



Highlights Report 2019

UPMC Palliative and Supportive Institute

**UPMC**  
LIFE CHANGING MEDICINE

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## A message from our leadership

At the UPMC Palliative and Supportive Institute (PSI) we believe that patients with serious or life-limiting illnesses deserve innovative, compassionate care that reflects their wishes and values. And, we know that it is incumbent upon us to take as much care in addressing what matters *to* patients as it is to offer the resources to address what is the matter *with* them from a clinical perspective.

Since our inception in 2011, PSI has grown increasingly nimble in our ability to support patients and families during what is perhaps the most difficult time in their lives. Our multi-disciplined teams have grown more adept each year in meeting the physical, emotional, and spiritual needs of patients — wherever and whenever we can. We continue to make great strides in being able to serve patients in the environment that makes the most sense for them, including their own homes, skilled nursing facilities, outpatient clinics, and, of course, UPMC hospitals.

As PSI has evolved in meeting patient needs wherever patients are, we've also made significant progress in advancing both primary and specialty palliative care across the continuum of care. We've made education available to clinicians at every UPMC site so they can hone the skills that make excellent palliative care possible. We continue to empower clinicians with training that instills the confidence and courage to initiate difficult, but imperative, conversations about goals of care with patients and families.

Through education, research, clinical programs, and invaluable collaboration with community partners, PSI is proud and honored to deliver a breadth of palliative services that allow patients and families to experience dignity in being heard, in the relief from suffering, and in living the best possible quality of life.

Sincerely,

**Robert M. Arnold, MD**  
*Medical Director, UPMC Palliative and Supportive Institute*



**Tami Minnier, MSN, RN, FACHE**  
*Chief Quality Officer, UPMC*



## Our mission and vision

The mission of the UPMC Palliative and Supportive Institute is to ensure high-quality, coordinated care for patients with serious illnesses, to increase palliative care capacity and expertise across the UPMC continuum of care, and to provide access to consistent education, training, and technical assistance for health care professionals who care for people with serious illness.

Our vision is to promote enhanced quality of life for all patients and families living with the burden of serious illness through attentive symptom management, including hospice. We recognize the importance of treating patients and their families according to their own goals and wishes for care, whatever the illness or prognosis.

The clinicians of the UPMC Palliative and Supportive Institute work collaboratively with other health care professionals throughout UPMC to provide the support and services that can make life's transitions less stressful. We focus on managing and treating symptoms, and helping patients to have the best possible quality of life during their illness.

We are here to ensure that patients, families, and caregivers have the opportunity to live each moment with dignity and grace.

“When we first started delivering palliative care, we had a small program with a couple of good doctors. Now we have so many amazing clinicians who are contributing to palliative care and research, and expanding the knowledge and capabilities of the entire institution.”

— **Dr. Robert Arnold**  
*Medical Director,  
UPMC Palliative and Supportive Institute*





# Clinical Programs

At UPMC Palliative and Supportive Institute (PSI), we're always employing new ways to make our patients and their families feel more empowered and comfortable throughout difficult times. The growth in the number of patient visits speaks to our increasing reach in both hospital and outpatient settings. We're honing our approach to chronic pain management, especially in light of today's opioid crisis. And we've also developed programs that support family members at the bedside and in grief.

## Reaching more patients and families than ever before

In the last two years, PSI has delivered more than 66,200 total visits from the hospital and outpatient clinics to long-term care and private homes.

### UPMC PALLIATIVE AND SUPPORTIVE CARE PATIENT VOLUMES

#### OUTPATIENT CLINICS

**Hillman Cancer Center**

Total CY18: 2,669 | Total CY19: 2,574

**Magee-Womens**

Total CY18: 621 | Total CY19: 646

**Mercy**

Total CY18: 255 | Total CY19: 223

**Passavant**

Total CY18: 194 | Total CY19: 210

**Benedum, CLC, DDC, East, HVI, St. Margaret**

Total CY18: 647 | Total CY19: 650

#### INPATIENT

**UPP/Oakland**

Total CY18: 20,482 | Total CY19: 221,307

% Change: +4%

**Community**

Total CY18: 7,121 | Total CY19: 8,435

% Change: +18%

**Overall**

Total CY18: 27,603 | Total CY19: 29,742

% Change: +8%

### Opioids have a place and a purpose in palliative care

Even in the midst of a national opioid epidemic, experts agree that opioids have a place in the palliative care journey. Using them appropriately and safely, however, is critical to a patient's health and well-being. Through research, education, and innovative programs, physicians at the Palliative and Supportive Institute are leading the way in helping patients, families, and health care professionals make wise and appropriate decisions about addiction and chronic pain management.

### Surveying professionals and establishing addiction best practices

In 2018, the Center for Disease Control and Prevention (CDC) released guidelines for prescribing opioids for patients with chronic pain. Dr. Jessica Merlin, Associate Professor of Medicine, Section of Palliative Care and Medical Ethics, believes many of those guidelines apply to palliative care patients with chronic cancer pain. She's developed a survey to find out if palliative care professionals are aware of the guidelines and, if so, how they are being used.

"Doctors who study palliative care aren't often trained in how to treat chronic pain," says Dr. Merlin. "We need to better understand the role of opioids, and learn how to weigh the risks and benefits for each patient."

Her survey asks practices if they are following CDC guidelines, such as:

- **Assessing patients for opioid addiction**
- **Looking for concerning behaviors that arise, such as lost or stolen prescriptions**
- **Monitoring patients using urine drug tests**
- **Getting informed consent through waivers to provide morphine for opioid addiction**

Ultimately, Dr. Merlin believes chronic pain care involves one-on-one discussions with patients, informing them of their options — both pharmacological and non-pharmacological. "There is no one right way to treat chronic pain. We can reduce the dose of opioids. We can look at other modalities. We can consider cognitive behavioral therapy, stress-reducing mindfulness, acupuncture, yoga, and tai chi," she explains. "We treat so many patients today who survive cancer. We need to consider the long-term effects of opioids in those patients."

In a related initiative, Dr. Julie Childers, Associate Professor and Medical Director for Palliative Care Clinical Services at UPMC Presbyterian, is studying addiction in the palliative care community, and sharing her findings with others.

"When people have a serious illness in addition to an addiction, it compounds the chaos," says Dr. Childers. "They're often chasing down the substance they use. They have trouble making it to doctor's appointments or oncology appointments. It causes a lot of family strife at a time when families need to come together. These patients are often too sick for programs where they would get appropriate treatment, so we're trying to build care models that can help them."

This year, Dr. Childers was selected to present at the American Society of Addiction Medicine Annual Conference. She is hoping to teach addiction medicine physicians how to find ways to work with palliative medicine and hospice providers to offer addiction treatments that are accessible to individuals with serious medical illness.

Dr. Childers also believes more training is needed in the palliative care community. "For many patients, prescribing opioids, even in very high doses, is the right thing to do," she says. "But we also need to be able to discern when opioids might be causing problems instead of helping the overall situation."

### Making psychiatric care top of mind in palliative care

It's no surprise that many palliative care patients and their families experience distress, including anxiety, depression, loneliness, and difficulty coping while transitioning to end-of-life and coping with grief. Over the last decade or so, UPMC has recognized the need for mental health services as an integral part of palliative care, introducing psychiatric care as part of palliative care at Presbyterian and Montefiore Hospitals.

It's a natural fit, according to Dr. Pierre Azzam, Medical Director, Palliative Care Psychiatry. "There are a lot of overlapping themes in palliative care and psychiatric care," says Dr. Azzam. "The focus is on reducing distress, improving people's quality of life, and ensuring that we are honoring their values and goals."

Mental health services for palliative care patients and their families range from psychotherapy and medication to mindfulness-based relaxation and anti-anxiety techniques. "It's a pretty holistic approach," remarks Dr. Azzam. "We determine together what sort of care would provide the greatest value for the patient." Situations like mechanical ventilation or difficulty breathing often result in substantial anxiety or depression. Diagnosis of a life-limiting illness can also cause demoralization. Dr. Azzam sees psychiatric care as a way to reduce these symptoms and bring comfort in a difficult time.

In the future, Dr. Azzam would like to involve palliative care services earlier in the care of people with chronic disease. He also believes it's crucial to educate primary teams about the services palliative care can provide. "I'd like to reduce the stigma that might be associated with either palliative care involvement or psychiatric involvement," he says. "If we can expand education and increase the availability of our services, we can lessen the burden for patients earlier in the course of their treatment."

### UPMC Shadyside CaRES Program — comfort on wheels

Imagine being at the bedside of a loved one who is dying. You don't want to leave — even for a moment. How comforting would it be if someone came by and offered you hot tea and a snack? That's the idea behind the UPMC Shadyside CaRES (Comfort and Relief, End-of-life Support) Program.

“When people have a serious illness in addition to an addiction, it compounds the chaos. We’re trying to build care models that can help them.”

— *Dr. Julie Childers, Associate Professor and Medical Director for Palliative Care Clinical Services, UPMC Presbyterian*

This new pilot program consists of two comfort carts, filled with beverages and non-perishable snacks that visit the rooms of end-of-life patients, offering free refreshments to families and friends. The goal is to provide comfort and help maximize the time loved ones are able to stay at the bedside.

Shadyside CaRES was created through a partnership between Food and Nutrition Services (FNS) and the Palliative and Supportive Care team. It is made possible by a grant from the Shadyside Hospital Foundation, and FNS has pledged its continued support.

#### **Volunteers offer support and receive rewards beyond measure**

Losing a loved one is never easy. Bereavement volunteers offer a voice of support through phone calls to see how family members and friends who have become involved with the Palliative Care and Supportive Institute are coping.

“When I call, many family members and friends readily express their feelings about the loss of their loved one,” says Elaine Patalski, Bereavement Volunteer at UPMC Shadyside. “A husband related his concern for keeping up the garden his wife tended to every year. Another spouse was grateful that she and her husband were able to make plans before he died. Others expressed comfort in knowing that their loved one was finally at peace.”

The volunteers are often amazed at how rewarding it can be to work with families facing a loss. “Speaking to bereaved families has been a powerful experience,” says Joan Mosey, Bereavement Volunteer, UPMC Passavant. “I never expected I would be getting more from the experience than I give. It’s such a privilege to be able to offer my support to these families.”

#### **Big help for little ones and their families**

Palliative care in the world of pediatrics is relatively young and still fairly rare. “Even 16 years ago, it was not something that was well-known or understood,” says Carol May, RN, MSN, MBA, CHPPN, Manager of the Supportive Care Program at UPMC Children’s Hospital of Pittsburgh (CHP). May developed this leading-edge program in 2003 and continues to oversee it today.

The Supportive Care Program is designed to bring comfort and extra support to children with life-threatening illness and their families. It offers help with pain and symptom management, decision-making, end-of-life care, and bereavement. While its offerings are similar to adult palliative care, the program’s approach is especially geared to the unique needs of children, their siblings, and parents.

“Pediatric palliative care is different than adult palliative care,” says May. “We recognize that kids are complex people. They’re not little adults.”

The program’s first medical doctor, who joined in 2010, agrees. “We tend to know our patients for an average of more than 500 days,” says Dr. Scott Maurer, Chief, Division of Palliative Medicine and Supportive Care, CHP. “We get involved a lot earlier in the course of their disease, even when patients are still seeking aggressive medical treatment. If things go great, then we’re the first people there, cheering for them. If things don’t go the way we would hope, we’re right there for them, aiding in decision-making and helping to control pain and symptoms.”

The Supportive Care Program at CHP has been highly successful. “We have about 200 patients at home who are on our service,” says May. “And on average, we see anywhere from 35 to 45 inpatients a day. Clearly, we’re a busy service.” Currently, this is the only pediatric palliative care program in western Pennsylvania.

Although the Supportive Care Program functions as a distinct and separate group, the team collaborates with PSI for research, education, and mentorship. The group is working to grow pediatric palliative care, including a perinatal palliative care program at the University of Pittsburgh which Dr. Maurer co-founded.

Says Dr. Maurer, “If we can make this difficult road a little bit easier, if we can help parents cope with the loss of their child, or make this time more precious by taking away pain, then maybe we’ve helped these families for years to come. It’s very fulfilling.”

“Speaking to bereaved families has been a powerful experience. It’s such a privilege to be able to offer my support to these families.”

— *Joan Mosey, Bereavement Volunteer, UPMC Passavant*



## Palliative care is not about dying: One patient's story

Life took a dramatic turn for Tim Shuckhart and his wife, Lori, earlier this year when Tim's defibrillator, placed years prior when a viral infection left his heart damaged, suddenly activated. Tim blacked out in the car, minutes from arriving at the hospital. He awoke in UPMC Presbyterian with a LVAD (Left Ventricular Assist Device) implanted to sustain his cardiac function. He was placed on the heart transplant list.

Tim admits it was difficult to get his bearings amidst this rapid sequence of events. The LVAD was uncomfortable at times, he was having trouble sleeping, and he was distraught imagining the trauma Lori had experienced as witness to all that had occurred. And then he met Tammy Brinker, CRNP in the Palliative and Supportive Care Clinic within the UPMC Heart and Vascular Institute. "She was the one who made me laugh again," Tim recalls.

Tammy spent time with Tim in the hospital and helped him normalize his feelings and emotions under these extraordinary circumstances. She has remained involved in his care through his subsequent heart transplant and his outpatient recuperation. Tim says Tammy is a huge support to him and to Lori, noting, "You couldn't have found a better person to do that job."

"When I tell people I am getting palliative care, they say, 'are you dying?'" says Tim. "It's not what people think it is, and I am here to tell you, that is the farthest thing from my experience. They are here to help you get through things. Palliative care is not about dying."

Tim continues to improve on the other side of his heart transplant. He hopes to be cleared to drive soon, and eventually return to his joys: fishing, biking, and a vacation in the Outer Banks.

Today, Tim's message is one of appreciation. "It was a hard-fought journey to get to this point, but it's been a good experience. Everyone says I look great, and I'm looking forward to the next part of my life."

*Editor's note: Tim's brother, Tony, provides graphic design services to UPMC and contributed to this project.*



# Care Models in Integrated Systems

Palliative care is opening eyes — and new doors — throughout the health care community. It is inspiring other health care professionals to view patient care through a new lens — helping doctors and nurses to recognize and meet patient goals around comfort and quality of life. This education is resulting in new and exciting collaborations that are easing suffering for patients and resulting in improved, coordinated care.

## On a mission to avoid readmissions

When seriously ill patients are discharged from the hospital and begin receiving home health care, the transition can be a challenge. “These patients are at high risk for readmission to the hospital,” says Susan Saxon, CRNP, Clinical Director, Home Care Management Services. “We’ve developed a post-acute home transition program for UPMC Health Plan members that works in tandem with UPMC Home Healthcare to provide extra support.”

The new program adds a nurse practitioner and social worker from palliative care to support the Home Health Agency team in the post-acute period. “It’s basically a home care program on steroids,” says Saxon. The program has proven successful, reducing hospital readmissions over the critical 30-90 days after discharge. Patients who are seen during the episode of home care who are seriously ill can be subsequently followed by the Advance Illness Care Program.

## End-stage Renal Disease Concurrent Care: An innovative program overcomes barriers to patient relief

“If you’re looking at end-of-life outcomes, dialysis patients face some of the least desirable,” says Dr. Jane Schell, Assistant Professor of Medicine, Section of Palliative Care and Medical Ethics. “They’re less likely to receive hospice compared to any other condition or diagnosis. We saw the need to create an innovative partnership and program to help reach dialysis patients who are close to death earlier in their journey and improve their quality of life in the time they have left.”



Unfortunately, the traditional model of hospice care requires that dialysis patients give up the life-prolonging treatment they've come to rely upon over the years. "Moving away from dialysis into a new focus of care can be scary," says Dr. Keith Lagnese, Medical Director for UPMC Home Healthcare. "This program allows earlier hospice access to a group of chronically-ill patients who rarely die comfortably at home."



“**People are very thankful to be able to stay in their homes without having constant doctor or clinic visits. We're able to provide them with both skilled care and supportive services at home where they are most comfortable.**”

— *Mary Burgunder, Vice President, UPMC Home Health Care*

The innovative program teams UPMC's world-class health system, Family Hospice, part of UPMC, PSI and Dialysis Clinic, Inc. (DCI), the largest non-profit dialysis provider in the country. "We call it renal concurrent care," says Dr. Lagnese. "For patients who want to transition to hospice, it covers up to 10 dialysis treatments that are purely palliative, focused on quality, not quantity."

It's a new way to look at end-of-life renal care. "One of the best parts about this program is the collaboration between the hospice team and the dialysis team," remarks Dr. Schell. "Our goal is to improve education in dialysis units so they can start to identify these patients and bring them into the program."

Funding comes from the Family Hospice Foundation, which provided and recently renewed a \$50,000 grant to fund a finite amount of dialysis treatments for patients who are transitioning to a focus on comfort.

"It's about empowering patients and their families," says Dr. Schell. "We've talked to family members of patients who have come through our program, and their gratitude is overwhelming. They felt like they were doing what was right for their loved one, without having to make a difficult decision to stop the treatment that was keeping that loved one alive."

### **Palliative Home Care: Adding a new dimension to home health care**

Patients with serious, chronic, or life-limiting illnesses, who are living at home, and still undergoing treatment now have home-based palliative care as a form of support. "While some of these patients have other kinds of skilled care at home, our program gives them the opportunity to get help from specialty nurses trained in palliative care," says Mary Burgunder, Vice President, UPMC Home Healthcare. "These nurses are specialists in leading goals of care conversations as well as providing symptom management and care coordination with physicians and care teams. They're really the eyes and ears of the care team. Their goal is to help patients and families achieve the highest possible quality of life."

Currently, the program has two palliative nurses on staff. They work seven days a week on a regular schedule to provide patients with continuity of care. Burgunder hopes to grow the program to up to 12 nurses. The team also includes a social worker.

Says Burgunder, "People are very thankful to be able to stay in their homes without having constant doctor or clinic visits. We're able to provide them with both skilled care and supportive services at home where they are most comfortable."

### **Hospice: Evolving to meet patient need**

Eighty-five percent of hospice patients receive care at home or in a non-skilled nursing facility under the "routine" level of hospice care. Tom Iorio, RN with Family Hospice in Erie, has been delivering this care for 18 years. He and his team (social workers, hospice aides, chaplains) provide patients and families the support and resources they need to treat discomfort successfully, prepare for the stages of illness, and to develop confidence in their progressive decision-making. Says Tom, "We try to avoid crises. For the patient and family, sometimes just knowing they can pick up the phone and call the nurse to guide them through an assessment or give a medication makes all the difference."

For the remaining patients, a higher level of care is necessary. Often, this is delivered under the "inpatient" level of care. "The sickest patients need to be in a dedicated inpatient unit, hospital, or nursing facility," says Dr. Lagnese. "We're recognizing the need to provide these services in a standardized manner to improve the dying experience at all UPMC facilities." While Family Hospice continues to operate an inpatient facility in Lawrenceville, it is also looking to improve the inpatient hospice services at 11 UPMC hospitals, starting with UPMC Presbyterian.

"We're going to create a comfort care unit in Presby that will provide care to the inpatient hospice population in that setting," says Dr. Lagnese. "We've spent a lot of time with clinical and administrative hospital leaders and the Palliative Care Department to collaborate on this initiative."

These new initiatives will strengthen care of all of Family Hospice's patients. "We currently care for about 700 hospice patients on a daily basis across the UPMC system. While only a small percentage require the inpatient level of care in a facility, we have committed the appropriate resources to make sure all hospice experiences for our patients are exceptional," says Dr. Lagnese.





## Training and Education

As the emphasis on patient-centered care continues to grow, so does the need to bring palliative and end-of-life care to the forefront of the health care community. Every year, PSI is creating and advancing opportunities to communicate with others about the importance of understanding patients' values and goals and facilitating discussions through which best practices can be shared.

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### **Hospice and Palliative Care Symposiums: Spreading a philosophy of expanded access**

How do you assess where patients are on their health care journey? How do you overcome barriers to help patients get the comfort care they need? How do you create greater utilization of hospice and palliative care in a health care community? These are just some of the issues addressed by the Hospice and Palliative Care Symposiums, events co-sponsored by Family Hospice, part of UPMC and UPMC Palliative and Supportive Institute.

This year, the second series of symposiums took place in Pittsburgh and Altoona. Each showcased experts in hospice and palliative medicine and brought awareness of these important topics to doctors, nurses, social workers, and health care administrators.

"The responses have been overwhelmingly supportive," says Eric Horwith, Director of Growth and Business Development, Family Hospice. "Educational opportunities like these are essential to encouraging collaboration to help patients transition and get the right care at the right time and place."

In the past, the symposiums have taken the form of a speaker panel with Q&A. In the future, Horwith envisions a more tailored, interactive approach. "We're looking to have a keynote speaker with breakout sessions where people can elect to learn about specific topics."

**NephroTalk, GITalk: Making difficult conversations easier**

All specialty clinicians are well-trained in providing treatments and treatment options. What they're often not taught to do is talk about a patient's priorities and values. This skill becomes particularly crucial when patients are seriously ill. To fill this need, a program called VitalTalk was developed by Dr. Robert Arnold, Medical Director, UPMC Palliative and Supportive Institute. Now PSI physicians are taking the basics of this nationally recognized program and customizing it to meet the needs of their respective specialties, including Oncology, Critical Care, Neonatal Critical Care, Pediatric Critical Care, Cardiology, Nephrology, Gynecologic Oncology, Neurology, Gastroenterology, Hospitalists, and Advanced Practice Providers.

"Many patients with advanced kidney disease, particularly older patients, may not gain a lot of survival time on dialysis, and the time that they do have might be spent mostly in the hospital or a skilled nursing facility," says Dr. Schell. "For some people, their goals and values don't fit that sort of trajectory. There are other ways to take care of these patients that involve what we call conservative care."

For her work on NephroTalk, Dr. Schell received the 2018 Hastings Center Cunniff-Dixon Physician Award, which aims to foster models of good medicine for physicians and demonstrate the necessity of end-of-life care as it relates to the doctor-patient relationship. "Having difficult conversations is never going to be easy for a clinician or a patient, but NephroTalk helps nephrology clinicians deliver bad news, address prognoses, and assist with treatment decision making."

GI Talk is another effort led, in part, by Dr. Amar Bansal, Assistant Professor, Division of General Internal Medicine and the Section of Palliative and Medical Ethics at the University of Pittsburgh. GI Talk is geared towards gastroenterology fellows who are frequently toward seeing patients with a variety of serious conditions such as liver failure.

"Physicians are often asked to put feeding tubes in patients who may not benefit from them," says Dr. Bansal. "GI Talk helps doctors have conversations that involve evaluating options and making difficult decisions." While his project is in the first year, he notes that the response has been very positive.

"These communication training programs are designed to give providers the skills they need to be able to have tough conversations from addressing goals of care to frank discussions with patients about a poor prognosis," says Dr. Jane Schell, Nephrologist and Palliative Care, UPMC.

Schell developed NephroTalk to help doctors have serious conversations about end-of-life care with patients being treated for advanced kidney disease.

2018/19 Trainees' Classifications



2018/19 Specialties Trained Communications Skills-GOC



"Every single learner said that they'd recommend this training to others," says Dr. Bansal. "Every single one of them said that the training should be a required part of their fellowship."

Each of these programs is designed to train fellows, often using a one- or two-day retreat. Dr. Schell is working on making her program scalable, so that it's easily available to more people.

"We just developed an online curriculum on conservative care," she says. "We use modules of videos teaching conservative therapies and communication skills. It really expands our toolbox and the kinds of ways we can help patients. I only see it growing from here."

**End-of-Life Nursing Education Consortium (ELNEC): Teaching nurses how to help dying patients and their families**

Nurses spend more time with patients who are facing the end of life than any other health care professional, yet many are uncertain about how to best meet their patients' needs at this difficult time.

ELNEC is the benchmark educational program through which nurses learn how to approach end-of-life care with knowledge, sensitivity, and confidence. Training modules address everything from palliative nursing care, pain management, and symptom management to ethical/legal issues, cultural considerations, communication, care in the final hours, and bereavement.

A group of palliative nurses trained in ELNEC is delivering this important program locally. "We're sharing these best practices with other nurses, empowering them to use their skillsets and make the end-of-life experience what it should be," says Elena Nosal, Director of Clinical Operations at Family Hospice, part of UPMC. "We can't change the outcome when someone is dying. What we can change is the experience."

So far, the group has collaborated to offer one full-day program, which took place November 2018 at UPMC Magee-Womens Hospital and was free of charge to all UPMC employees. Now the team is working to take the show on the road. "The need is certainly there, and the response has been great," says Janet Leahy, CRNP, Supervisor Advanced Practice Providers Hospital and Outpatient-Based Palliative Care Services at UPMC Palliative and Supportive Institute.

Once nurses have this training, they become agents for change. "Nurses who have been through the program become champions on the floor," says Nosal.

**Day of Conversation Campaign: Advancing awareness of the need for advanced care planning**

Many people find it difficult to discuss end-of-life issues, but having a conversation before a crisis is much easier and less chaotic than waiting until someone is seriously ill. That's the central theme that drives The Day of Conversation, an annual UPMC campaign supported by the Beckwith Institute.

"It's a very important issue for Nick and Dotty Beckwith," says Cassie Heinle, Manager of the Beckwith Institute, an endowed fund at UPMC that champions new ideas to improve the patient experience. "They want to help make sure that people are having those conversations with family members at an early time in their lives, before situations become urgent."

The Day of Conversation coincides with National Health Care Decision Day, an event that takes place every April. "Each year, the event looks a little different, depending on what the trends are," says Heinle. "Ultimately, it's about awareness and helping direct care staff understand the resources that are available and encouraging them to take the time to incorporate advanced care planning into their discussions with patients."

The Day of Conversation initiative often spans over the course of the month. Past efforts have included outreach to churches, synagogues, and low-income neighborhoods. This year's campaign was directed internally across the UPMC health system and included a series of videos, articles, and social media activity, driving home the theme, "Just Talk About It."

"When patients are unable to vocalize what they want their care to be, the responsibility falls to a surrogate, such as a family member," says Stace Hook, Critical Care Improvement Specialist, UPMC ICU Service Center. "There's often a lot of confusion and pressure to make decisions for their loved one. The PARTNER program supports them with nurses who are trained to ensure that their questions are answered."

Currently, more than 210 nurses and social workers in 31 units across 12 hospitals are trained to deliver the program. "The goal is to have up to 10 nurses with PARTNER training in every ICU in the UPMC system," remarks Hook.

One of the most important tools in the program is a question prompt list. "Nurses sit with the families and go over the questions. Then they'll have a family meeting with the providers. When the meeting is over, the families feel more satisfied that their questions were answered. Everybody is on the same page and has a better idea of what's going on," says Hook.

Nurses then make sure the patient's care stays on track with the family's wishes. "The nurses give us feedback that they feel more empowered in their role as partners. They can have conversations that are often difficult with providers and family members, and they truly feel like they're able to advocate for patients and their families," adds Hook.

### **PARTNER Program: Supporting families with critically ill loved ones**

The PARTNER Program is a family support program for those with critically ill family members. Its goal is to support decision makers when they are faced with a very vulnerable and difficult time, which sometimes leaves them to make a decision that their loved one may not have planned for. When a loved one meets the criteria for the program, a PARTNER nurse reaches out to family members within 48 hours and continues to meet with them on a regular basis as long as the loved one remains in the ICU. The program offers these families help in making medical decisions that are consistent with their loved one's wishes.

**48 Hours** A PARTNER nurse will reach out to family members within 48 hours of a patient meeting program criteria.

**“There’s often a lot of confusion and pressure on families to make decisions for their loved one. The PARTNER program supports them with nurses who are trained to ensure that their questions are answered.”**

— **Stace Hook**, Critical Care Improvement Specialist, UPMC ICU Service Center

## Palliative care across the globe

Last year, Family Hospice, part of UPMC and PSI, hosted a group of Russian doctors and administrators who visited Pittsburgh to learn more about hospice and palliative care in the U.S. A non-profit organization called GlobalPittsburgh helped connect the groups and created an eight-day program for the first palliative care-themed program for Russia. Among the topics discussed were pain relief for patients, training for doctors and nurses in palliative care, communicating with seriously ill patients, and advancements within UPMC to improve the patient experience with technology.

"Palliative care is a young field in Russia, and services are not widely available," says Dr. Richard Weinberg, Clinical Associate Professor of Medicine and Associate Medical Director for Community Palliative Care for PSI. "We shared curricula developed at UPMC that focuses on communication skills and symptom management. We discussed how PSI has sought to make palliative care available to patients at each point of care."

UPMC and the University of Pittsburgh were honored with a visit from Dr. M. R. Rajagopal, celebrated as the father of palliative care in India. A Nobel Peace Prize nominee, Dr. Rajagopal's mission is to bring ethical practice to modern medicine through whole person care, starting in his home country of 1.2 billion people. He advocates for a global-health system that focuses on serious health-related suffering and meaningful, accessible relief from pain.

Dr. Rajagopal's visit included a talk with PSI and the University's Section of Palliative Care and Medical Ethics about global challenges and opportunities in the delivery of ethical medicine.



**Above:** PSI and the University of Pittsburgh were honored with a visit from Dr. M.R. Rajagopal, celebrated as the father of palliative care in India, last year.

**Left:** PSI, Family Hospice, and Canterbury Place staff meet with a palliative care delegation visiting from Russia.



## Our Team

### PSI Administrative Leadership

**Tami Minnier, MSN, RN, FACHE**

Chief Quality Officer for University of Pittsburgh  
Medical Center  
Executive Director, Beckwith Institute

**Robert M. Arnold, MD**

Medical Director, UPMC Palliative and  
Supportive Institute

**Deborah S. Brodine, MHA MBA**

President, UPMC WPH  
President, Senior Services

**Mary Ann Sander, MHA, MBA, NHA**

Vice President, Palliative Care and  
Supportive Services

**Cynthia L. Wilson**

Senior Director, Community-Based  
Supportive Services

**Kimberly L. Gottschalk, MBA**

Director, Inpatient and Outpatient Palliative  
Care Services

**Susan Saxon, CRNP**

Clinical Director, Home Care Management Services

**Janet Leahy, CRNP**

Supervisor APP, Inpatient and Outpatient  
Palliative Care Services

**Richard L. Weinberg, MD**

Associate Medical Director, Community  
Hospital-Based Palliative Care Services

**Mamta Bhatnagar, MD**

Medical Director, Community-Based Palliative  
Care Services

**Anita Lyons, MD**

Medical Director, Home-Based Palliative  
Care Services

### Palliative Care Physicians

**Robert M. Arnold, MD**

Distinguished Service Professor of Medicine  
Chief, Section of Palliative Care and Medical Ethics

**Amar Bansal, MD**

Assistant Professor of Medicine  
Associate Program Director, Nephrology  
Training Program

**Karl Bezak, MD**

Clinical Assistant Professor of Medicine

**Mamta Bhatnagar, MD**

Clinical Assistant Professor of Medicine  
Medical Director, UPMC Shadyside Palliative  
Care Clinical Services

**Julie Childers, MD**

Associate Professor of Medicine  
Director, Communication Skills Training  
Medical Director, UPMC Presbyterian Palliative  
Care Clinical Services

**Rene Claxton, MD**

Associate Professor of Medicine  
Director, Hospice and Palliative Medicine  
Fellowship Program

**Tara Cook, MD**

Clinical Assistant Professor of Medicine

**Scott Freeman, MD**

Clinical Assistant Professor of Medicine

**Richard Hoffmaster, MD**

Medical Director, UPMC St. Margaret Palliative  
Care Clinical Services

**Linda King, MD**

Assistant Professor of Medicine  
Associate Chief, Section of Palliative Care and  
Medical Ethics

**Heather Mikes, DO**

Medical Director, UPMC East and McKeesport  
Palliative Care Clinical Services

## Palliative Care Physicians *(continued)*

### **Lisa Podgurski, MD**

*Clinical Assistant Professor of Medicine*

### **Eva Reitschuler-Cross, MD**

*Assistant Professor of Medicine  
Medical Director, UPMC Magee-Womens  
Hospital, Palliative Care Clinical Services*

### **Rebecca Sands, DO**

*Clinical Assistant Professor of Medicine  
Assistant Director, Hospice and Palliative  
Medicine Fellowship Program*

### **Jane Schell, MD**

*Assistant Professor of Medicine*

### **Andrew Thurston, MD**

*Clinical Assistant Professor of Medicine  
Medical Director, UPMC Mercy Palliative  
Care Clinical Services*

### **Richard Weinberg, MD**

*Clinical Associate Professor of Medicine*

### **Syeda S. Zaidi, MD**

*Medical Director, UPMC Passavant Palliative  
Care Clinical Services*

## Palliative Care Research Faculty

### **Halley Bulls, PhD, MA**

*Assistant Professor of Medicine*

### **Dio Kavalieratos, PhD**

*Assistant Professor of Medicine  
Director of Implementation Research  
Associate Director, Palliative Research Center*

### **Jessica Merlin, MD, MBA, PhD**

*Associate Professor of Medicine  
Associate Director, General Internal Medicine  
Research Fellowship  
Associate Program Director for Research,  
General Internal Medicine Residency*

### **Jennifer Pruskowski, PharmD, BCPS, BCGP, CPE**

*Assistant Professor of Pharmacy*

### **Yael Schenker, MD, MAS**

*Associate Professor of Medicine  
Director, Palliative Research Center*



## Awards and Honors: Reaping the rewards of passion and commitment

The passionate people who collaborate and innovate to support UPMC Palliative and Supportive Institute in helping seriously ill patients to access high-quality, compassionate care are also award winning.

This year, many of our team members were recognized locally, nationally, and internationally for their accomplishments. Through process improvements, new programs, and original thinking, our team is advancing palliative care at UPMC and beyond.

### **Robert Arnold, MD**

#### ***ASP Eric G. Neilson, MD, Distinguished Professor Award***

This award is presented annually to a physician who has demonstrated outstanding leadership and support of specialty internal medicine.

#### ***Hastings Center Fellow***

This designation honors Dr. Arnold for outstanding efforts that have informed scholarship and public understanding of complex ethical issues in health, health care, science, and technology.

### **Jane Schell, MD**

#### ***Hastings Center Cunniff-Dixon Physician Award***

Selected for the Early Career Award by The Hastings Center, The Cunniff-Dixon Foundation, and the Duke University Institute on Care at the End of Life for her development of NephroTalk, Dr. Schell was one of five recipients selected to receive the award, which aimed foster models of good medicine for physicians and demonstrate the necessity of end-of-life care as it relates to the doctor-patient relationship.

### **Sandra Blakowski, MD**

#### ***VA Pittsburgh's 2018 Outstanding Physician***

Recognized by the VA Pittsburgh Healthcare System for her work in establishing two ground-breaking end-of-life programs, No Veteran Dies Alone and the Honors Escort. No Veteran Dies Alone relies on 24-hour volunteers to sit with and comfort dying veterans during their last hours. The Honors Escort ceremony is provided for veterans who have died in a VA Pittsburgh facility.

**UPMC Palliative and Supportive Institute  
10th Anniversary Fine Award**

Awarded by the Jewish Healthcare Foundation and The Fine Foundation. Deemed the “Wired for Excellence” award, the \$15,000 award honors institutions that successfully implement, sustain, and expand programs to other departments within their organizations. Says Kim Gottschalk, Director, Inpatient/Outpatient Palliative Care Services for PSI, “It’s a true honor to be recognized by an outside organization for the quality and innovative care we provide for our patients.”

**Scott Freeman, MD**

**Patient Experience Physician Champion of the Month**

This palliative medicine physician was recognized by UPMC Shadyside for his commitment and dedication to providing patients with an excellent health care experience.

**Denise Verosky, CRNP, Clinical Director,  
Palliative Services**

**UPMC Mercy Frances Warde Award**

This award annually recognizes a care team member who exemplifies the hospital’s values and mission.

**Stephanie Boehm, MSW, Social Worker,  
Palliative and Supportive Institute at  
UPMC McKeesport**

**“Above and Beyond” Award**

Stephanie was recognized for helping a seriously ill patient, who was unable to attend his wife’s funeral service, be able to say a final goodbye at the funeral home.

**Jennifer Pruskowski, PharmD, BCPS,  
BCGP, CPE**

**2018 ACCP New Clinical Practitioner Award**

This award recognizes a person who, after less than six years since completion of training, has made outstanding contributions to the health of patients and to the practice of clinical pharmacy.

**Dio Kavalieratos, PhD, Assistant Professor of  
Medicine, Section of Palliative Care and  
Medical Ethics at the University of Pittsburgh**

**2019 American Academy of Hospice and Palliative  
Medicine (AAHPM) Early Career Investigator Award**

Dr. Kavalieratos is the first-ever PhD ever to win this award which recognizes a developing research leader who shows promise in making contributions to the building of a scientific foundation for practice and research and who conducts and facilitates research by others that advances the field of hospice and palliative medicine.

**Andrew Thurston, MD, and Yael Schenker, MD  
Named as Fellows of the American Academy of  
Hospice and Palliative Medicine (AAHPM)**

This is the highest honor AAHPM can bestow on a physician.

**Julie Childers, MD, Jane Schell, MD, and  
Yale Schenker, MD**

**Named as Emerging Leaders in Hospice and  
Palliative Medicine**

This award recognizes their career accomplishments, involvement in the Academy, mentoring of residents and students, and participation in charitable work.

**Keith Lagnese, MD, Chief Medical Officer for  
Family Hospice, part of UPMC**

**Recipient of UPMC’s Award for Commitment and  
Excellence in Service (ACES) for 2019**

“Dr. Lagnese makes a profound difference to patients and their families during the most difficult time they may ever experience,” says Jennifer Vennare, Vice President, Clinical Operations, Family Hospice.

**Katrina Clacks, CRNP, UPMC McKeesport  
Recipient of UPMC’s 2019 Dignity and Respect  
Champion Award**

Katrina, who is part of the palliative care team at UPMC McKeesport, was recognized during a ceremony held at the UPMC Club at Heinz Field.



- A. Robert Arnold, MD**  
ASP Eric G. Neilson, MD, Distinguished Professor Award
- B. Jane Schell, MD**  
Hastings Center Cunniff-Dixon Physician Award
- C. UPMC Palliative and Supportive Institute**  
10th Anniversary Fine Award
- D. Scott Freeman, MD**  
Patient Experience Physician Champion of the Month
- E. Denise Verosky, CRNP**  
UPMC Mercy Frances Warde Award
- F. Stephanie Boehm, MSW**  
“Above and Beyond” Award
- G. Jennifer Pruskowski, PharmD, BCPS, BCGP, CPE**  
2018 ACCP New Clinical Practitioner Award
- H. Dio Kavalieratos, PhD**  
2019 American Academy of Hospice and Palliative Medicine (AAHPM) Early Career Investigator Award
- I. Keith Lagnese, MD**  
Recipient of UPMC’s Award for Commitment and Excellence in Service (ACES) for 2019
- J. Katrina Clacks, CRNP**  
Recipient of UPMC’s 2019 Dignity and Respect Champion Award



# Research and Quality Initiatives

**Palliative Research Quality Initiatives: Bigger, broader, and bolder**

Traditionally, a great deal of palliative care research has focused on older patients with cancer. Though it's a population in which research is of value, UPMC sees the importance of taking a lead role in bringing palliative care research to other underserved populations who could potentially derive significant benefits from this care as well. At the same time, quality improvement efforts are ensuring that we are good stewards in sharing our depth of insights about palliative care with our colleagues and partners throughout the health system.

Our colleagues at the Palliative Research Center (PaRC) at the University of Pittsburgh are important collaborators in these efforts. PaRC includes a growing team of faculty, post-doctoral fellows, medical students, undergraduates, and staff whose research focuses on improving quality of care for patients with serious illness and their families through the development, evaluation, and dissemination of evidence-based palliative care interventions. PaRC collaborates with clinicians at patient care clinics across the UPMC system and beyond to implement intervention-based research projects.

### Rethinking Rare Diseases: Valuable cystic fibrosis research brings palliative care to a new population

Researchers at UPMC are participating in the first-ever clinical trial of palliative care in cystic fibrosis, a fatal genetic disease. “We’re changing the paradigm of how we think about palliative care,” says Dr. Dio Kavalieratos, Associate Professor of Medicine & Director of Palliative Care Research, Emory University (formerly Assistant Professor of Medicine, University of Pittsburgh).

Some of the questions that Dr. Kavalieratos is hoping to answer through a study focused on adults with advanced cystic fibrosis include: how might palliative care support people who have had a disease from childhood, how could it be implemented earlier so we can help patients both manage symptoms and prepare for symptoms and circumstances they may face down the road.

Though people with cystic fibrosis have likely been surrounded by a circle of health care experts since birth — pulmonologists, dietitians, respiratory therapists, endocrinologists, and others — Dr. Kavalieratos believes palliative care could serve as an additional level of support. “Historically there hasn’t been a person on the care team who takes care of things like symptom management, exploring the patient’s goals of care, and preparing them for the rest of their lives,” says Dr. Kavalieratos. “We’re testing what happens when you redesign the care team to include a palliative care specialist.” About 70,000 people in the U.S. have cystic fibrosis. Some of them may be presented with care options that do not reflect their values and needs. Faced with an aggressive care option, a lung transplant for example, would present a situation where a palliative care provider could initiate conversations about goals of care.

“Palliative care can be the pause button that allows a patient and their provider to talk about the ramifications of a particular treatment option,” says Dr. Kavalieratos. “While a procedure or treatment might be a good option for one patient, it may not be the best choice for every patient.”

After conducting a successful pilot program, Dr. Kavalieratos (while still at UPMC) was granted \$3 million from the Cystic Fibrosis Foundation to fund a three-year project that includes 264 adults with advanced cystic fibrosis in five sites across the U.S. and Canada: Emory University, University of North Carolina at Chapel Hill, University of Alabama – Birmingham, University of California San Diego, and St. Michael’s Hospital (Toronto, Canada). Half of the participants will receive care from a palliative care nurse practitioner in addition to their usual CF care, while half will continue to receive usual care from their existing team. Dr. Robert Arnold, Medical Director of UPMC’s Palliative and Supportive Institute, will remain involved in the study, providing input on developing training for the study’s nurse practitioners.

Dr. Kavalieratos hopes to discern the benefits of adding a palliative care specialist to the team. He’s also curious to see if the cystic fibrosis teams begin to develop and hone their own palliative care skills as a result of working with the palliative care specialists.

### Advance Care Planning: Is it easier in person or online?

Advance care planning is important for everyone, but it is particularly helpful for patients with advanced cancer. To make sure these patients have their wishes honored, Dr. Yael Schenker, Associate Professor, Section of Palliative Care and Medical Ethics at the University of Pittsburgh, recently received a \$3.1 million NIH grant to determine the most effective and efficient advance care planning strategies.

“While a procedure or treatment might be a good option for one patient, it may not be the best choice for every patient.”

— Dr. Dio Kavalieratos

*Associate Professor of Medicine, Emory University*

*Former Assistant Professor of Medicine, University of Pittsburgh*

The study compares two options: one is having the cancer patient complete the advance care plan in person with a nurse or social worker, the other is web-based and can be completed at home or in a doctor's office. "These strategies are both widely used — but they are very different in terms of the time and costs involved," says Dr. Schenker, who seeks to arrive at the best way to engage patients and families to complete the planning. "People with serious illness and their families often face difficult treatment decisions. With this study, we hope to understand the best way to support those choices."

### Studying pain management in patients with HIV

Opioids are often used to treat chronic pain for people living with HIV. However, it's been shown that this treatment doesn't always result in substantial improvement in outcomes. It also contributes to the growing opioid epidemic. Dr. Jessica Merlin, Associate Professor of Medicine for the University of Pittsburgh, focuses on palliative care and addiction, and recently received a National Institutes of Health grant to study behavioral interventions for people living with chronic pain from HIV.

"Behavioral interventions are among the most effective and safest treatments for chronic pain in the general population," says Dr. Merlin. "This is a highly understudied area, with great potential to improve pain and function among HIV patients."

Dr. Merlin's research seeks to develop and test pain self-management interventions tailored to the needs of people living with HIV. "I'm excited to be able to do this work," she says. "If effective, this intervention has the potential to be an important tool that HIV clinicians can use to help their patients who struggle with chronic pain."

### Quality Improvement Projects: Getting better from within

Dr. Dio Kavalieratos, former Director of Implementation Research, UPMC Palliative and Supportive Institute, and now Associate Professor of Medicine, Emory University, who oversaw all of the quality improvement at UPMC for palliative care, appreciates the value of improving palliative care within the health system. "No other health system that I know of has as much quality improvement in palliative care as UPMC does," he says.

Overall, the breadth of palliative care initiatives within UPMC focus on changing the health care system so that palliative care can be delivered by providers other than palliative care specialists. The goal is to teach clinicians from cardiologists and nephrologists to intensive care doctors, nurses, and others how to provide fundamental palliative care without having to go to school or do a palliative care fellowship.

Dr. Kavalieratos recently published a paper about the results of coaching internal medicine residents in basic palliative care skills. The residents met with palliative care physicians two times a week, discussed difficult conversations they had experienced with patients, and received coaching on how to approach these situations.

"The benefits were clear," says Dr. Kavalieratos. "We showed that coaching improved the trainees' confidence and competence in palliative care skills. It also improved the documentation of patients' goals. That's important, because then there's a record of what the patients want if they become unable to speak for themselves."

### The nurse's role in primary palliative care

Nationwide, most patients with advanced cancer lack access to palliative care specialists. New models of primary palliative care — meaning palliative care provided by non-specialists — are needed. PaRC researchers are investigating the feasibility and efficacy of such care models. Led by Yael Schenker, MD, MAS, the NIH-funded CONNECT project is evaluating an oncology nurse-led primary palliative care intervention for patients with advanced cancer and their family caregivers in western Pennsylvania. CONNECT is an acronym for Care management by Oncology Nurses to address supportive Care Needs Trial. The trial is made possible by a \$2.8 million award.

In 2016, 26 UPMC Hillman Cancer Center oncology nurses were trained to deliver the CONNECT intervention, which includes nurse-led provision of four key primary palliative care domains: symptom management, advance care planning, emotional support, and care coordination. The three-day CONNECT nurse training includes the opportunity to practice and receive feedback on palliative communication skills.

Judi Resick, MSN, MPH, RN, serves as Nurse Project Manager for CONNECT. Her role includes staying in close communication with CONNECT nurses to provide ongoing mentorship and support. As Resick describes it, the nurses expressed a sense of personal and professional fulfillment from learning and delivering these primary palliative care skills.

Nicole Miller, RN, is a participating nurse in Indiana, PA. When asked about how this experience impacted her, Miller reflected, "I always want to support my patients, but to do so on a different level is so rewarding. The CONNECT visits created protected time with my study patients and allowed me to talk with them about more than just their symptoms. I could explore their fears and questions about their treatment and planning for the future."

The most valuable aspect of the education and mentorship is something simple and powerful, according to Resick. "Serious illness is a different language," Resick explains. "Having the words to use in difficult situations is so important. We employ patient 'actors' and scripting to allow the nurses to practice new communication skills. Combined with their training in managing symptoms, nurses can use CONNECT communications skills to help patients voice their goals of care and cope."

"Our goal is to test new ways of providing palliative care for patients who lack access to palliative care specialists," adds Dr. Schenker.

The ongoing trial, which completed enrollment of 672 patients with advanced cancer and 441 of their family caregivers in October 2019, assesses the impact of the CONNECT nurse intervention model on patients, family caregivers, and health care utilization. Patient outcomes include quality of life, symptom burden, and mood. Similarly, for the caregiver, the trial is examining caregiver burden and mood. The final analysis is the potential impact of CONNECT on health care utilization, such as hospital stays, emergency department visits, and/or hospice. The trial extends through 2021.



**Having the words to use in difficult situations is so important. We employ patient 'actors' and scripting to allow the nurses to practice new communication skills."**

— Judi Resick, MSN, MPH, RN



## Our Partners

Our vision is to bring more and better palliative care to people throughout the region. We wouldn't think of doing it alone and thanks to strong relationships with existing organizations whose values align with our own, we don't have to. Together, we can provide the appropriate level of care in the right setting for seriously ill patients while offering support to their families.

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### **The RAVEN Initiative: A partnership that's growing in innovative ways**

Avoiding unnecessary and stressful trips to the hospital for residents in nursing facilities is a key goal of RAVEN (**R**educe **A**voidable hospitalizations using **E**vidence-based interventions for **N**ursing facilities in Pennsylvania), an Aging Institute and CMS project supported by PSI.

One of RAVEN's many tactics to achieve that key goal is to provide clinical interventions at 15 nursing facilities across western Pennsylvania that participate in the initiative. These interventions are performed by on-site nurse practitioners and enhanced care nurses, many of whom receive training from PSI. "They help with the on-boarding process of new clinical staff," says April Kane, Project Co-Director - CMS RAVEN Initiative. "PSI allows RAVEN staff to shadow their expert clinicians to build familiarity with palliative care services."

Other RAVEN initiatives include education services through the Jewish Healthcare Foundation, pharmacy management, and telemedicine services. "Telemedicine is our most novel intervention," says Kane. "This program enables patients to receive clinical assessments remotely"

“The frontline nursing staff is very busy,” says Kane. “Utilization hasn’t been as high as we anticipated.” The telemedicine team came up with a unique solution in tandem with Curvai™, their telemedicine partner. “This year, we’re introducing a telepresenter role, which will reduce the burden on facility staff to initiate and prepare for a telemedicine consultation.” When frontline nurses notice a change in a patient’s condition, they can contact the telepresenter, who triages the call and, if necessary, dispatches a telepresenter to the facility within one hour.

“These individuals have a clinical background and are trained in the use of telemedicine,” says Kane. “They can present the patient, manage the cameras, and perform any hands-on activities to complete the exam.” Currently, there are seven facilities supported by this new program.

#### **UPMC Home Healthcare: Bringing palliative care to more patients at home**

Patients recuperating at home could always count on UPMC Home Healthcare for skilled care. Now, thanks to a partnership with Family Hospice, part of UPMC and PSI, Home Healthcare is offering much more — especially for patients who are undergoing aggressive treatments or have serious illness.

“We’ve had specialized programs with the UPMC Health Plan through Advanced Illness Care. Now we’ve incorporated a palliative care program that’s available to anybody,” says Paula Thomas, President, UPMC Home Healthcare.

“We want to support these patients and families who are facing progressive illness,” says Thomas. “With palliative home care, patients have the freedom to choose more aggressive treatment and also receive the psycho-social, spiritual, and pain management they need. It’s all about quality of life and keeping patients comfortable and managing their symptoms while allowing them to stay at home.”

The cases are managed by RNs who have additional training in palliative care. When appropriate, they seize the opportunity to have goals of care conversations with patients and their families. Some of the home health care agencies that are more advanced in the program have interdisciplinary team meetings during which Family Hospice and PSI take part in reviewing care.

An unexpected benefit is improved communication among the care teams and sharing of resources. “We’re filling in the gaps,” says Thomas. “We coordinate care plans and work with patients’ doctors. It really enhanced the care we can offer to these patients.”

#### **UPMC Senior Services: A resource for patients and families**

UPMC Senior Services and PSI have a long history of collaboration, and the partnership is a natural one, according to Richard Morycz, PhD, Associate Professor, University of Pittsburgh School of Medicine and Geriatric Services, UPMC Western Psychiatric Hospital. “Fifty to 75 percent of palliative care patients are over the age of 60, so there is a lot of overlap in issues relating to palliative care treatment and the considerations of growing older.”

UPMC Senior Services connects older adults, their loved ones, and their caregivers with supportive resources and programs throughout their communities. One of its main offerings is a call line, which provides resources and referrals for older people, their families, and caregivers. “It’s particularly helpful for patients who have just been discharged from the hospital or who are living at home with a serious illness,” says Morycz. “We help patients and families get information on resources, and we also follow up to make sure they successfully connect with those resources.”

One newer initiative at UPMC Senior Services is supporting the placement of social workers throughout senior care facilities and the PSI network. “There are many topics in aging that our social workers really focus on, such as family caregiver burden, as well as grief, loss, and depression,” says Morycz.

“Palliative care patients often struggle with issues of aging, including adapting to new circumstances, and how to cope and deal with depression,” Morycz adds. “Families who support palliative care patients often struggle with the changes they see in a loved one who has a serious illness and may be facing death.” UPMC Senior Services continues to look for new ways to partner with PSI and respond to the challenges of older patients in palliative care.

#### **Jewish Healthcare Foundation Death & Dying Fellowship: It’s not taboo if you talk about it**

Five years ago, the Jewish Healthcare Foundation (JHF) created the Death & Dying Fellowship to teach aspiring health care professionals how to talk about something no one wants to face — the end of life.

The annual program accepts 30-35 students who are pursuing health care-related careers. Over an eight-week period, participants learn how to broach the difficult topic of death with terminally ill patients and their families.

This year, PSI and Family Hospice, part of UPMC, joined in supporting the effort. Dr. Robert Arnold, Medical Director, UPMC Palliative and Supportive Institute, spoke at the Fellowship’s last meeting. “Patients are fearful about the end of their lives and doctors lack the incentive to discuss it,” Dr. Arnold told the fellows. “We collude not to talk about it.” He encouraged the participants to make end-of-life care part of their professional skill set.

By targeting future physicians, pharmacists, social workers, medical ethicists, and others, the JHF Fellowship hopes to create champions for end-of-life discussions throughout the medical community and promoting ways to assist patients in weighing the merits of more procedures versus more conservative care options.

“The Death & Dying Fellowship was a wonderful learning opportunity,” says Emily Kistler, fourth-year pharmacy student at the University of Pittsburgh School of Pharmacy. “I was able to learn in an interdisciplinary environment about a topic that is not talked about often. I got valuable insights from physicians, nurses, chaplains, directors, and others in the field. By the end of the fellowship, I felt more confident in my ability to navigate conversations about death and dying, and support patients and families.”



**With palliative home care, patients have the freedom to choose more aggressive treatment and also receive the psycho-social, spiritual, and pain management they need.”**

— *Paula Thomas, President, UPMC Home Healthcare*





## Our Benefactors

The UPMC Palliative and Supportive Institute gratefully acknowledges the invaluable support of benefactors committed to expanding the palliative care expertise of all providers and improving the quality of life for patients and families across the continuum.

Arthur Vining Davis Foundations

Ms. Marianne Chapas Bonfield

Mr. William L. Getson

Richard and Linda Gustafson

Ms. Anne M. Immekus

Jewish Healthcare/Fine Foundation

Mr. Matthew F. Kluk

Ms. Caroline Mendis

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VitalTalk

Mr. Cyril Walther

Mr. Jerry L. Williams Sr.

Mrs. Kristy A. Wright

### Honoring their mothers by helping others

Richard “Gus” Gustafson was living in Northern Virginia when he got the call that his mother had been brought to UPMC Presbyterian where it was learned she had life-threatening internal bleeding resulting from medications to treat long-term liver disease. Gus and his wife, Linda, drove the five hours to be with her and Gus’ siblings.

Ila Pianka’s body was fragile and the family soon learned she would not survive without heroic interventions. Years before Ila had made it clear to Gus, his brothers, and sisters that she did not want a liver transplant, nor did she want to prolong her life for the sake of longevity.



Richard “Gus” Gustafson and his wife Linda

It was a time of sadness and extreme emotions for the family. Gus recalls little of those days except for the compassion and support provided by the UPMC palliative care team. “They got us through the decision-making process,” he says. “Even though we knew what mother wanted, it was difficult.” Ila was three weeks shy of her 70th birthday when she passed away peacefully on December 3, 2004.

Sadly, Linda had lost her own mother, Joanne Sagen, age 58, to breast cancer some years before. Although Joanne did not receive palliative care, she did have hospice for the last two years of her life, and for that Linda is profoundly grateful.

To honor their mothers, Gus and Linda established the Ila G. Pianka and Joanne D. Sagen Memorial Fund in the Section of Palliative Care to support new areas of research as well as training for palliative care specialists. The Gustafsons continue to support the fund through annual contributions.

“Initially, I thought that we didn’t have the level of resources needed to do anything substantial,” Gus says. “But we are really pleased to see how the fund has grown and to receive reports on what our gifts have made possible.”

“The palliative care people ... I can’t begin to tell you how absolutely wonderful they were in helping our family. I get tears in my eyes thinking about it. We are so happy to be able to help this great work continue.”

“Initially, I thought that we didn’t have the level of resources needed to do anything substantial, but we are really pleased to see how the fund has grown and to receive reports on what our gifts have made possible.”

— Richard “Gus” Gustafson

### An Arthur Vining Davis Foundations Award: Addressing disparities in palliative care

As palliative care grows at hospitals across the country, efforts to improve the care are growing as well. A \$250,000 award from the Arthur Vining Davis Foundations aims to bring diversity to a field that is disproportionately Caucasian. The award funds a cross-cultural, multi-center initiative led by UPMC Palliative and Supportive Institute to address disparities in palliative care specialists.

“Our workforce should reflect the growing population of minority older adults, many of whom will benefit from palliative care,” says Yael Schenker, MD, MAS, Director of the Palliative Research Center at the University of Pittsburgh and co-principal investigator of the Arthur Vining Davis project. “Our hope is that through these key collaborations, we can start to address some of the disparities in access and quality of palliative care services. We are deeply grateful to the Arthur Vining Davis Foundations for making these efforts possible.”

The award provides funding for PSI to collaborate with three minority-serving medical schools to train minority physicians in providing palliative care. As part of the project, palliative care physicians from UPMC will visit Morehouse School of Medicine, Howard University College of Medicine, and the University of Puerto Rico School of Medicine to mentor faculty about incorporating palliative care into student and resident education.

UPMC faculty will also provide web-based educational materials and consultations on case reviews, pharmacy updates, and other topics to help physicians-in-training at the schools. In addition, the UPMC team hopes to build on the project by collaborating with Duke University on racial and ethnic disparities in palliative care.

“

Our workforce should reflect the growing population of minority older adults, many of whom will benefit from palliative care.”

— Dr. Yael Schenker



Dr. Yael Schenker, Annie Bryan from The Arthur Vining Davis Foundations, and Dr. Robert Arnold.

“Our goal is to help medical faculty embed palliative care into their resident student education,” says Dr. Robert Arnold, Medical Director of PSI. “To make this happen, we will train faculty at each of these institutions to serve as local palliative care mentors to students from under-represented groups.”

The funding is part of the Arthur Vining Davis Foundations’ efforts to advance humane, respectful, end-of-life care. UPMC is one of six organizations selected as Arthur Vining Davis Foundations Designated Partners for palliative care funding from 2018-2020.

## **UPMC PALLIATIVE AND SUPPORTIVE INSTITUTE**

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