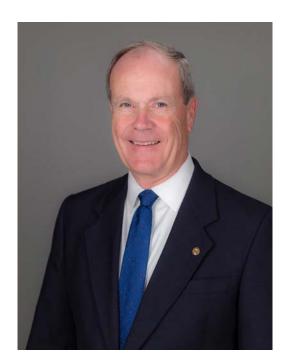


# Leadership Message



Timothy J. Adams Chair, Moffitt Institute Board of Directors

#### Dear Friends,

At Moffitt Cancer Center as we boldly pursue new and better ways to transform health, our primary focus is all about the patient.

In this issue, Dr. Philippe Spiess discusses treating men with penile cancer, a rare yet potentially debilitating disease. His initiatives include tissue sparing surgery for eligible patients, and he leads international research this cancer.

Dr. Iman Washington's focus as a radiation oncologist is on making life better for her patients with breast cancer. She describes her interest in reducing radiation treatment side effects while providing the optimum level of treatment for women with breast cancer. Additionally, she is working with colleagues to better understand why black women with triple negative breast cancer have higher rates of recurrence.

Joe Gallagher and Phil Scheidt each volunteer at Moffitt to honor loved ones they have lost and to ensure that their courage lives on. They, like the nearly 700 people who volunteer at Moffitt, were inspired to participate by the courage they've witnessed in their experiences with cancer - as a patient, a caregiver or through a loved one's journey.

In 2019 Moffitt earned its second designation as a Magnet facility by the American Nurses Credentialing Center. Achieved by only 8% of U.S. hospitals, the designation is considered the gold standard of excellence in nursing. The recognition also shows commitment to the patient and to their quality care.

On World Cancer Day Olympic gold medalist Scott Hamilton released a new book, "Fritzy Finds a Hat." The story helps families talk with their to learn more about better treating children as they tackle the difficult topic of cancer. For Hamilton, a member of Moffitt's national Board of Advisors, the subject is personal. As a teenager he lost his mother to cancer and later faced and survived his own diagnosis of cancer. The book teaches children a powerful message of how their love and support sometimes can be the best medicine, while expressing to parents how children want to be involved and to help in some way.

> We hope you will enjoy reading these stories that offer a glimpse into the various roles Moffitt patients, volunteers, advocates and team members play and their dedicated commitment to innovation and progress in cancer care.

# Inside this Issue

#### **Courage Comes In Many Forms**

Their own fan club: Teddy brings smiles each Thursday Tribute to an angel: handmade quilt provides comforting presence

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"Fritzy Finds a Hat" tackles topic of cancer

#### Penile Cancer?

Speak up and keep asking questions International study gains traction

#### Radiation Therapy and Breast Cancer

Exploring treatment strategies; reducing side effects

#### Gold Standard in Nursing Excellence

Moffitt earns second Magnet designation; innovation is recognized



**Eliciting Smiles** Teddy makes his rounds



**Inspiring Others** Children can have positive impact

#### ON THE COVER

Moffitt visitor Gianna Romulus shares a happy moment with Teddy, the pet therapy dog.

Cover photography by Nicholas Gould



**Tackling Health Disparities** Better understanding of breast cancer



# COURAGE LIVES ON

# Two volunteers honor loved ones through continued commitment to Moffitt

By Ann Miller Baker

Courage comes in many forms at Moffitt Cancer Center, as evidenced by the nearly 700 individuals who give of their time through Moffitt's Volunteer Services programs. From teens to seniors and even their family dogs, the vast majority of volunteers have been inspired to participate by the courage they've witnessed in their experiences with cancer – as a patient, a caregiver or through a loved one battling this dreaded disease.

For Joe Gallagher and Phil Scheidt, volunteering at Moffitt is one way to honor loved ones lost and ensure that their courage lives on.

#### THURSDAYS WITH TEDDY

Phil Scheidt spends each Thursday visiting clinic waiting rooms throughout the Muriel Rothman Building on Moffitt's Magnolia campus, dispensing smiles and the reassuring words only a fellow cancer patient can sincerely deliver. Phil has been a patient at Moffitt for two different types of cancer. But it's his companion that gets the most attention: Teddy, the dancing toy Maltese poodle mix in the Moffitt Pet Therapy vest. The pair has clocked nearly 400 hours since they started volunteering at Moffitt in October of 2017.

"We often joke that they have their own fan club," says Pet Therapy Volunteer Coordinator Debbie Emory.

Their biggest fan was also the reason they began volunteering at Moffitt. Phil's wife, Nancy, was diagnosed with advanced ovarian cancer in 2011, a change that prompted her to retire from a busy career with a long commute. That meant more time for something she'd long wanted – a dog. Specifically, a toy poodle.

"Nancy and I had both had German Shepherds in the past and I assumed she would want a larger dog, not a froufrou dog," Phil recalls. "I told her to get what she wanted but I would not bond with a toy poodle." The 9-week old bundle of fur that Nancy brought home had other plans. Teddy soon wormed his way into both Nancy and Phil's hearts. He also brought a lot of joy to Nancy through all she endured to keep her cancer under control, including multiple chemotherapy protocols and three clinical trials. It was a tough, eight-year battle for Nancy. Yet for seven of those years, she tirelessly volunteered in Moffitt's Infusion Clinic. Phil recalls one time when Nancy was receiving a 12-hour infusion of chemo and adamantly insisted that she needed to begin her volunteer shift still hooked up to the IV. Not long afterward, Nancy was honored with Moffitt's Volunteer of the Year Award for 2017.

### "We often joke that they have their own fan club."



Photography: Nicholas Gould



Photography: Nicholas Gould

### "I see their faces light up. They're not thinking about why they're here, what they have to do."

That's when Nancy suggested that Phil and Teddy ought to volunteer at Moffitt as well. Phil thought it might be something he'd like to do. Along the way to getting Teddy certified as a therapy dog, Phil saw the effect he had on people, like the senior citizens at a local nursing home where Teddy was put through his final exam for certification. Holding this little ball of fur brought tears to one resident's eyes. "As we left, I told Nancy this isn't something I might like to do, it is something I have to do," recalls Phil.

Making their rounds at Moffitt, Teddy has a routine that's sure to bring smiles to patients and staff - and special treat for him. He'll walk up to a patient and rub his head against their leg. Then he'll back up and stand on his hind legs, staring at Phil until he gets his reward: a tiny piece of cheese. Teddy's been known to stand up for quite a while. "I once timed him at 45 seconds," says Phil, quickly reassuring that Teddy is never forced to do anything.

Clearly, most people who meet Teddy are delighted by his antics. "I had a man come up to me one day and he told me how his father had met Teddy three weeks before and had not stopped talking about him," recalls Phil. "He said his dad had just had surgery and asked if I could bring him up to the fourth floor. That turned out to be an hour and a half visit as other patients came out of their rooms to see Teddy. "I see their faces light up. They're not thinking about why they're here, what they have to do. Teddy had that effect on Nancy too. He calmed her. She loved him from day one." Except for those rare occasions when Phil is traveling, there's only been one Thursday when the duo didn't make it to Moffitt for their volunteer shift: the Thursday that Nancy passed away. The coincidence isn't lost on Phil, but he says it strengthens his commitment to be at Moffitt each Thursday with Teddy.

"I actually went to grief counselling," says Phil. "My counselor said, 'You know, I've had a lot of people that won't go within five miles of Moffitt after losing a loved one to cancer; they'll go out of their way to stay away from it.' For me, it's just the opposite.

"Nancy truly loved this place. And so do I."

## TRIBUTE TO AN ANGEL

ON AN AVERAGE DAY, MORE THAN 200 PATIENTS WILL PASS THROUGH the Diagnostic Imaging waiting room on Moffitt's Magnolia campus. Some are seeking a diagnosis for what ails them. Others are regular visitors here, awaiting tests to determine whether their cancer is responding to treatment. All of them share the same sense of anxiety.

On Thursdays, Joe Gallagher is a calming presence escorting patients back to the CT Scan Unit. He knows many of the "regulars" by name and treats them like old friends. After all, many of them are; Joe's put in more than 2,700 hours since he began volunteering here in March of 2009.

Joe and wife Colleen signed up together as Moffitt volunteers, thankful for the surgeons who'd saved her life when Colleen was diagnosed with fallopian cancer in 2008. It was not her first brush with cancer: diagnosed with breast cancer in 1999, Colleen survived with chemo and a double mastectomy. But this time, the battle would be long and hard. For 10 years, Colleen's Moffitt care team always came up with another option whenever Colleen's cancer progressed.

"She would ask them, 'What's the toughest chemo? I want that one.' It didn't make any difference how it made her feel," recalls Joe. "This disease was not going to get the best of her."

"She would ask them, 'What's the toughest chemo? I want that one."



# "She was an angel put on this earth to guide women through cancer with a positive attitude."

Her goal was always to get back to volunteering in the Breast Imaging Center on Moffitt's McKinley campus. The women she guided back to changing rooms before their mammograms or biopsies seldom learned about Colleen's own cancer journey. She was always more focused on hearing their stories and sharing strength that comes from knowing you're not alone. "Look at these patients here, all facing the same thing," she'd often tell them. "You can talk to us."



"She was an angel put on this earth to guide women through cancer with a positive attitude," says Joe.

Colleen's way with patients didn't go unnoticed, particularly by Blaise Mooney, MD, a diagnostic radiologist and director of Breast Imaging at Moffitt. Whenever one of Mooney's patients was struggling emotionally, he'd seek out her help – not realizing how much she would eventually do to help him.

Shortly before Thanksgiving 2013, Mooney got news that a small tumor he'd been battling had morphed into stage four cancer. The biopsy results came on a Monday, Colleen's volunteer day. "She came into the reading room and said, 'I heard you got some bad news," Mooney recalls. It was only then that he learned what Colleen was going through. "She was the first person to sit down with me and say pull up your bootstraps and fight this thing."

Subsequent surgery cost Mooney parts of his tongue, jaw and neck that had to be rebuilt with tissue from his leg. Through months of recovery, he read radiologic studies on a home workstation and strove to return to Moffitt.

The day he did, Colleen was there to welcome him with more wisdom. "She said you've got this now, and it's never going to go away. It will always be in the back of your mind. But you can't let it rule your life," he recalls. "Use what you've learned to help your patients."

Mooney wasn't the only team member Colleen cared for. Away from Moffitt, she loved to sew, making custom quilts whenever anyone had a baby, got married or celebrated a major life event. "Every quilt was like a work of art, but also a work of love," says Jolie Filer, McKinley concierge services coordinator and volunteer liaison for the Breast program. "She'd stitch on the back of each one: Specially made for you by Colleen."

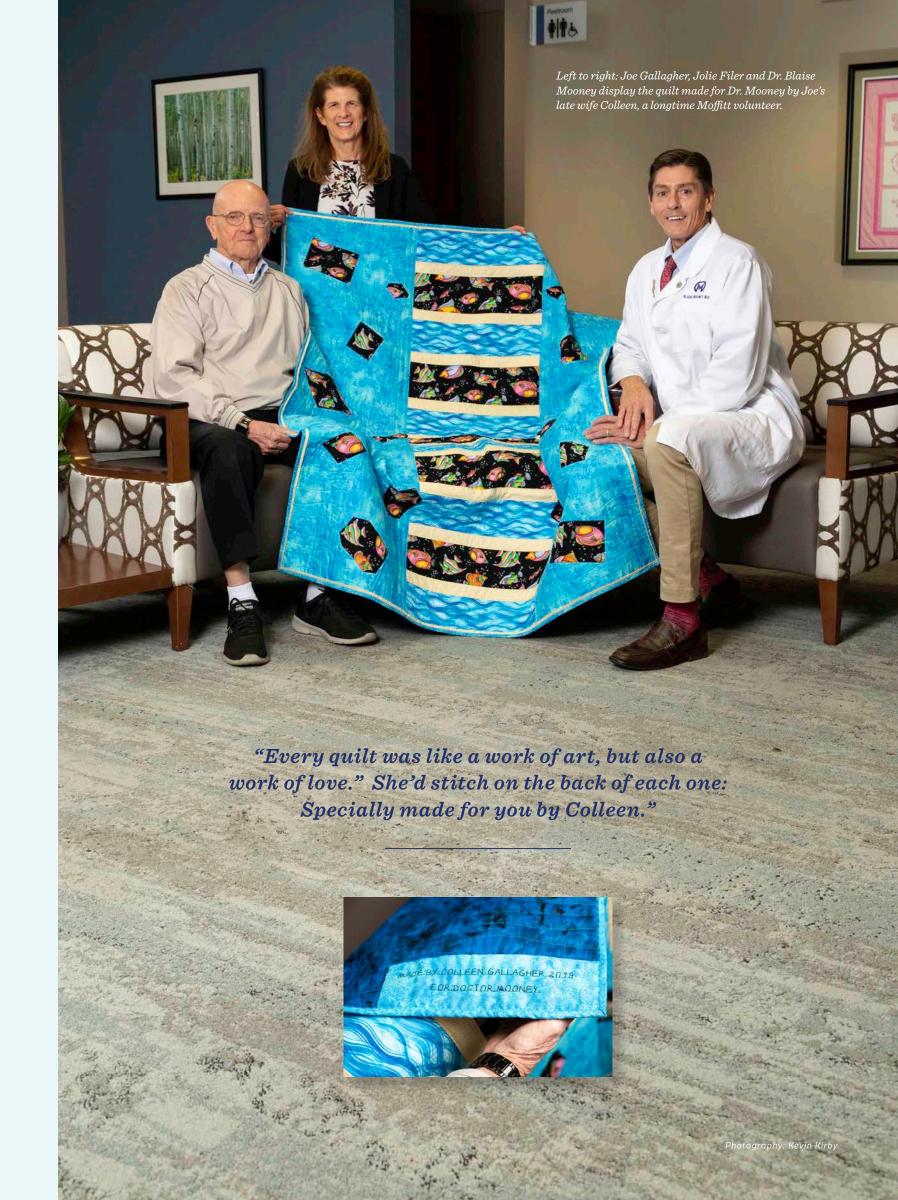
There was one last quilt on Colleen's sewing table when her cancer took a turn for the worse last year. She'd designed the ocean scene after Mooney mentioned living in the Caribbean and how much he wanted to share that with his sons. When the time came for Colleen to enter hospice care, she turned to her best friend and fellow quilter, Judy Woerner, to finish it for her.

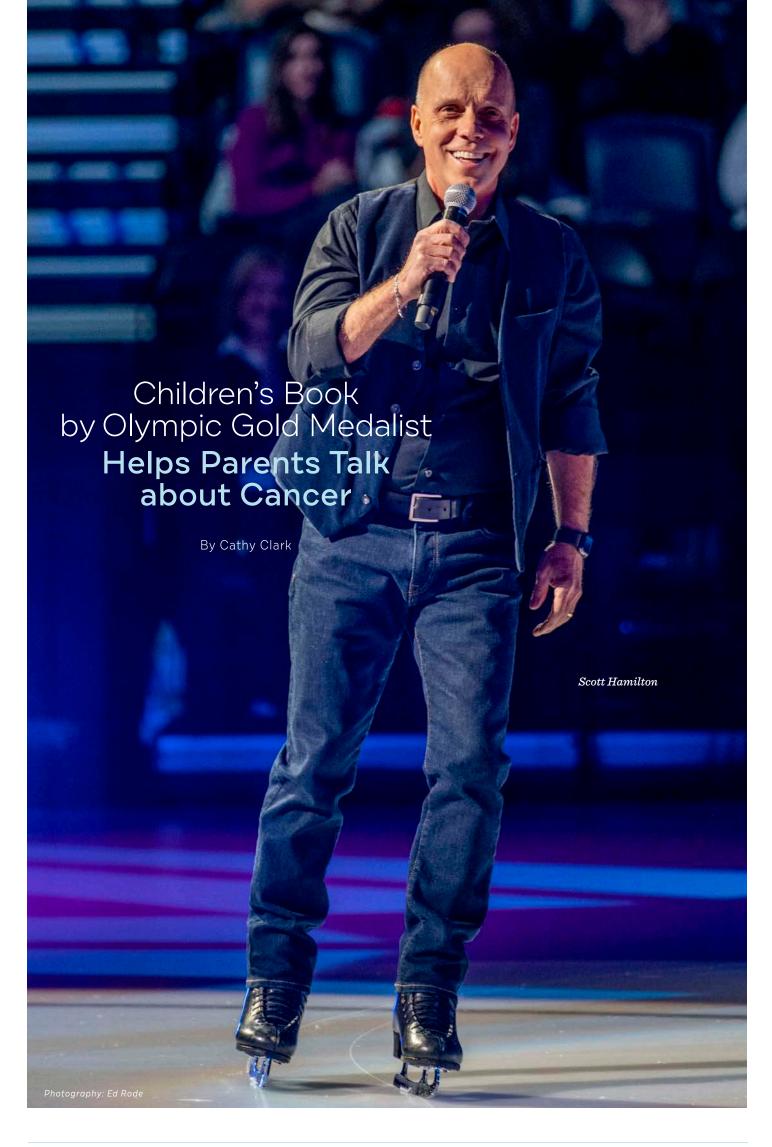
The tears and stories flowed when Joe and daughter Kathleen surprised Mooney with the treasured quilt last October, just three months after Colleen passed away. "I had no idea she'd been making it for me," Mooney says, "Just the power of it all – it blew me away."

Mooney and the Breast Imaging team made sure some of that power remains at McKinley. Another beautiful quilt Colleen made for the diagnostic waiting room has been framed along with her picture and story for patients to read while they wait. "The idea was to have Colleen present in that room," says Mooney, "to keep shepherding our patients – and me – along our journey."

Back on Moffitt's Magnolia campus, Joe keeps shepherding patients back to the CT Scan unit each week. He knows it's what Colleen would have wanted, just as she wanted to be buried in her Moffitt Volunteer uniform. "I keep on volunteering in tribute to her, to my angel," Joe says with a catch in his voice. "And as long as I keep waking up, I'll be here every Thursday. It's the least I can do, considering all Moffitt did for her."

"I keep on volunteering in tribute to her, to my angel."





## Story of a young skater helps teach message of love and support

"Fritzy Finds a Hat," a new book by Olympic gold medalist Scott Hamilton, helps families talk with their children as they tackle the difficult topic of cancer.

The story follows Fritzy, a young boy who loves to skate and learns his mom has cancer. Throughout the imaginative picture book, Fritzy searches for the perfect hat he can give his mom to wear as she undergoes cancer treatments.

The book teaches children a powerful message of how their love and support sometimes can be the best medicine, while expressing to parents how children want to be involved and to help in some way. The subject is personal for Hamilton, who as a teenager lost his mother to cancer and later faced and survived his own diagnosis of cancer. He has founded several education and survivorship programs and is a member of Moffitt Cancer Center's national Board of Advisors.

Hamilton and Mary Coffeen, Moffitt Foundation special projects administrator, worked to develop the story. "Scott is so inspiring. Obviously, he is an Olympic champion, but also his dedication to curing cancer and to finding ways to help cancer patients is so impressive, so genuinely touching, and I was honored to work with him on the book and excited about the opportunity to tell his story, too," said Coffeen. They turned to Moffitt's oncology social workers in the cancer center's Families First Program for input on ways to communicate to both children and parents.

#### FAMILIES FIRST HELPS ADDRESS CHILDREN'S NEEDS

Moffitt's Families First Program is designed to help parents and their children adjust to the changes that occur within the family when a parent has cancer. The program's experience has shown that education, preparation and support enable families to cope successfully in the face of crises.

"Raising children, maintaining their routines, and adhering to a treatment schedule can be challenging for parents. Amid all the demands of cancer treatment, children's needs may inadvertently be overlooked. Children can be impacted in multiple ways, and parents often are unsure about how their children will cope with crises," said Jolene Rowe, manager, Inpatient Social Work. "We recognize, too, that in the midst



of everything children may have additional needs and parents may need some assistance in meeting those needs."

Rowe has been with Moffitt Cancer Center for 28 years, where she started as a pediatric social worker. (Moffitt cared for children in its pediatric unit from its opening until 1995.) Realizing how much she enjoyed working with children, Rowe was one of the social workers who started the Families First Program.

Giving parents tools such as information about children's normal reactions to serious illness in the family, their common fears and misconceptions and what they need to cope can ease parents' worries. Books are a wonderful way to do this. It is not always easy to know what children are thinking because they often are not able to articulate what they are feeling. Highlighted in this book are some of the common fears that children have about a parent's cancer diagnosis such as whether the disease is contagious or whether they may have caused the cancer. A big issue for children is a parent's hair loss because it is a visible sign that something is different and that the parent is ill.

The book also touches on a way in which children can feel helpful and included in what is occurring in the family. "For example, children want to know that they can contribute to a parent's recovery, that they can help their mom or dad get better. Fritzy finds a way to make his mom feel better and that makes him feel better, too," said Rowe. "The book highlights the way kids think, what they worry about and what they need to cope."

Reading the book together provides a way for parents and children to communicate about a difficult topic. "It's a great opportunity for parents to learn what is on their children's

# "The book highlights the way kids think, what they worry about and what they need to cope."



L-R: Jonathan Merkh, president and publisher of Forefront Books, Scott Hamilton and Mary Coffeen, as they present Scott with one of the first copies of "Fritzy Finds A Hat" at the Scott Hamilton & Friends event, Nashville, Tenn., Nov. 24, 2019.

minds and for children to find the words and the courage to share their concerns. Children often don't know how to articulate what's bothering them or if it is OK to share their worries, and that's why books like 'Fritzy Finds a Hat' are such wonderful tools for children and parents alike," said Rowe.

#### **EMPOWERING CHILDREN IN A HEALTHY WAY**

"There was a big period of time where cancer was the 'C' word – you didn't say it. And I think times have changed a lot since then [in terms of] the different options for treatment, how we celebrate survivorship, how we celebrate those battles won," said Hamilton, a father of four children. "But still, for a child to witness a parent or a loved one going through harsh treatments, it is good to be able to empower them to participate – in a healthy way – so that they know they can really have an impact and go through it with their loved one."

Asked what kind of reassurances he thought children need when they hear their parents have cancer, Hamilton replied, "Ultimately, everybody wants to know that mom is going to be OK. But I think there is also that other point of it where it becomes, 'Let's help mom; let's help dad; she needs our help; she needs our support. She needs to know we are there for her and can do all these things [to help].' Family life is bumpy. There's always going to be these little bumps

in the road, challenges – wherever they come from. It seems like it's constant that we always have to deal with something, but when it is something like this, everybody wants to feel like they are doing the right thing to help.

"I think this book creates a conversation, it creates a really healthy path toward people knowing that they can do something, that they can participate in this thing and be a part of the healing or provide assistance or to let that person going through cancer know that they are not alone in this, that we are here to support."

The book helps facilitate a different conversation, notes Hamilton. "We don't necessarily have to shield our children as a default; we can empower our children and in a way that is healthy and cool and fun.

"It's awesome to give our kids that level of power and confidence that they can do something [to help] in that way. Kids like the idea of rolling up their sleeves and getting to work and being a big boy or big girl. When things are going on in the family, they want to help. 'I'll do it!' How many times have we heard our kids say that? It's a really cool thing when you have a way to give kids that power and that responsibility, so they can do whatever they can as they try to help."

Hamilton asked his friend country music superstar Brad Paisley, who also is a father and an artist, to create the hat illustrations, which add a creative, whimsical touch to the gentle storyline.

# "Ultimately, everybody wants to know that mom is going to be OK."

The hard-cover, 32-page picture book created for ages 5 to 8 also appeals to parents and older children. Proceeds from the book sales will benefit cancer research at Moffitt and research funded through the Scott Hamilton CARES Foundation. Proceeds also will benefit the Families First Program at Moffitt.

Books are available at Moffitt.org, scottcares.org and wherever books are sold. Additionally, the book will be available at Lori's Gifts, located on the Moffitt Magnolia campus.



# Getting To Know Scott

Scott Hamilton's outlook on life could be summed up by a quote appearing on his website: "The only disability in life is a bad attitude."



Scott and Tracie Hamilton (center) with their four children. Left to right: Evelyne, Aidan, Tracie, Scott, Maxx and Jean Paul.

skating star in the world, having won 70 titles. His awards and honors include an Emmy Award nomination, induction into the United States Olympic Hall of Fame and a privileged member of the World Figure Skating Hall of Fame.

His positive attitude, coupled with skill and perseverance,

led Hamilton to become the most recognized male figure

At a young age Hamilton lost his mother to cancer, and he later survived his own battle with cancer. As an activist, he aims to inspire others as a speaker and humanitarian. Hamilton lives in Nashville, Tennessee, with his wife, Tracie, and their four children.

Let's hear what he has to say.

#### **FAVORITE BOOK (BESIDES "FRITZY FINDS A HAT"):**

Self-help/self-realization books during this season of life to help strategize "how to get to the finish line in the healthiest, best way."

#### **YOUR HERO:**

On this earth, my hero would be – it's always my mom. She's always been my hero; she was always the most sacrificial, most loving person I've ever known. There's not a day that goes by I don't think about her and talk about her. I lost her 42 years ago, and it feels like yesterday in so many ways. She's always at the top of the list for me, no matter what.

#### **THREE FAVORITE SKATING SONGS:**

- "In the Mood"
- · "Walk This Way"
- "Hair" ("Because I was losing mine!" he laughs)

They're all really fun; anytime I can get out there and have fun putting on a show, I really enjoy it.

#### **COFFEE OR TEA DRINKER:**

Coffee!

#### **PROUDEST MOMENT:**

There are so many moments. My mom passed away, and I needed to respond in a way that was healthy while at the same time trying to be that person she always saw I could be. So, the proudest moment was making that choice to honor her and become more accountable and more responsible and to do things right and well.

# The Cancer No Man Wants To Talk About

## Early Assessment of Penile Cancer Can Prevent Devastating Effects

By Cathy Clark

"If you have a problem, get seen by a specialist, because it is only going to get worse if you don't," said James Wright. Wise words from a man who has experienced firsthand a diagnosis of penile cancer, followed by tissue-sparing surgery.

"I think people sometimes feel these things can't happen to them, that they can't develop cancer in places like the penis," said Philippe Spiess, MD, assistant chief of Surgical Services and senior member, Department of Genitourinary Oncology at Moffitt Cancer Center. "But the reality is such cancers occur, and it is essential for the patient to have the condition identified and evaluated as quickly as possible by the right specialist."

## "If you have a problem, get seen by a specialist, because it is only going to get worse if you don't."

Penile cancer usually forms on or along the penile glans or shaft and is often curable when found early. If left untreated, however, the cancer can spread rapidly to regional nodes or beyond and become potentially life threatening.

The most common age of penile cancer diagnosis is between 60 and 80 years. "But I've seen 30- and 40-year-olds present with this disease, and unfortunately several have died of this horrible cancer. The unfortunate thing is that it is aggressive, and patients suffer when they present with advanced disease," said Spiess, who sees about five to 10 cases of penile cancer per month. He recommends vaccination against the human papillomavirus in sexually active men and women because HPV is thought to be one of the strongest risk factors for developing penile cancer, with an estimated 60%-80% of penile cancers being HPV related. In 2018 the U.S. Food and Drug Administration approved the expanded use of the GARDASIL 9 vaccine to include men and women ages 27

to 45. (Previously, the vaccine was approved for individuals ages 9 to 26.) The vaccine, which protects against nine types of HPV, prevents cancers and diseases, including genital warts, penile cancer, anal cancer and the spread of HPV to sexual partners.

#### **DELAYED OR MISDIAGNOSIS**

"Although an infrequent cancer in North America, for the men it affects, the physical and emotional effects can be devastating," said Spiess. The National Cancer Institute reports about 2,000 cases per year. "Because penile cancer is so rare, there is much variety in how patients are cared for, depending on where they go for diagnosis and treatment. Sadly, some men are not recognized as having this disease and are left untreated or treated with antibiotics for a suspected infection, often delaying the diagnosis for many months. Then by the time some of these patients come and see us, they have advanced tumors, and we wish they would have come much earlier because the prognosis would have been much better."

Wright, 55, says his initial diagnosis was delayed due to embarrassment. "About three years ago I noticed a lump that had come on, and it was embarrassing so I didn't do anything about it." He was living in Atlanta at the time. After moving to Florida about three years ago, Wright found a physician and during a routine checkup asked, "Oh, by the way, can you look at this while I'm here?" His physician immediately insisted he get the lump removed and referred him to another doctor.

Wright quickly made an appointment, and the referred doctor removed the lump. Because the pathology report revealed Wright had a low-grade cancer and there was still tumor at the edges of where it had been resected, it was necessary for him to have more tissue removed. Then all was fine for about a year, until the cancer came back, "even bigger than before."



# "Although an infrequent cancer in North America, for the men it affects, the physical and emotional effects can be devastating."

At that point Wright visited Moffitt, had a biopsy and also visited a cancer center in another state. Two different surgeons advised to have what sounded to him like radical surgery. "He [one of the physicians] was talking about cutting the whole thing off!"

Wright ultimately decided to come to Moffitt to be near his home and not have to fly back and forth. He made an appointment at Moffitt, "and then somehow or another – thank God! – Dr. Spiess got ahold of me. I liked what he told me, and I also liked the plastic surgeon" [Gerard Mosiello, MD].

The surgery took place in July 2019 and went well. "When I went to have the surgery, I had packed a bag and was expecting to stay a few days. Much to my surprise, they sent me home the same day!" He recuperated at home for 10 days, and then was able to resume his active life as the owner of an insurance brokerage company. "It can be pretty travel intensive because I do business all over the place." Wright and his wife also like to travel to see family. He has a son in New York City, and most of his family is in Atlanta. His wife is from Russia, so they often travel to Europe to visit with her family; their most recent trip was to Seville, Spain.

"I couldn't say enough good things about the hospital, about



#### TISSUE-SPARING SURGERY

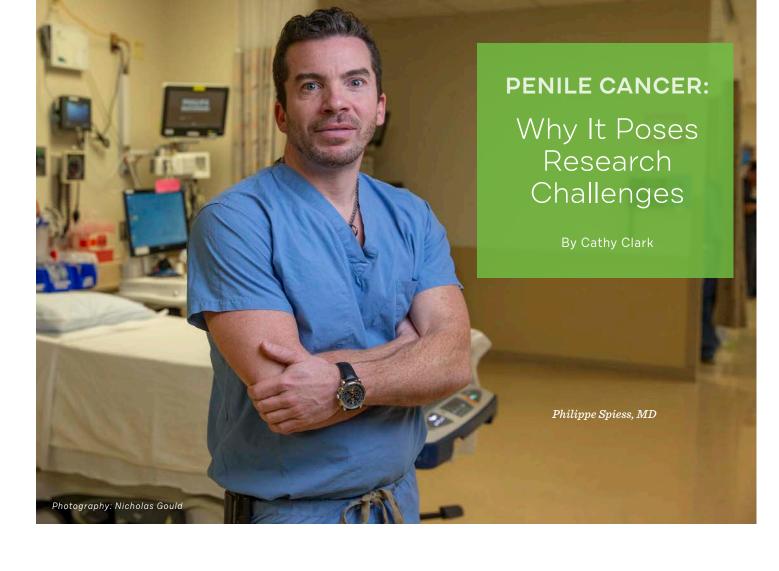
"I've had a few patients come to me and say they were told they could not have any form of tissue-sparing surgery or treatment. And I examined them and found these tumors are in fact amenable to this as they have favorable characteristics and are situated in a favorable location for organ preservation to be performed. Helping such patients is a matter of working with colleagues in reconstructive surgery or being a little more innovative in one's surgical approaches. And if you do that, it's been shown in very small studies, and I see in my patient population, it is possible for the patient to be able to maintain sexual function and ultimately a high quality of life," said Spiess.

Spiess cautioned against obtaining information from undependable sources and recommends – in addition to seeing a qualified specialist – searching out expert and trustworthy educational resources such as those offered within the National Cancer Institute and the National Comprehensive Cancer Network®.

#### SPEAK UP; ASK QUESTIONS

Spiess stresses the importance of being comfortable with one's own body and to keep asking questions. "If something looks unusual, there's never anything to be ashamed of, or wrong with having it assessed by a physician and just taking a look. And if you don't necessarily get the answers that you feel comfortable with, getting a second opinion or giving physicians the opportunity to perform an exam and give their thoughts would be greatly beneficial," said Spiess. "I can't tell you how many cases I've seen, from pilots for major commercial airlines to lawyers and other highly educated professionals, who have had significant penile tumors and lesions and they were dismissed, either by themselves or by physicians. So my advice is that it's always wise to go get assessed and checked out."

"These doctors don't take anything personally. You might be embarrassed, but they are not. To them it's their job, what they do, and they are there to help you," said Wright.



"GOOD NEWS," "BAD NEWS," although the condition is in no way a joking matter for the approximately 2,000 men in the United States diagnosed each year. The fact that cancer of the penis is very rare certainly is a relief. The bad news, however, is that progress in discovering new and better ways of treating penile cancer has been hampered by its rarity, because of the limited number of patients that can be recruited to clinical trials.

The reported mortality risk is fairly low, with an approximately 90% five-year survival, because there are many patients who present with nonaggressive cancers. "At Moffitt Cancer Center the cancers we see here are very different. We often see patients in advanced cases where the cancer has gone into the lymph nodes, so those patients do much worse, and at that point we're talking about five-year survival rates of 25%-30%," said Philippe Spiess, MD, assistant chief of Surgical Services and senior member, Department of Genitourinary Oncology.

These low survival rates for individuals with advanced penile cancer are disappointing, notes Spiess, adding this is where the importance of research comes into play.

"The more we understand about this disease, the more we are realizing that the current medications to treat it, the chemotherapies we are using, are not as effective as we once thought. And, unfortunately, for patients with a rare cancer like this, we are not able to do the large studies necessary to better understand the natural history of the disease, the prognosis and how patients do on certain therapies. Because of that we have to review data in large data registries or establish large collaborations in order to advance the field."

#### LOW RESPONSE RATES CALL FOR MORE RESEARCH

Generally, there has been a lack of new treatments for penile cancer. "There have been a few studies that have shown some novel forms of targeted therapies which may have a benefit for a subset of patients. But when you scrutinize the studies, we find response rates typically in the range of about 30%-40%. So, this is quite disappointing and suboptimal," said Spiess.

In 2018 Spiess and colleagues, including collaborators from Italy, looked at factors that predicted survival in patients with advanced penile cancer. "The bottom line is that radiation and chemotherapy did not improve survival in the analysis,"





said Spiess. "That's a disappointing thing; it was a point of reflection for us. And it said to us, clearly, we may help some patients with chemotherapy – but the group of patients benefitting from chemotherapy is much lower than we once thought. It's a frustrating thing as a clinician, and that's where you want to take a next step and not just accept this is as good as we can do. We clearly need to do better."

This led Spiess to initiate and serve as principal investigator across all North America (USA, Canada) sites as part of the

largest international study designed to advance the care of patients with advanced penile cancer and attempt to determine whether having surgery after chemotherapy, or after chemotherapy with

radiotherapy, is better than having surgery alone and whether having additional surgery to remove the pelvic lymph nodes that are farther away from where the cancer first appeared is better than not having this additional surgery. This study is called the InPACT (International Penile Advanced Cancer Trial); the trial is open across all sites that are part of the European Organisation for Research and Treatment of Cancer. At Moffitt this is Clinical Trial 19319, and it is historically the first of its kind to be developed.

#### INTERNATIONAL STUDY GAINS TRACTION

"This study is truly innovative because it took about five years to get enough momentum for the study – to get recognition and approval from the National Cancer Institute as a trial that was worthy of adoption," said Spiess. "And it took an effort

across Europe, the United Kingdom and the United States to collaborate. It was clear to us when we put this trial together that the only way we would be successful was if we collaborated across numerous centers. The goal is about 50 centers across both North America and Europe, and across Latin America in specific places." As of Jan. 1, 2020, the study has opened at 10 sites in the United States and Canada and 19 patients have been enrolled in the study. "It looks as if the study is beginning to gain traction and that we are going to be able to answer these meaningful questions," said Spiess.

Additionally, the study will look at human papillomavirus (HPV) and other factors to see if they help predict whether patients could respond to certain treatments.

Spiess hopes the study will provide opportunities to conduct future studies. "From this study we are identifying other institutions that have an interest and commitment to do this kind of research. The goal of myself and the other organizers of the study is that it will form the basis of centers of excellence

that care for this disease nationally and globally."

Moffitt's Genitourinary Oncology Program has a high patient volume, focuses on treating even the rarest

malignancies and many program physicians are fellowshiptrained in urologic subspecialties.

Jad Chahoud, MD, MPH, recently joined the growing program. Chahoud's clinical expertise includes advanced stage genitourinary malignancies, with a specific focus on advanced kidney and penile cancer. He received funding from the Conquer Cancer Foundation through the ASCO Young Investigator Award in 2018 to study viral and immune biomarkers for metastasis and poor survival in penile squamous cell carcinoma.

"Jad has been a wonderful complement to our program because he is interested in developing new medical therapies for penile cancer," said Spiess. "It's a nice complement that we can work together and elevate this research program here."

## "It looks as if the study is beginning to gain traction and that we are going to be able to answer these meaningful questions."

#### UNDERREPORTED; HUGELY IMPACTFUL

How might penile cancer affect a person's sex life? "The reality is, this topic is underreported," said Spiess. "I put a book together on highlights in this field and asked a well-regarded behavioral therapist to write a chapter on this specific topic. He came back to me and said, 'Phil, there's not much literature for me to write a chapter about it!"

Patients with penile cancer often are not being asked those questions of how the condition has affected them, continued Spiess. In his clinic, "we don't necessarily do counseling, but the topic has become an integral part of our conversation before we do any form of treatment when we diagnose patients. And, similarly, we follow patients for that.

"Surgery can be hugely impactful on their sexual relationships, on their marital relationships, relationships with partners or interactional relationships. When you are talking about younger patients, in addition to the diagnosis of cancer and the impact of that, the impact on their sex life and the ability to be close with their partners in that manner is huge. Fortunately, so many of the treatments we are doing today for smaller and better defined lesions is about preserving as much of the sexual function as possible, using appropriate, less-aggressive surgical or nonsurgical treatment options. The field has evolved a lot in the last 10 years."

#### **HPV AND PENILE CANCER**

HPV is probably the strongest risk factor for developing penile cancer, and it is estimated that 60%-80% of penile cancers are HPV related.

Spiess and Anna Giuliano, PhD, have collaborated for several years in the area of HPV vaccination and cancer prevention through review articles, presentations and other projects. Giuliano is the founding director of the Center for Immunization and Infection Research in Cancer at Moffitt. Her work has contributed significantly to HPV vaccine protection against multiple diseases in women and men.

"Anna has been an integral part of our research program," said Spiess. "Her research and our research overlap, and I think she's able to give us a lot of direction on the research side in terms of where the role of vaccinations is going, and we join efforts in terms of prevention of cancer with HPV vaccines, which clearly makes a lot of sense.

"In addition, Dr. Peter Johnstone, vice chair of the Radiation Oncology Program at Moffitt, has been another integral and multidisciplinary care member of our clinical and research team caring for penile cancer. Peter and his team have made meaningful discoveries related to better understanding of why these tumors have innate resistance to radiation therapy related to the unique tissue and gene expression characteristics of these tumors."

Even for patients who already have penile cancer, Spiess is advocating HPV vaccination. "The thought process behind that is if you are able to boost someone's immune system, even though they have a tumor, you can enlist antibodies and all the benefits one receives from vaccinations, which potentially may help people who have the cancer, even at that point."

#### **GENEROUS GIFT BOOSTS RESEARCH OPTIONS**

The R.S. Evans Foundation donated to Moffitt Cancer Center a research gift of \$500,000. The gift has fostered many additional opportunities for Spiess and his colleagues to perform research with the aim of saving and improving the lives of patients with cancer.

"The gift is allowing us to do some innovative things," said Spiess, about the funded research that is focused on HPV with Giuliano as well as with researcher Shari Pilon-Thomas, PhD, in developing tumor-infiltrating lymphocytes (TIL) specific to penile cancers. "This research is allowing us to find whether these treatments work and if they could be used in the potential development of ways to use intralesional vaccines for penile tumors.

"Especially in this current era in which national funding for biomedical research is so limited that even excellent grants often do not receive funding, the Evans Foundation research gift is vital, much appreciated and serves as the lifeblood for the discovery and development of future successful treatment strategies," said Spiess.

"The gift is allowing us to do some innovative things."

"This study is truly innovative

because it took about five years to get

enough momentum for the study."



Photography: Kevin Kirby

#### DR. IMAN WASHINGTON, NOW A RADIATION ONCOLOGIST

in the Breast section of Moffitt's Department of Radiation Oncology, thought of becoming a judge or a doctor as a child. She opted for the premed track in college.

While in college she also considered whether to pursue a career in the nonprofit sector. "I developed other interests in addition to medicine, including efforts to reduce the recidivism rate and to improve conditions for at-risk youth, along with improving educational resources for that population," said Washington. "If I had chosen a different path from medicine, it probably would have been in that area."

During time between her undergraduate studies and medical school, Washington worked as a research intern for the Safer Foundation in Chicago. The nonprofit's vision is achieving Equal Employment Opportunities for people with criminal records, thereby transforming communities and generations. She also worked for a former professor who was writing a book on education reform.

Given her strong social conscience, her research and clinical interests that include improving cancer care for underserved populations are a natural tie-in. "I'm interested in the area of research aimed at investigating the disparities that exist for black women with breast cancer," said Washington.

According to the National Institutes of Health, black women are less likely than white women to develop breast cancer, but they are more likely to die from it. Another serious disparity is that premenopausal black women are more likely to have triple negative breast cancer, which is a more aggressive subtype of the disease that is harder to treat than other subtypes of breast cancer.

"I'm working with colleagues to better understand why black women with triple negative breast cancer have higher rates of local regional recurrence."

As a physician her focus is on making life better for her patients, most of whom have breast cancer. In addition to

her work in eliminating cancer health disparities, Washington is interested in early and locally advanced breast cancer, metastatic breast cancer and techniques aimed at minimizing radiation-related normal tissue complications.

"I'm interested in the treatment of women with breast cancer at all stages of disease and in the methods of delivering radiation, whether that be during the planning process or treatment delivery techniques," said Washington. "I think it's important for us to continue to investigate ways of avoiding overtreatment and exploring different radiation treatment strategies to reduce short-term side effects as well as late complications."

Side effects from radiation treatment can be reduced, based on the intensity of treatment itself or based on planning of the administration of treatment.

An example of planning to help reduce toxicity is utilizing prone breast position, which involves the patient lying on her stomach with the breast requiring treatment hanging away from the body. Radiation exposure can be minimized to the surrounding organs and tissues. Women with larger breasts and left side breast cancer are among the women who may benefit the most from this position. Another technique for women with left breast cancer is called the deep inspiration breath hold technique, which uses deep breaths during treatment to reduce dose to the heart.

Her work includes determining whether overall radiation treatment can be reduced for women with breast cancer who have one to three positive lymph nodes. "That is a group of women who over the years have received less surgery, but we do not know if we can administer less radiation and still obtain similar outcomes," said Washington. "This is the objective of clinical trial CCTG MA.39, a trial that we now have open at Moffitt. If we can de-escalate radiation treatment safely, there is a potential for less side effects and better quality life for more women treated for breast cancer."

Breast cancer radiation oncology trials led by other Moffitt physicians include determining whether women who have undergone a mastectomy, require radiation therapy and plan on reconstruction can receive reduced overall treatment time, which would eliminate almost two weeks of treatment. Another trial is looking at whether radiation therapy can be omitted for women who presented with positive axillary lymph nodes and had a complete response in the lymph nodes after neoadjuvant chemotherapy.

Washington has a confident and calming demeanor, and she likes to see that her patients are at ease. "I think radiation is less intuitive than, say, surgery for instance. So, part of communicating with them involves describing the logistics and potential side effects in detail, as well as addressing fears that arise from the unknown," said Washington. Women

## "I'm working with colleagues to better understand why black women with triple negative breast cancer have higher rates of local regional recurrence."



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## "I think anytime one hears the 'C' word, that's a frightening thing, but most women with early-stage breast cancer have good overall survival and good cure rates."

who are receiving whole breast radiation therapy after a lumpectomy, and even those receiving post-mastectomy radiation therapy generally do very well with treatment. "I often hear, 'that went by faster than I thought,' or 'that wasn't as bad as I thought."

Over the years, radiation therapy has become more advanced. "It's definitely changed, and often you can tell the difference," said Washington. "For example, if a woman who had breast cancer and was treated in the late 1980s and then treated more recently to the other breast, the appearance of the two breasts is different. There are more changes to the breast that was treated decades ago."

She offers hope to women by reminding them that radiation therapy specifically helps improve survival and reduce the likelihood of cancer returning. "I think anytime one hears the 'C' word, that's a frightening thing, but most women with early-stage breast cancer have good overall survival and good cure rates," said Washington. "I like to remind them of that, because I think that fact can get lost in all of the details of the treatment and as women are simply just trying to process the diagnosis itself. And for patients with metastatic disease that is not curable, radiation can offer palliation for sites that are causing symptoms or pain. I also believe from the standpoint of improving quality of life, radiation plays a big role for women with breast cancer."

For her own self-care, Washington enjoys spending time with family and friends and incorporating some meditation into her week when possible. To unwind, she enjoys painting (her preferred media is acrylic). "I find it very relaxing, and I've done some form of art for as long as I can remember; that form of expression is an important part of who I am," Washington said.

If an office could represent aspects of a person, Washington's office might be such a reflection. Her office displays her creative side; a painting on one wall is done in bold redorange shades, along with soothing lavender and green. A pillow with a flower design graces a small black rocking chair, and a decorative book sits on a side table beside a fancy glass dish filled with lavender-colored candies, evoking cordiality and hospitality. Juxtaposed along another wall, a solid bookcase contains large medical and radiation oncology books, reflective of her years of dedicated study, medical training and expertise, and ongoing commitment to the well-being of her patients.

Washington sums up her key wish for the patients she sees: "My hope for the future is that all women feel like they have the resources and the opportunity to get adequate health care and screening. Further, that all women feel that their medical community is a caring and safe place for them to receive and be active participants in their care."



"My hope for the future is that all women feel like they have the resources and the opportunity to get adequate health care and screening. Further, that all women feel that their medical community is a caring and safe place for them to receive and be active participants in their care."

# Moffitt Nursing Achieves MAGNET REDESIGNATION

By Cathy Clark

# Appraisers Confer Exemplars in Patient Care and Innovation

In 2019 Moffitt earned its second designation as a Magnet facility by the American Nurses Credentialing Center, the credentialing body of the American Nurses Association.

The designation was granted following a three-day site visit with more than 550 interactions with nurses and interdisciplinary team members to confirm compliance related to 88 standards. The designation recognizes nursing professionalism, teamwork, quality patient care and innovations in nursing practices.

Only 8% of U.S. hospitals achieve designation as a Magnet organization, a recognition considered the gold standard of excellence in nursing. Once earned, the designation is not guaranteed to renew. Moffitt first received Magnet designation in 2015, and almost immediately after the exuberant celebration began planning and working toward meeting and exceeding the redesignation expectations faced in 2019.

Especially challenging was that Moffitt had to apply for redesignation using the manual newly released in 2019, which expected Moffitt to show even more quality indicators related to nursing satisfaction and patient satisfaction than required.

"The American Nurses Association had revised the manual, and we happened to be the very first group that had to write our application based on the new manual's standards and be surveyed under the new manual," said Jane Fusilero, RN, MSN, MBA, NEA-BC, vice president, Patient Care Services, and chief nursing officer, who led the Magnet steering committee. During the redesignation process, Moffitt earned six exemplars which demonstrated exemplary professional practice. "An



exemplar means that an institution went far and above a particular standard, making the institution an example," said Leslie Rogers, PhD, MBA, BSN, RN, director, Surgical & Procedural Units and Magnet Program Director. Rogers guided the Magnet application process, which included all campuses, all levels of nursing and teammates across the cancer center.

Several of the exemplars were focused on patient engagement, patient education and courtesy and respect, all of which outperformed the benchmark measurements for these categories.

"It is so difficult to achieve exemplars using the new manual, and we had six!" said Fusilero.

"An exemplar means that an institution went far and above a particular standard, making the institution an example."

"It is so difficult to achieve exemplars using the new manual, and we had six!"



During the site visit, the appraisers verified that Nursing is actively involved in and leading many innovations at the cancer center. "The Nursing team was especially proud of receiving an exemplar in the category of New Knowledge and Innovation," said Fusilero.

In addition to recognizing the innovative, sustained use of scalp cooling technology, the appraisers explored several extraordinary examples of innovation in meetings and unit visits. An amazing example of an innovation within the cancer center involving nursing is the use of a simulation tool for education, the Simulation Toolkit for Chemotherapy Administration. Developed by Moffitt leaders, the toolkit promotes safe chemotherapy administration and patient safety. The toolkit was made available for free use to other organizations, and more than 100 organizations have downloaded the toolkit. Additionally, Moffitt developed a full day of simulation to support nurses in learning complex skills related to chemotherapy administration, communication techniques and more.

"These scenarios not only engage the clinical nurses at Moffitt Cancer Center, but they also engage the Patient-Family advisors, supportive care staff and DNP [director of nursing practice] students in the provider role," said the Commission on Magnet in its report in recognition of Moffitt's second designation as a Magnet organization.

"Achieving an exemplar in Innovation is uncommon. Also, Moffitt went into the site visit with no deficiencies," said Rogers, who also has served as a Magnet appraiser for 17 years. "Of course, everyone wants that, but it is so rare."

"Achieving Magnet designation not only demonstrates nursing excellence, but it also shows a commitment to the patient and commitment to the quality care we provide to them," said Fusilero.

As Moffitt continues to expand, Magnet standards are involved in all areas. Fusilero and Rogers already are planning for 2023 when the next redesignation application will be due.

"The Magnet process is a journey," said Rogers. "You don't arrive at Magnet and say, 'we got there and we are done."

#### MAGNET DESIGNATION STANDARDS ARE TIED TO PATIENT CARE

Magnet-designated facilities consistently demonstrate:

- Higher patient satisfaction with nurse communication, availability of help, and receipt of discharge information
- Lower risk of 30-day mortality and lower failure to rescue
- Lower rates of falls
- Higher job satisfaction among nurses

In order to be Magnet designated, a facility must undergo a rigorous process, which includes a lengthy application, on-site visit, review by the Commission on Magnet Recognition and show compliance in more than 80 areas, some of which include:

- Competent, dedicated and skilled nurses
- Continued innovation within staff knowledge
- Clinical practice and systemic improvements
- Empowered staff properly prepared to face all challenges
- Outcomes measurement systems in place throughout the entire organization
- Visionary leadership transforming the organization to meeting changing needs

"The Magnet process is a journey. You don't arrive at Magnet and say, 'we got there and we are done."

#### **ABOUT MOFFITT CANCER CENTER**

Moffitt Cancer Center in Tampa, Florida, has made a lasting commitment to the prevention and cure of cancer, working tirelessly in the areas of patient care, research and education.

#### **MISSION**

To contribute to the prevention and cure of cancer

#### **VISION**

To transform cancer care through service, science and partnership

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## Notable

The Department of Defense awarded a four-year \$8.3 million Breakthrough Award, to advance immunotherapy research for patients whose breast cancer has metastasized to the brain. The award will fund a phase 2 clinical trial led by Brian Czerniecki, MD, PhD, chair of Moffitt's Breast Cancer Oncology Department.

Moffitt launched a contract research organization (CRO) focused on accelerating immunotherapy research. The wholly owned, for profit subsidiary will provide a one-stop-shop for pharmaceutical and biotech companies to accelerate their immuno-oncology and cell therapy research through collaborative clinical trial support and administration.

Moffitt has partnered with Bay Pines VA Healthcare System and James A. Haley Veterans' Hospital to expand its clinical research to include veterans being treated at the two Tampa Bay area VA facilities. The partnership will give veterans in and around the Tampa Bay area increased access to cutting-edge therapies.

A new Moffitt clinic is completely dedicated to immune cell therapy. The Immune Cell Therapy (ICE-T) clinic has 12 inpatient beds and eight treatment bays for outpatient visits. Cellular therapy patients can receive their chemotherapy in the outpatient area of the new ICE-T unit, and then when it is time for therapy and recovery, they will be admitted to the inpatient side of the clinic. Cellular immunotherapy can be used to treat several different types of cancer, and the ICE-T clinic is designed to give patients and their caregivers a better treatment experience.

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