 400, Chicago, Illinois 60606.

# 2000–2017 CIRCLE OF LIFE AWARD WINNERS

*For updates on the work of these organizations, see [www.aba.org/circles-of-influence](http://www.aba.org/circles-of-influence)*

2000

The Hospice of the Florida Suncoast  
*Largo, Florida*

Louisiana State Penitentiary  
Hospice Program  
*Angola, Louisiana*

Improving Health Care Through the  
End of Life  
Franciscan Health System  
*Gig Harbor, Washington*

2001

Department of Pain Medicine and  
Palliative Care  
Beth Israel Medical Center  
*New York, New York*

Palliative CareCenter & Hospice of the  
North Shore  
*Evanston, Illinois*

Compassionate Care Focus  
St. Joseph's Manor  
*Trumbull, Connecticut*

2002

Children's Program of San Diego  
Hospice and Children's Hospital  
and Health Center  
*San Diego, California*

Hospice of the Bluegrass  
*Lexington, Kentucky*

Project Safe Conduct  
Hospice of the Western Reserve  
and Ireland Cancer Center  
*Cleveland, Ohio*

Population-Based Palliative Care  
Research Network (PoPCRN)  
Special Award Winner  
*Denver, Colorado*

2003

Hospice & Palliative CareCenter  
*Winston-Salem, North Carolina*

Providence Health System  
*Portland, Oregon*

University of California Davis  
Health System  
*Sacramento, California*

2004

Hope Hospice & Palliative Care  
*Fort Myers, Florida*

St. Mary's Healthcare System  
for Children  
*Bayside, New York*

University of Texas M.D. Anderson  
Cancer Center  
Symptom Control and Palliative  
Care Program  
*Houston, Texas*

2005

High Point Regional Health System  
*High Point, North Carolina*

Palliative and End-of-Life Care Program  
Hoag Memorial Hospital Presbyterian  
*Newport Beach, California*

Thomas Palliative Care Unit  
VCU Massey Cancer Center  
*Richmond, Virginia*

2006

Continuum Hospice Care  
*New York, New York*

Mercy Supportive Care  
St. Joseph Mercy Oakland  
*Pontiac, Michigan*

Transitions and Life Choices  
Fairview Health Services  
*Minneapolis, Minnesota*

2007

Covenant Hospice  
*Pensacola, Florida*

University of California San Francisco  
Palliative Care Program  
*San Francisco, California*

Woodwell  
A Program of Presbyterian SeniorCare  
and Family Hospice and Palliative Care  
*Oakmont, Pennsylvania*

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2008

Pain and Palliative Care Program  
Children's Hospitals and Clinics  
of Minnesota  
*Minneapolis/St. Paul, Minnesota*

Haven Hospice  
*Gainesville, Florida*

Pediatric Advanced Care Team  
Children's Hospital of Philadelphia  
*Philadelphia, Pennsylvania*

2009

Four Seasons  
*Flat Rock, North Carolina*

Oregon Health and Science University  
Palliative Medicine and  
Comfort Care Program  
*Portland, Oregon*

Wishard Health Services  
Palliative Care Program  
*Indianapolis, Indiana*

2010

Kansas City Hospice & Palliative Care  
*Kansas City, Missouri*

Snohomish Palliative Partnership  
*Everett, Washington*

Department of Veterans Affairs  
VA New York/New Jersey  
Healthcare Network  
*Brooklyn, New York*

2011

The Center for Hospice &  
Palliative Care  
*Cheektowaga, New York*

Gilchrist Hospice Care  
*Hunt Valley, Maryland*

St. John Providence Health System  
*Detroit, Michigan*

2012

Haslinger Family Pediatric Palliative  
Care Center  
Akron Children's Hospital  
*Akron, Ohio*

Calvary Hospital  
*Bronx, New York*

Sharp HealthCare  
*San Diego, California*

2013

The Denver Hospice  
*Denver, Colorado*

Hertzberg Palliative Care Institute  
Mount Sinai Medical Center  
*New York, New York*

UnityPoint Health  
*Iowa and Illinois*

2014

Baylor Health Care System  
Supportive and Palliative Care Services  
*Dallas, Texas*

Lehigh Valley Health Network  
*Allentown, Pennsylvania*

Yakima Valley Memorial Hospital  
and Foundation  
*Yakima, Washington*

2015

Care Dimensions  
*Danvers, Massachusetts*

2016

Palliative Medicine  
Bon Secours Richmond Health System  
*Richmond, Virginia*

Cambia Palliative Care Center of  
Excellence at UW Medicine  
*Seattle, Washington*

Susquehanna Health Hospice and  
Palliative Care  
*Williamsport, Pennsylvania*

2017

Bluegrass Care Navigators  
*Lexington, Kentucky*

Providence TrinityCare Hospice &  
TrinityKids Care, Providence Little  
Company of Mary Medical Center  
Torrance, and Providence Institute for  
Human Caring  
*Torrance, California*



