

WINTER 2016

Believe IN A CURE

UF HEALTH CANCER CENTER NEWS



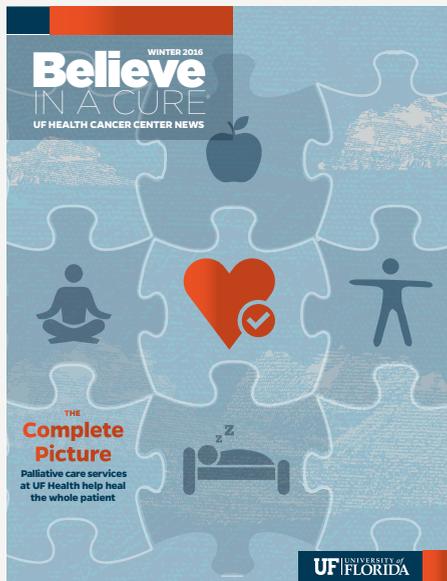
THE
**Complete
Picture**

Palliative care services
at UF Health help heal
the whole patient

- 3 From the director's desk**
A few words from the new director of the UF Health Cancer Center
- 4 Tailoring treatment**
Study uses computer simulation to model patient cancer DNA
- 6 The complete picture**
Palliative care services at UF Health help heal the whole patient
- 10 Climbing for Dad**
Siblings climb Mount Kilimanjaro to raise money to help cancer patients, honor their father
- 11 Faculty spotlight**
Cancer pain researcher works to bring palliative care to forefront



About us



Believe in a Cure is the newsletter for the UF Health Cancer Center, home to cancer care and research for the Southeast's most comprehensive academic health center. In each issue, we will bring you stories about the progress and patient-centered care occurring at the center, as well as the partners who help make it happen.

Are you a patient?

For more information about care and services offered at the UF Health Cancer Center, call **352.273.8689**.

To support the work of the UF Health Cancer Center, call the UF Health Cancer Center Development Office at **352.273.8689**, write to P.O. Box 103633, Gainesville, FL 32610, or visit "Make a Gift" at **www.cancer.ufl.edu**.

To receive or opt out of receiving this newsletter, email Marilee Griffin at **margri@ufl.edu**.

ON THE COVER

There are many misconceptions about palliative care — the most harmful one being that it is for patients who've given up. In this issue, we examine the important role it plays for cancer patients throughout treatment and look at the palliative care services available through the UF Health Cancer Center.

PUBLISHED BY UF HEALTH COMMUNICATIONS

Director, UF Health Cancer Center

Jonathan D. Licht, M.D.

Chief Communications Officer, UF Health

Melanie Fridl Ross, M.S.J., E.L.S.

Editor

Marilee Griffin

Designer

J&S Design

From the director's desk

It's an exciting time for the University of Florida Health Cancer Center, and I am excited to be here.

It is an honor to be inheriting this letter, along with the title of UF Health Cancer Center director, from Dr. Paul Okunieff, whose five years of leadership were instrumental in establishing the center's national reputation. Since coming aboard in October 2015, I've seen firsthand the excellent foundation that's been set in place for the center to reach the next level as a cancer leader in the state and nation.

One of my first steps as director has been to investigate the possibilities right here on the UF campus. I want to know: How can we facilitate collaboration among departments, divisions and schools across the entire university? How do we find potential new collaborators and create new opportunities for existing faculty? What novel resources, research and technologies could offer meaningful solutions to the cancer problem, so as to speed the development of new therapies for our patients?

So far, I've found there is significant cancer research taking place all across campus. This type of impactful research often correlates with funding from major agencies, such as the American Cancer Society, the National Institutes of Health, the Department of Defense and the National Science Foundation. It's also research and collaborations like these that are most likely to have tangible relevance to the causation, detection and treatment of cancer.

Another one of our major goals will be to aggressively recruit leaders for the cancer center, representing investigators as well as basic researchers. We will also do our utmost to develop the careers of existing and newly recruited faculty and afford them the resources to further their cancer research and educational goals. We have a growing



JONATHAN D. LICHT, M.D. DIRECTOR

clinical practice, and we want to extend investigator-initiated clinical trials to as many people as possible to improve treatment outcomes for patients. For many cancers, standard therapy is just not sufficient, which is why we want to match our patients with the right experimental, therapeutic treatments.

In the coming years we will expand our National Cancer Institute-funded research portfolio of basic and translational research, which may be further facilitated by state support through the Florida Consortium of National Cancer Institute Centers Program.

Meeting these goals and others will be challenging, but it's a challenge I'm excited to have. With the number of Floridians aged 65 and older — the age group that bears the greatest cancer incidence — projected to swell to an estimated 25 percent of the state's population over the next two decades, our work has never been more important. Together, we will make great strides toward ending cancer.

Best regards,

Jonathan D. Licht, M.D.
Director, UF Health Cancer Center



Tailoring treatment

UF Health researcher Jatinder Lamba, Ph.D., UF Health physician and researcher Christopher Cogle, M.D., and co-founder of Cellworks Group Inc. Taher Abbasi

Study uses computer simulation to model patient cancer DNA

At University of Florida Health, researchers have launched a clinical trial that tests a new method of translating thousands of gene mutations into treatment options for patients. Using computer simulation modeling, the researchers will examine if the computer program will accurately predict how a person reacts to the cancer therapies their doctor has prescribed, depending on the person's genes. Not only will the software take the genes of a patient's cancer into account, it also will examine the genes that govern how a person reacts to a particular medication.

UF Health physician and researcher Christopher Cogle, M.D., lead investigator of a clinical trial that will study the effectiveness of this computer model, treats and studies different types of blood cancers and typically sees patients whose cancer has relapsed. To determine the best course of treatment for individual patients, Cogle needs to map thousands of genes within each patient's cancer that can drive aggressive growth. Cancer often involves hundreds to thousands of gene abnormalities, which raises one of the most difficult challenges in medicine: how to decode the numerous DNA misspellings that drive disease.

Cogle is teaming up with Jatinder Lamba, Ph.D., a member of the UF College of Pharmacy and a cancer pharmacogenomics researcher. Together, they will examine 91 genes involved in the movement of drugs within the body. These so-called "pharma-genes" will then be tested to identify which treatments are safest and most effective for the patient.

"The cancer genes are genes we believe will give us prognostic and treatment information, and the pharma-

genes will tell us how well the patients will respond to the drugs we prescribe," said Cogle, an associate professor of medicine in the UF College of Medicine.

This kind of close examination is a new approach to cancer treatment, taking into account not only how well a therapy targets cancer but also how that therapy impacts the health of a patient. Typically, to find the significance of a cancer mutation, cancer doctors use a manual approach through PubMed, a free search engine overseen by the National Institutes of Health that catalogues studies in life sciences and biomedicine. But searching for one gene, a medication to treat it and how that medication might react in a person's body could take hours, Cogle said.

That's where Cellworks Group Inc., a California-based company, comes in. The company created a simulation technology to generate a computer model of each person's cancer. Cellworks can then model how the cancer responds to standard chemotherapies.

If the computer method is proven valid, this prediction technology could help doctors and patients choose drugs with the greatest likelihood of shrinking the cancer and avoid harmful drugs with a low chance of success. For patients who aren't responding to standard chemotherapy and for patients whose cancer has relapsed, each patient's computer model could be used to search for other FDA-approved drugs that may be more effective.

UF Health researchers must first develop accurate and precise tools for predicting cancer shrinkage and side effects. Their ultimate goal is to ensure that individual patients are matched to tailored treatments best treats their cancer and causes the least amount of harm.

"Each patient should receive a therapy that's best for that patient — that's what we're trying to do," Lamba said.

The clinical study launched in June 2015.

—Morgan Sherburne

HALLOWEENER DERBY

On Oct. 17, the Climb for Cancer Foundation hosted a four-legged race to the finish line with the annual Halloween Derby at Kanapaha Veteran's Memorial Park. Residents of North Central Florida enjoyed a dachshund-only race, a pet costume contest for all breeds, food and music. All proceeds from the event went to Climb for Cancer, a local nonprofit that supports cancer patients and their families at UF Health.



A GOOD CAUSE

COMMUNITY

◀ A DOSE OF FASHION

The Climb for Cancer Foundation hosted a fashion show fundraiser, "A Dose of Fashion," at the Gainesville Woman's Club on Sept. 10. The event showcased 500 years' worth of fashion trends, with models embodying characters such as flappers and suffragettes while attendees enjoyed tea. The event raised money for the local nonprofit Climb for Cancer Foundation and oncology programs at UF Health.



JOEY'S WINGS ▶

For the entire month of September — Childhood Cancer Awareness Month — 2,000 origami cranes were on display in the UF Health Shands Children's Hospital Sebastian Ferrero Atrium. This display honored the lives of approximately 2,000 children lost to cancer every year in the U.S.

Kathy Liu lost her son Joey in November 2014 from renal cell carcinoma, a type of kidney cancer. In March 2015, she established a nonprofit charity in memory of her son: Joey's Wings Foundation. Its mission is to support researchers whose work is focused on pediatric kidney cancer — and to promote education and advocacy efforts for parents. Liu and volunteers made the crane display to raise awareness about childhood cancer.



THE Complete Picture

Palliative care services at UF Health help heal the whole patient

MORGAN SHERBURNE



Near the end of a young patient's life, Emily Sullivan and a group of University of Florida Health volunteers visited him in his hospital room.

The patient, whose leukemia had relapsed, had one instruction for them: Throw him a party, or he would haunt them forever.

So Sullivan, director of Streetlight, the UF Health adolescent and young adult peer support program, and several of the volunteers did just that — after he went home, only a few days before he died.

"We watched his favorite YouTube videos," Sullivan said. "We did all the things that would dignify him."

The Streetlight program is designed to help

young people ages 13-25 through chronic illnesses, including cancer, by supporting them socially and psychologically.

This kind of care is often misunderstood as care given only when a patient has a terminal illness. But health care providers at UF Health and the UF Health Cancer Center are working to change that perception.

"Many doctors and many patients are reluctant to be referred to a palliative care program because they think it means end-of-life and end of care," said C. Parker Gibbs, M.D., the deputy director of medical affairs at the UF Health Cancer Center. "'Palliative' means relieving pain or alleviating a problem without dealing with the underlying cause. We're going to take care of your symptoms while other doctors address your cancer."

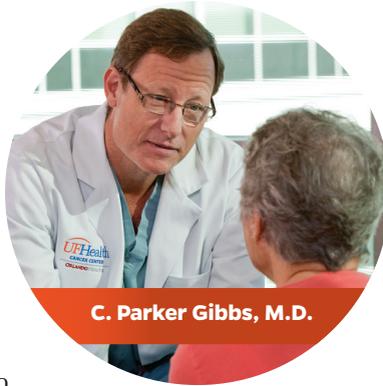


Tammy Bernard, M.Ed., is a yoga practitioner in the UF Health Integrative Medicine Program who works with patients living with chronic health conditions ranging from arthritis to cancer.

“We see the best possible chance for a cure is to start palliative care at the time of diagnosis.”

—Sheri Kittelson, M.D.

Sheri Kittelson, M.D., a hospitalist at UF Health Shands Hospital, helped establish UF Health’s first palliative care program — offered to all patients, not just those with cancer — in 2012. She is currently completing a fellowship in palliative care at the University of Colorado, after which she will return to become chief of palliative care at UF Health.



C. Parker Gibbs, M.D.

“We see the best possible chance for a cure is to start palliative care at the time of diagnosis,” Kittelson said.

For example, if physicians are able to ease a patient’s pain, address her ability to eat and soothe worries about what the future may bring, the patient may have a better chance of responding to treatment

“A recent study shows patients who receive palliative care at the time of diagnosis have a better quality of life and even live longer, despite less aggressive care,” Kittelson said. “Palliative care is a young discipline and there is not enough research in the area, but what we anecdotally believe is that if you feel better overall, it’s easier to tolerate your cancer-treatment regimen. When your symptoms are managed, you’re going to sleep better, you’re going to eat better, your stress level is down and your immune system works better.”

During a consult, an interdisciplinary team including physicians, advance practice nurses,



The Streetlight program



UF Health Shands Arts in Medicine musician-in-residence Danielle DeCosmo, left, singing to patient Peggy Drummond.

social workers and chaplains visit with the patient and his or her family after conferring with the patient’s primary oncologist to develop a treatment plan based on the patient’s goals of care. This plan includes pain and other symptom management as well as supporting the patient’s spiritual and religious needs.

In the UF Health Cancer Center, individual physicians talk with their patients about symptom management, pain control and end-of-life issues, Gibbs said. Physicians also refer their patients to other UF Health programs that focus on palliative care.

“We have an outstanding integrative medicine program, run by Dr. Irene Estores,” Gibbs said.

Estores, M.D., leads the UF Health Integrative Medicine Program, which was established in 2013 and has recently expanded. The program offers services such as guided imagery, medical acupuncture and yoga.

“Integrative medicine addresses the needs of the whole person — mind, body, spirit — in the context of community,” said Estores, the program’s medical director. “We’re coming back to our roots and honoring what was



Diana Wilkie, Ph.D., R.N., FAAN

Palliative care allows patients to participate more fully in their care.

—C. Parker Gibbs, M.D.

effective in other healing traditions and using that to be able to be more effective in caring for our patients.”

Part of the program includes yoga led by a practitioner, Tammy Bernard, M.Ed., certified to work with oncology patients. Yoga helps patients focus on breathing, which Bernard says can support a reduction of various stress hormones. The National Institutes of Health backs this up: it reports that relaxation techniques such as deep breathing may be effective as part of an overall treatment for anxiety, depression and some types of pain.

To help establish palliative care and palliative care research throughout the whole health science system, Diana Wilkie, Ph.D., R.N., FAAN, was brought to UF. She will help build the Center of Excellence in Palliative Care Research, which will be housed in the College of Nursing.

“The center will be interdisciplinary, including people from all health science colleges and the UF Institute of Food and Agriculture Sciences,” said Wilkie, the College of Nursing’s Prairieview Trust – Earl and

Margo Powers Endowed Professor. “We are trying to think very broadly about how palliative care research is conducted and disseminated to care for people who have life-threatening illnesses.”

The center will focus on end-of-life care as well as management of pain and symptoms for people with serious, but curable, illnesses. The center will also examine whether palliative care delivered at the same time as cancer treatment will allow patients to have better outcomes and live longer.

The center’s research will augment palliative care clinical trials already ongoing at the UF Health Cancer Center. Some of these supportive care clinical trials test medications that could help patients better tolerate the side effects of chemotherapy.

But not all disease and cancer diagnoses result in cure, and it’s important for health care providers to acknowledge this, Wilkie said. Physicians and social workers can help a patient plan for end of life, although Wilkie recommends outlining an advance care plan as a healthy adult.

“This can help when you are diagnosed with cancer. You would know where your priorities are, and how you would like to focus your energy,” Wilkie said. “It’s hard



Chaplain Debra Hepburn in the Sanctuaries of Silence and Peace, located at the UF Health Shands Cancer Hospital.

to think of those things once you get a cancer diagnosis because you’re so busy fighting cancer. But the whole idea of what you’re fighting for is really important.”

For Gibbs, palliative care can mean empowering his patients, who can feel vulnerable and powerless when facing a cancer diagnosis.

“Palliative care is a much more collaborative doctor-patient relationship and allows patients to participate more fully in their care,” Gibbs said. “It means they can do something — eat better, exercise, meditate and take some control over their lives that is now being taken away from them.”



PALLIATIVE CARE FAQ

What is palliative care?

Palliative care is given to improve the quality of life of patients who have serious or life-threatening illnesses like cancer or congestive heart failure. Rather than curing the patient, palliative care is aimed at treating and providing relief from symptoms such as pain, loss of appetite and depression. Palliative care — sometimes called comfort care, supportive care or symptom management — also focuses on the patient’s psychological, social and spiritual well-being.

Why is palliative care used in cancer treatment?

Palliative care may help patients deal with cancer symptoms and treatment side effects like shortness of breath, insomnia and fatigue through medications, physical therapy, nutrition therapy and breathing techniques. Cancer patients may also seek emotional and spiritual counseling.

Can a friend or family member receive palliative care?

Yes. It’s common for family members to feel overwhelmed when caring for a sick loved one. Palliative care can help patients’ families cope with stress and fear and give them the support they need.

If a cancer patient accepts palliative care, does it mean treatment is not an option?

Not at all. Palliative care is used in addition to regular cancer treatments to make a patient feel comfortable and at ease. It helps patients with the symptomatic and emotional aspects of cancer, and can assist with the transition to end-of-life care, such as hospice.

What is the difference between palliative care and hospice?

Hospice is actually a form of palliative care. It’s given to patients with a terminal diagnosis when treatment options have



been exhausted, as part of their end-of-life care. Meanwhile, palliative care can begin at diagnosis and continue through treatment, including follow-up care and — if necessary — hospice.



At the summit of Mount Kilimanjaro, Amy and Chris called their parents from a satellite phone.

Climbing for Dad

Siblings Amy and Chris Bucciarelli took to Africa's highest peak to honor their father, Dr. Richard Bucciarelli, and raise money to help cancer patients.

They climbed the final steps toward the summit of Mount Kilimanjaro arm in arm, big sister and little brother, each holding onto a piece of a Gator flag emblazoned with dozens of names.

John, Matthew, Linda, Rick ...

Tears welled in her eyes as Amy Bucciarelli, M.S., ATR-BC, LMHC, reached the summit with her brother, Chris Bucciarelli, M.D. They had been waiting for this moment for months, ever since Amy, an art therapist for UF Health Shands Arts in Medicine, had proposed the idea of participating in the Climb For Cancer Foundation's annual climb as a tribute to their father and to raise funds to combat the disease that took his life a few days after they reached the top.

Their father, Richard "Rick" Bucciarelli, M.D., a longtime faculty member in the department of pediatrics division of neonatology and former chair of the College of Medicine department of pediatrics, was diagnosed with an aggressive form of melanoma two years ago. After initial surgery and therapy two years ago, he relapsed last year. He passed away Sept. 20, surrounded by loved ones.

"I experienced this feeling of sheer helplessness," Amy said. "I help people every day, but I felt like there

To learn more about the **Climb For Cancer Foundation**, a Gainesville-based nonprofit that supports patient needs and cancer research projects at UF Health Shands Hospital, visit <http://www.cfc-foundation.org>.

was nothing I could do to help my dad."

So Amy signed up to go on the climb, a part of which included raising at least \$25,000 for the foundation.

Although Chris, a resident in the department of emergency medicine in the College of Medicine, was in full support of Amy's trip, he wasn't sure if he could go. It's challenging for residents to take long chunks of time off, and the trip would last two weeks.

"When my dad relapsed, I felt like it was a sign," Chris said. "This is literally a once-in-a-lifetime thing."

With the support of friends and family, Amy and Chris raised \$28,000 for the Climb for Cancer Foundation while preparing for the climb in July.

The approaching trip also changed how the family handled what they were going through. Since Rick's diagnosis, the family had kept much of their struggles to themselves. But preparing for the climb gave them reason to open up to more people.

"It was this community that was built around this experience," Amy said.

"When we did the actual climb, it felt like we had hundreds of people behind us."

In July, Amy and Chris left for Mount Kilimanjaro. It took five-and-a-half days to make it to the summit. By the time they saw the signs that they were about to reach the highest point, Amy started to tear up.

"In that moment I was overwhelmed with making it to the top, the air was already thin. It made it even more difficult to breathe when I started to cry."

Arm in arm, Amy and Chris walked the remaining 50 yards to the summit.

Their father chronicled the moment his children called him from the top of the summit on his blog, writing, "At 12:12 am. EDT via satellite phone one of the most welcomed sounds we have heard in a long time! 'We're are on the top!' 'The view is spectacular!' 'We feel terrific!' It was wonderful to hear their voices from half a world away and know they have hit the mark and are safe."

—April Lacey



Richard Bucciarelli with his children, Amy and Chris, and wife, Lynda.

Pioneer in palliative care

Faculty Spotlight

Diana Wilkie, Ph.D., R.N., FAAN

Cancer pain researcher works to bring palliative care to forefront

Diana Wilkie firmly believes that palliative care isn't only for people with life-threatening illnesses. While some associate palliative care primarily with end-of-life care, she says it should be available to anyone suffering from pain.

"Symptom or pain management is something that everyone needs if they're having any health concerns. I've believed that for my entire career," said Wilkie, Ph.D., R.N., FAAN, an internationally known pain expert who specializes in palliative and end-of-life care.

Her interest in these areas was sparked by a patient with pancreatic cancer who made the decision to enter hospice care, only to find out there wasn't a nurse available at that center who was able to take care of him.

At the time, hospice care was run on a volunteer basis. Wilkie came on board to take care of the man, and quickly realized that improving pain management, particularly for people with cancer, was where she wanted to focus her career.

Wilkie, who joined UF Health earlier this year, is currently leading efforts to establish the Center of Excellence in Palliative Care Research within the College of Nursing. As center director, her research involves working with other health colleges at UF to better manage pain in patients — even animal patients via the College of Veterinary Medicine. It's exciting to work at UF Health because there's support for the idea that palliative care is a multifaceted area of care, Wilkie said.

"UF Health provides us with the opportunity to have a very broad foundation for our palliative care center, which will really set us apart from other palliative care centers," she said.

While Wilkie has always believed palliative care should be given to anyone battling serious illness — not just

terminally ill patients — she said the larger health care community has more recently adopted that way of thinking.

Research shows that palliative care such as pain reduction or treatment of side effects can result in improved longevity and more tolerable treatments for patients with potentially life-threatening illnesses like cancer, Wilkie said.

"It's really important to recognize that palliative care provided during the time when someone is receiving treatment can result in better cancer care outcomes," she said.

Wilkie also believes better pain management through palliative care will also result in people being less afraid to go to the doctor.

"If we are able to promise people comfort, I think it will really change society's perception of health care," she said.

For the last 15 years, Wilkie's research has focused on people with serious chronic illnesses like cancer and sickle cell disease. Currently, she's looking at the mechanisms of sickle-cell pain to better treat the disease and improve the lives of sufferers.

Additionally, Wilkie is awaiting the results of a Chicago study of an app that enables patients with cancer to use tablets to monitor their symptoms and pain in real time from the comfort of their homes. The app sends this information to their clinicians with recommendations for appropriate interventions, which increases patient-provider interaction and improves care. She hopes to bring this app to Florida once the study has been completed.

Another study that Wilkie's excited to have underway involves working with nurses and chaplains to implement "dignity therapy" in clinical practice for patients receiving palliative care at UF Health. The aim of this therapy is to help patients set personal goals for their care and to take control of their lives while undergoing treatment.

—Katherine Brown

A GIFT OF GRATITUDE

DURING UF HEALTH CANCER CENTER grand rounds on Sept. 9, 2015, Gainesville resident Susan Santerre presented a special plaque and letter to her doctor — Karen Daily, D.O., an assistant professor in the division of hematology and oncology in the UF College of Medicine. In a short speech, Santerre said the plaque symbolized her gratitude for Daily, who cared for Santerre as she underwent breast cancer treatment. Santerre said she wanted to present the award in front of Daily's peers to honor her not only as a doctor, but also as a compassionate human being. "Sometimes we forget to recognize good things in our lives," Santerre said. "I didn't want to let the opportunity to be thankful pass me by."



EVENTS

SATURDAY, MARCH 5, 8 A.M.

The second annual **Joey's Run and Food Fest** takes place at Westside Park and includes a 5K and a children's obstacle fun run. The event, which is hosted by the nonprofit Joey's Wings, benefits childhood cancer research. Sign up: <http://bit.ly/1SdqyKr>

SATURDAY, MARCH 19, 6 P.M.

Ocala Royal Dames for Cancer Research Inc. is hosting its **30th annual Tiara Ball** at the Golden Ocala Golf & Equestrian Club. It is the organization's largest fundraising event of the year; a portion of the proceeds will go toward the UF Health Cancer Center. For tickets: <http://bit.ly/1KfRbqH>

SATURDAY, APRIL 16, 9 A.M.

The **2016 Hogtown 5K Beer Run** is a cross-country run that winds through Haile Plantation. All proceeds benefit the Climb for Cancer Foundation, a not-for-profit that supports cancer patients and their families at UF Health. Learn more: <http://bit.ly/1nd1JBt>



P.O. Box 103633
Gainesville, FL 32610-3633