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Volume 13, Issue 1

MOFFITT MOMENTUM®

CLOSE CALLS

Rob Higgins was diagnosed just weeks after his dad

A FATHER'S PROMISE

Zion Yamoah's story lives on with new proton therapy center

NO TIME TO WASTE

Experimental therapy targets deadly leptomeningeal disease

Leadership Message

Patrick Hwu, MD
President and CEO

Dear Friends,

At Moffitt Cancer Center, we are driven by one shared mission: to contribute to the prevention and cure of cancer. Our mission is advanced not just through clinical expertise and scientific discovery, but through the very real and personal motivation of the patients and caregivers we serve.

We recently received a letter from a patient who shared that while listening to a podcast, he heard a provider say the No. 1 factor in surviving a life-threatening illness was whether the patient believes they will survive. The patient reflected on his own journey and how from the moment he arrived at Moffitt, every person he encountered, from valet to infusion, acted as if he was going to be just fine. Because they believed it, he believed it, too.

He described Moffitt's culture in one word: uplifting. And though belief is not a substitute for science, it is strengthened by it. Culture and confidence matter. When a patient walks into a cancer center where expertise is evident, teams collaborate seamlessly and optimism is grounded in innovation, it changes the care experience, how they face treatment and what they believe is possible.

In this issue of Momentum, you will see that belief reflected in many forms. A father and son shouldering cancer together, determined to ring the victory bell. A mother enrolling in a first-in-human clinical trial, driven to push past a terminal diagnosis to watch her daughter grow up. A wife staying by her husband's side through cancer, cardiac arrest and months of rehabilitation, motivated to return to their life together. A man navigating treatment around daily life, determined to get back to his baseball stadium bucket list. And a doctor at Moffitt turning his own unimaginable loss into a promise to expand access to lifesaving proton therapy for patients in our community.

Each story is fueled by motivation and sustained by belief. At Moffitt, we have a responsibility to pair that belief with action, from expanding access to therapies to creating an ecosystem where cancer research and clinical care accelerate one another.

When culture, compassion and science align, patients receive more than just treatment for their cancer. They find hope. Together, this is how we move closer every day to a world without cancer.

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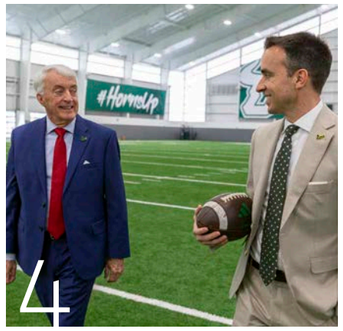
USF Athletics CEO Rob Higgins was diagnosed with colon cancer soon after his dad, Jack, was diagnosed with bladder cancer in 2024. They underwent treatment at Moffitt Cancer Center at the same time.



In It Together
From sports stands to waiting rooms

Promise of Proton
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Hope for Heather
Trial puts her in 'uncharted territory'

Close Calls

USF Athletics CEO Rob Higgins and his dad, Jack, were diagnosed just months apart

By Sara Bondell

Photos by Nicholas J. Gould

ROB HIGGINS
Cancer Survivor

A week before Christmas, Rob Higgins was in Orlando preparing for his first football bowl game as the University of South Florida CEO of Athletics. Kickoff was in a few hours.

His dad, Jack, was just miles away, en route from his home in Dade City. Jack hadn't missed a home football game the entire season.

When USF's basketball season began a month later, Jack was a fixture in the stands. In fact, the 76-year-old had rarely missed one of Rob's sporting events his entire life. Jack was often just a glance away whether Rob was a player, event organizer, director or CEO.

When Rob began cancer treatment in the fall of 2024, Jack was once again by his side – but in an unimaginable way. Jack was diagnosed with cancer just two months before Rob, and the father and son began fighting their toughest opponents at the same time.

A RED FLAG

Jack was on vacation in Greece with his family when he noticed blood in his urine. Doctors there told him to see a specialist when he returned home. Rob accompanied him to appointments at Moffitt Cancer Center after Jack was diagnosed with stage 2 bladder cancer. A discussion at one appointment about their family history of cancer – including Rob's grandfather's colorectal cancer diagnosis at a young age – gave Rob a bad feeling.

"I just had this weird premonition and went home and Googled about hereditary cancers," Rob said.

A week later, Rob, then 45, underwent his first colonoscopy.

"I thought it would be a traditional colonoscopy, but when I woke up I was surrounded by doctors and they shared they had found a 4-centimeter tumor," he said. "The shock and uncertainty was really tough to deal with. I remember getting back to the car and me and my wife just crying not knowing what exactly to expect."

Rob hadn't had any symptoms. His cancer wasn't a clear-cut case, and it was hard to pinpoint the disease's stage. After getting multiple opinions, Rob decided to join his dad at Moffitt.

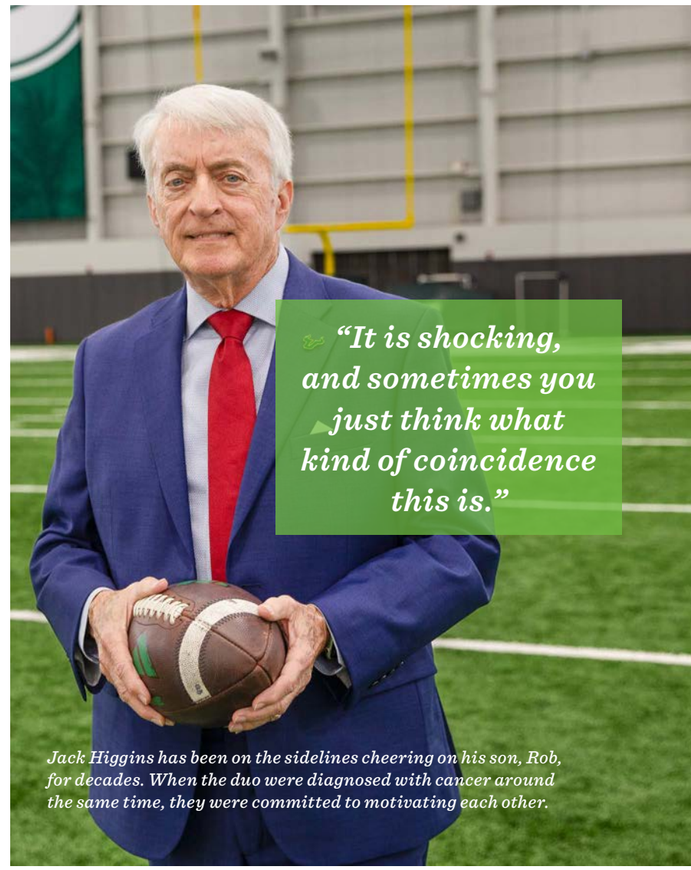
"Since he had a more unique situation, we presented his case to our tumor board and developed a multidisciplinary approach," explained gastrointestinal surgeon Julian Sanchez, MD, who oversaw Rob's care. "This was a great example of the benefits of the Moffitt approach to achieve a real win. We had multiple experts in gastrointestinal oncology opine on his treatment options with the goal to create a tailored treatment approach that adequately treated his cancer without overtreatment."

> ***"I thought it would be a traditional colonoscopy, but when I woke up I was surrounded by doctors."***

Rob began six weeks of chemotherapy and daily radiation in November 2024. He and Jack learned to balance being patients and caregivers at the same time. They often did family dinners at Rob's house and were constantly checking on each other to make sure the other was doing OK.

"It is shocking, and sometimes you just think what kind of coincidence this is. I couldn't take his place, so there is nothing you can do but pray and hope for the best," Jack said.

"It was a very surreal journey in terms of going in to get radiation and coming out to the waiting room and seeing my dad waiting for his radiation," Rob remembered.



Jack Higgins has been on the sidelines cheering on his son, Rob, for decades. When the duo were diagnosed with cancer around the same time, they were committed to motivating each other.

“Treatment has changed a lot in the last 10 years, and we have learned over time that we can tailor therapy based on an individual and their tumor.”

- Julian Sanchez, MD

Rob also leaned on his wife, Casey, their two children and his sister, Rebecca, for support. As a family, they decided they wouldn’t let cancer affect the things most important to them, which included Rob’s work at the time as the Tampa Bay Sports Commission director.

“I love my work and pouring myself into that, so I kind of refused to let cancer affect me in that way,” Rob said.

And with Jack about a month ahead of him in treatment and doing well, Rob had yet another reason to look up to his dad.

“Rob is so competitive so we jokingly would say, ‘I got through it, so he has to get through it,’” Jack said.

TOO IMPORTANT TO DELAY

Since the U.S. Preventive Services Task Force lowered the recommended age to start colorectal cancer screening from 50 to 45 in 2021, Sanchez says it has become more common to see younger patients and earlier stage cancers.

“Treatment has changed a lot in the last 10 years, and we have learned over time that we can tailor therapy based on an individual and their tumor. Part of the problem with younger patients getting cancer is that if you overtreat, they are dealing with those effects for the rest of their lives,” Sanchez said.

While there is a lot of apprehension around colonoscopies, Sanchez says it’s important to be your own advocate, like Rob.

“There is nothing easier in the world than putting off a colonoscopy. I want to share what I went through so others won’t put it off,” Rob said. “A lot of people are really busy – me being one of them – but you are never too busy to take care of your personal health.”

Delaying a colonoscopy can make a big difference when it comes to early diagnosis and treatment options.

“It’s easy for a one-year delay to become a two-year delay that becomes a five-year delay,” Sanchez said. “Colorectal cancer is a long-term developing disease from mutations that cause normal cells to develop into polyps that eventually transform into cancer, so that means we have 10 to 15 years to catch them.”

Current guidelines recommend people of average risk undergo colorectal cancer screening every 10 years from age 45 to 75. Those at increased risk for the disease, including individuals with a family history of colorectal cancer and those with a personal history of inflammatory bowel disease, should begin screening earlier.

Sanchez recommends those with a first-degree relative (parents, siblings or children) connection begin screening 10 years prior to the age their relative was diagnosed. While Rob’s cancer didn’t have a hereditary genetic link, his children will begin screening at 35.

“There is nothing easier in the world than putting off a colonoscopy. I want to share what I went through so others won’t put it off.”

For those at average risk who don’t feel comfortable with a colonoscopy, there’s an at-home fecal immunochemical test, or FIT. Individuals can self-collect a stool sample and mail it in for testing annually.

“The colonoscopy is the gold standard for detection because if there is a polyp, we can identify and remove it. A stool test will identify it but can’t treat it, so a colonoscopy will be needed as a follow-up,” Sanchez said.

A DOUBLE WIN

When Rob rang the bell at Moffitt to celebrate the completion of his treatment, there was only one moment he can think of that topped it: watching his dad ring the bell first.

“We were both ultraconcerned with the other person’s diagnosis, and it was so much more impactful and meaningful to see him ring the bell and vice versa,” Rob said.

Reflecting about what the pair just went through, Jack can’t help but get nostalgic. When he thinks about Rob passing him in the radiation waiting room, he sees the 8-year-old ball boy for the USF men’s basketball team. The young adult who broke his nose playing in the Jesuit High School alumni basketball league. The sports director who first brought the Women’s Basketball Final Four to Tampa. The man who now oversees 500 student-athletes in 21 sports.

For Rob, the experience has not only helped him grow even closer with his dad, but it’s also shifted his life perspective. He doesn’t want to take any moments for granted.

“A quote I lean into a lot about my cancer journey that I share with our student-athletes is that adversity doesn’t build character, it reveals it,” he said. “Oftentimes in sports, toughness and character are wrongfully used interchangeably. We will all face adversities in our life where we need to be transparent with ourselves and to not be viewed as tough, and that doesn’t mean we have any less character.”

Moving forward, Rob and Jack will walk in survivorship together, celebrating milestones and holding each other accountable for follow-up screening. And no matter what happens, they know they can lean on each other, on and off the sports field.

“A quote I lean into a lot about my cancer journey that I share with our student-athletes is that adversity doesn’t build character, it reveals it.”

Jack rang the bell first at Moffitt, with Rob celebrating the end of treatment soon after. Today, they continue to support each other in their survivorship journey.

A BETTER DAY FOR Brachytherapy

A generous gift paves the way for a smoother treatment experience for patients

By Annie Brant | Photos by Nicholas J. Gould

By late morning, Jeff Stulz is awake and talking with his wife after finishing his second prostate cancer treatment. That alone was noticeable.

Weeks earlier, the same procedure kept him in the hospital for nearly 14 hours. He drifted in and out of anesthesia while his wife, Kellie, waited for updates to determine where he would be taken next.

This time around, everything happened in one place.

Jeff was one of the first patients treated in Moffitt Cancer Center's new Richard Gonzmart Brachytherapy Suite. The radiation-shielded operating room allows imaging, treatment planning and precision radiation delivery without moving the patient.

"I went to sleep once and woke up once," Jeff said. "That was it."

He was admitted around 5:30 a.m. By noon, he was discharged.

Few patients undergo the same procedure in two very different ways. Jeff did. The contrast changed how he and Kellie not only saw the procedure but also their experience in cancer care.

"It felt like a true outpatient procedure," Kellie said. "That first time felt like we went through a battle."

A DIFFERENT KIND OF PLANNING

Jeff keeps a small brown book for a bucket-list project. The goal is to visit all 30 Major League Baseball stadiums and collect a stamp in the book from each team store. He and Kellie have checked off eight so far.

"We plan a vacation around which stadium we want to visit," Jeff said with a smile. "It's our thing."

Before cancer, that kind of planning defined their lives. Jeff ran his own recruiting business from home in DeBary, a suburb of Orlando. The couple traveled often, and he had begun to seriously think about retirement.

"Everything was great," Jeff said. "I hate to say boring, but we were just doing our thing – planning on retiring, nothing special."

That routine shifted in early 2024 at age 58 when Jeff went from collecting baseball stats to tracking medical test results.

He went to his family doctor feeling tired and asked for a testosterone test. That visit led to a referral to a urologist and a prostate-specific antigen (PSA) test, which measures a protein made by the prostate. His result fell within the normal range, but his provider recommended further testing because of his age.

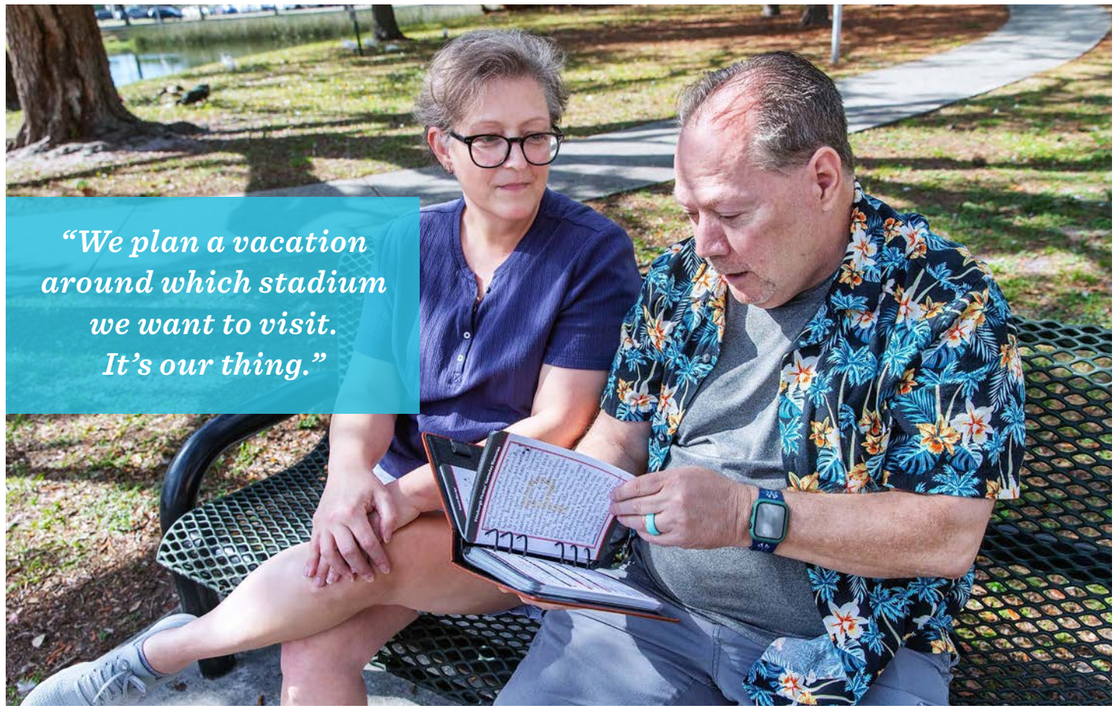
"We probably considered a half-dozen options. But we left Moffitt feeling very confident that we were going to make the right decision."

An MRI followed. The results revealed a lesion. A biopsy determined Jeff had low-grade prostate cancer, known as Gleason 6. It is the slowest-growing form of the disease, and many men choose to monitor it rather than treat it.

Jeff spent more than a year on active surveillance, returning regularly for blood tests and imaging. But then in March 2025, his PSA nearly doubled.

Further testing showed the lesion had grown, and a second area raised new concern. A follow-up biopsy confirmed the progression. It was still early, but something Jeff no longer felt comfortable just watching.

"That was my trigger," he said. "We went into full research mode."



Jeff Stulz and his wife, Kellie, have a bucket-list goal of visiting all 30 Major League Baseball stadiums and collecting a stamp from each team store. When he was diagnosed with prostate cancer, they wanted a treatment plan that got him back on track quickly.

CHOOSING A PATH

The Stulzes began comparing treatment paths, including surgery, proton therapy and other different forms of radiation. They wanted to focus on three things: cancer control, long-term side effects and how each approach would fit into daily life.

Brachytherapy stood out. The treatment delivers radiation directly into the prostate, limiting exposure to surrounding tissue and requiring fewer sessions than traditional radiation.

Brachytherapy treats cancer from the inside out. Instead of directing radiation from outside the body over many sessions, doctors place radiation sources directly into or near the tumor.

It is most often used for cancers in areas that are accessible by needle or catheter, including prostate, gynecologic and certain skin cancers.

“Brachytherapy was actually the first type of radiation therapy,” said Daniel Fernandez, MD, PhD, section head of brachytherapy at Moffitt. “Some of the earliest positive effects of radiation on cancer were seen by putting radioactive material near tumors.”

For prostate cancer, brachytherapy is delivered in two main ways. Low-dose-rate brachytherapy uses radioactive seeds that are implanted permanently and release radiation slowly over weeks or months. High-dose-rate brachytherapy uses temporary implants to deliver radiation over a short period of time, often 10 to 20 minutes per treatment.

High-dose-rate brachytherapy can be completed under anesthesia in one or two sessions rather than weeks of daily appointments as is often the case with more common external beam radiotherapy treatments. For many patients, like Jeff, the shorter timeline is a major advantage.

“We wanted to get it done and get back to baseline,” Jeff said.

But the procedure itself requires careful coordination of imaging, treatment planning and radiation delivery.

“That coordination is where the new suite really changes everything,” Fernandez said.

The Stulzes researched cancer centers across Florida when considering treatment. They met with multiple physicians and focused on those who specialized in prostate brachytherapy.

Moffitt rose to the top of their list.

“We probably considered a half-dozen options,” Jeff said. “But we left Moffitt feeling very confident that we were going to make the right decision.”

That confidence was boosted when they met Fernandez.

“Patients often come in with a lot of information,” Fernandez said. “Our job is to sort through that and help them understand what really applies to their situation.”

WHY DELIVERY MATTERS

Traditionally, the steps involved in high-dose-rate brachytherapy are performed at multiple locations within a hospital. Patients may move between imaging rooms, operating areas and radiation treatment spaces during a single procedure. Often, they are taken in and out of anesthesia multiple times.

“That would turn into a 10-to-12-hour day here for some patients,” Fernandez said. “Much of that day was spent with a lot of anxiety for patients trying to hold still in an uncomfortable position, worried that if they move too much, they could affect the quality of their treatment.”

At Moffitt, the newly opened brachytherapy suite was designed to change that.

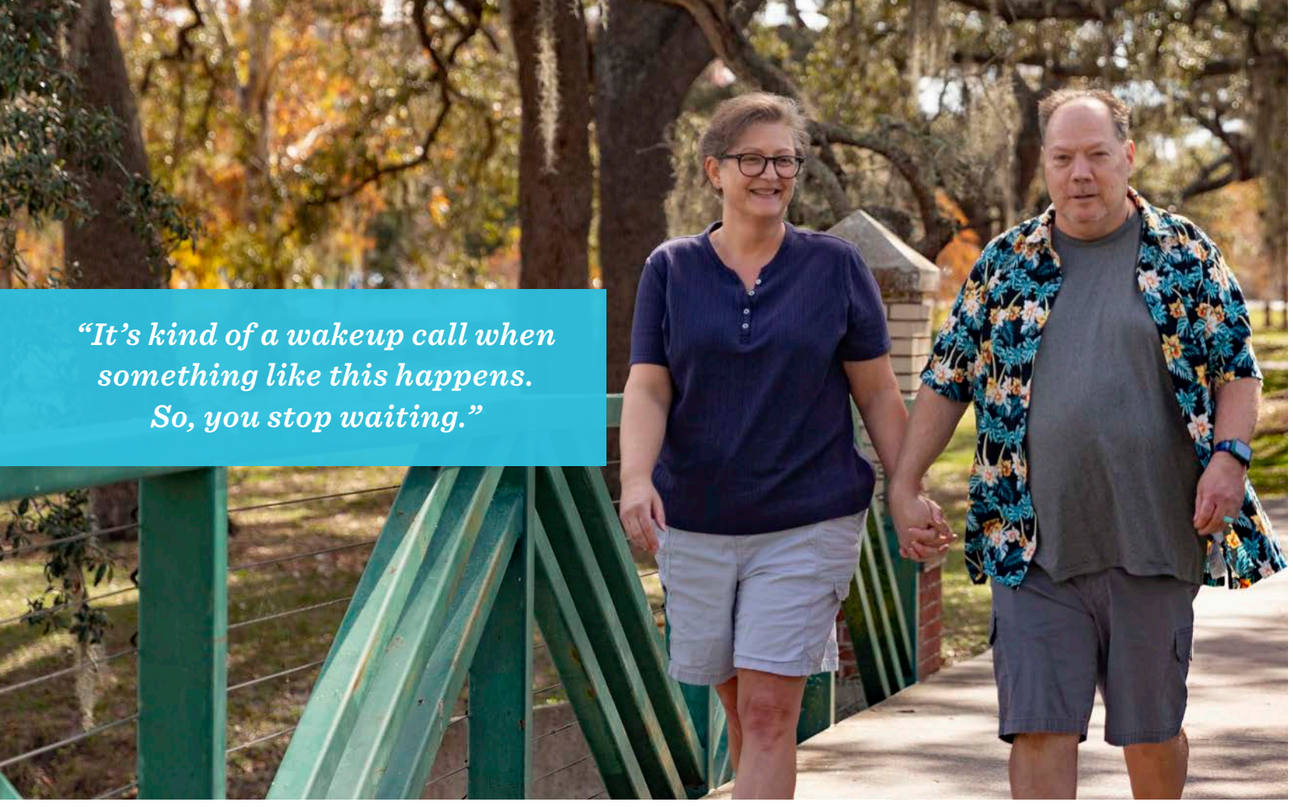
The radiation-shielded room brings advanced ultrasound, diagnostic quality CT imaging and high-dose-rate brachytherapy treatment planning and delivery technology into one space. Doctors can plan and deliver radiation without moving the patient or waking them up between steps.

“From a patient’s perspective, the treatment is vastly different where they go to sleep and 3½ to four hours later, they wake up, the needles have already been removed, the treatment has been delivered,” he said. “From our perspective, it allows us to be more precise and consistent.”

The suite also removes many of the variables that once complicated the treatment. Previously, moving patients between rooms sometimes caused implanted needles to shift, requiring additional adjustments.

“With this setup, we eliminate a lot of that uncertainty,” Fernandez said. “That benefits both the patient experience and the quality of care.”

Daniel Fernandez, MD, PhD, says that the new suite both improves the patient experience and enables physicians to be more precise in the treatment.



With the new Richard Gonzmart Brachytherapy Suite, one long day of treatment has been reduced to just a few hours. The Stulzes experienced this advancement firsthand.

A TALE OF TWO TREATMENTS

Jeff’s care coincided with the opening of the new suite. He underwent his first high-dose-rate brachytherapy procedure just before the suite opened in October 2025. Weeks later, he returned for his second treatment in the new space.

He said the difference was significant.

The first procedure was completed over the course of a long and fragmented day. Imaging, planning and radiation took place in separate areas of the hospital, and Jeff was moved several times. Each transition meant waking him up and putting him back under anesthesia.

Jeff also had a reaction to the anesthesia on that first day. He woke up nauseated, and that sickness extended his stay even longer.

The second time around was a different experience.

In the new suite, Jeff stayed in one place. He underwent anesthesia once and remained asleep while imaging, planning and radiation were completed. When he woke up, the procedure was over.

He spent about six hours at Moffitt. There was no nausea. He ate later that day and joked with hospital staff.

“It was easier on him,” Kellie said. “And it was easier on us.”

BETTER EXPERIENCE, BROADER IMPACT

While Jeff’s story highlights the patient experience, Fernandez says the new suite’s impact extends beyond it.

“This is not just about convenience,” he said. “It’s about expanding who we can help.”

The suite is named after Richard Gonzmart, fourth-generation owner of the Columbia Restaurant, Moffitt Foundation board member and a prostate cancer survivor who was treated with brachytherapy. He contributed $1 million toward the project located on Moffitt’s Magnolia campus.

With the expansion, the suite also increases the cancer center’s treatment capacity. The team can treat more patients and expand to other cancer sites, including certain gynecologic, gastrointestinal and rectal cancers.

“Now we can treat more patients, including those with different anesthesia needs or medical conditions,” Fernandez explained. “There are only a handful of centers in the country that are up to these standards.”

For prostate cancer patients like Jeff, that access can make a difference.

In earlier-stage disease, brachytherapy offers cancer control comparable to traditional external beam radiation but often with fewer long-term side effects, particularly when it comes to sexual function.

In higher-risk cases, combining brachytherapy with external beam radiation can significantly improve cure rates.

“For the right patients, adding brachytherapy can increase the chance of being cured nine years after treatment by about 20%,” Fernandez said. “That is a major advantage.”

The suite is part of a broader effort at Moffitt to improve how radiation is delivered across different cancers. That work includes targeted radiosurgery, radiotherapy planning that can be adapted to each patient and the expansion of proton therapy.

LIFE AFTER TREATMENT

Jeff now has a simple follow-up plan that consists of regular PSA tests and check-ins with his care team. When treatment ended, the shift was abrupt. Months of appointments, decisions and research stopped.

“It’s 100 miles an hour, and then it’s over,” Jeff said. “There’s nothing else to do.”

For care teams, that quiet is a sign of success.

“Years after treatment, our goal is that patients are cured and living their life normally, not constantly thinking about their cancer,” Fernandez said.

For Jeff, that life looks familiar again. The small brown book for baseball trips is back on the counter, ready to be filled. Yankee Stadium is next.

“That’s a celebration trip,” Jeff said.

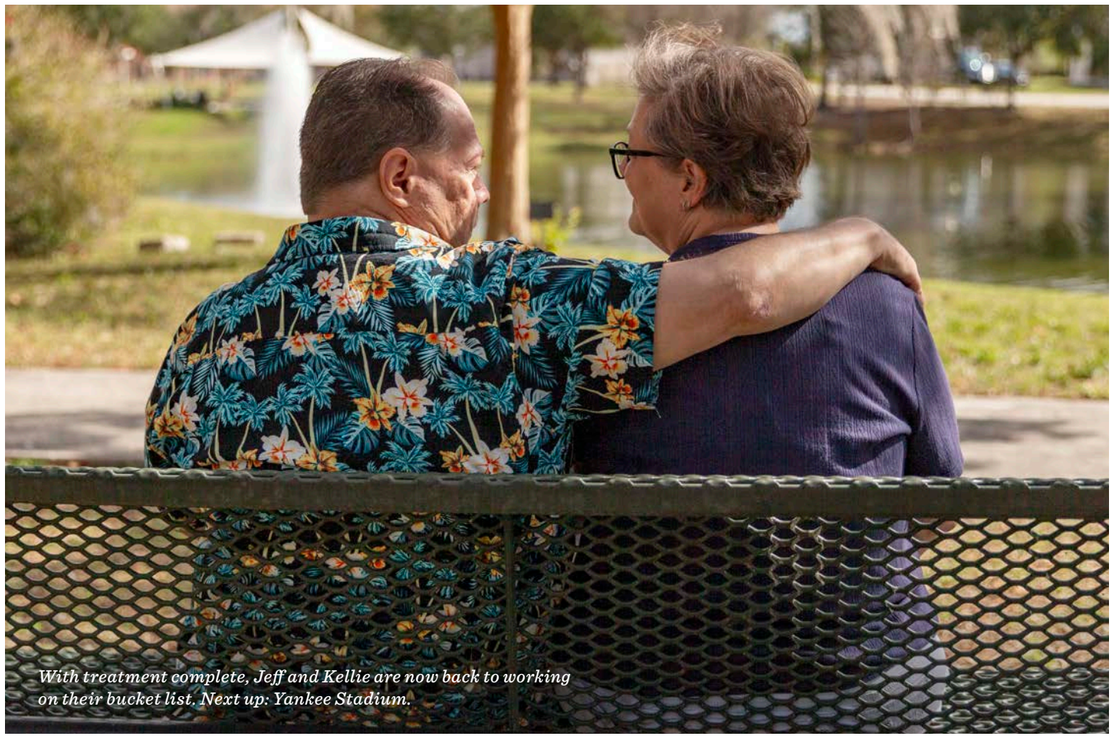
Before cancer, the Stulz family enjoyed traveling. After cancer, it’s something they don’t postpone.

“It’s kind of a wakeup call when something like this happens,” Kellie said. “So, you stop waiting.”

The new brachytherapy suite is more than just the technical jargon to Jeff. What stays with him is much simpler. One long day of treatment was reduced to just hours, and cancer no longer sets the pace.

“It let me get back to living,” Jeff said. “And that’s what I wanted all along.”

“It let me get back to living. And that’s what I wanted all along.”



With treatment complete, Jeff and Kellie are now back to working on their bucket list. Next up: Yankee Stadium.

A Father's *Promise*

By Amanda Sangster | Photos by Nicholas J. Gould and from the Yamoah family

Kosj Yamoah, MD, PhD, had just started working at Moffitt as a radiation oncologist when his son, Zion, was diagnosed with a rare and aggressive childhood brain cancer.

In his short life, Zion Yamoah left a long legacy that continues with new proton therapy center

KOSJ YAMOAH, MD, PhD, is a man accustomed to confronting life and death questions. As a board-certified oncologist, physician-scientist and chair of the Radiation Oncology Department at Moffitt Cancer Center, he has dedicated his life to studying and treating cancer.

A highly regarded expert in his field, Kosj currently leads a global translational research lab. He serves as a principal investigator for multiple well-funded national and international programs, and he has fostered the career development of multiple clinicians and scientists within the field.

Yet, no matter how prestigious the credentials or how accomplished the career, nothing could have prepared him for the most challenging role of his life: being a father to a son diagnosed with a rare and aggressive brain cancer.

A DEVASTATING DIAGNOSIS

In early 2015, Kosj was a young physician-scientist who had recently completed his medical residency and fellowship training in Philadelphia. He had earned a faculty position in Moffitt's Radiation Oncology Department, and his family was preparing to move to Tampa. Kosj was looking forward to the future and planning his research at Moffitt.

But in April of that year, Kosj and his wife, Jaymi, noticed subtle changes in their son, Zion. Just shy of his third birthday, Zion began having a slight limp and showing unusual fatigue while playing one morning. These symptoms would have seemed minor to many parents, but they sparked alarm for Kosj. Immediately recognizing Zion's symptoms as neurological, he knew the stakes were high.

"We brought him in immediately for evaluation, and an MRI was ordered that night," Kosj recalled. "The scan showed an 8-by-8-centimeter tumor in his brain. I felt like the floor had fallen out from under me. I'm a doctor. I'm supposed to understand disease, to fight it, to control it, but here was my child, and the rules were completely different."

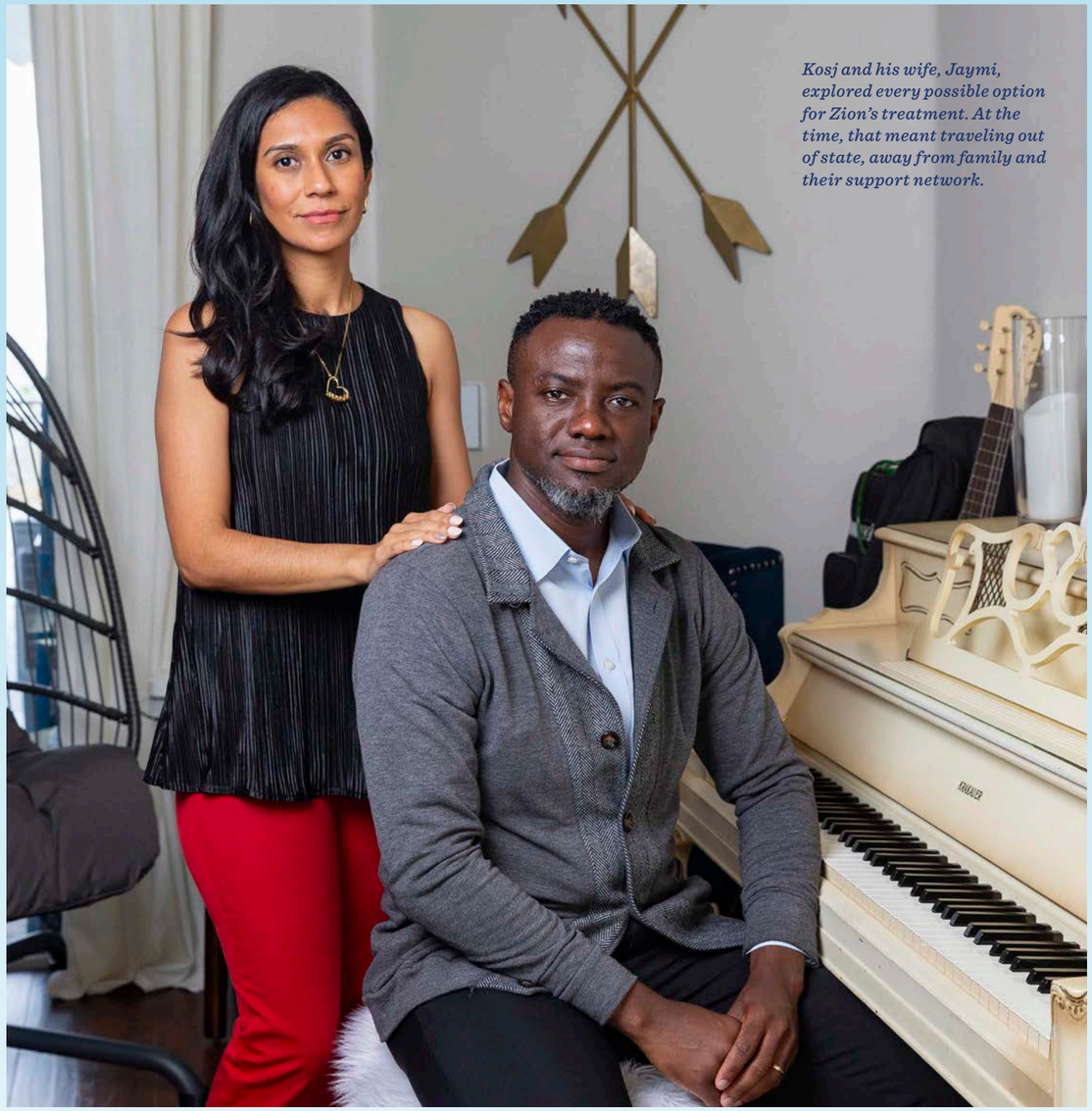
Zion's treatment journey began in May with surgery to remove the tumor. It took five hours.

"That wait was the longest," Kosj explained. "But he woke up like a champion with no neurologic deficits. He wanted to eat, wanted to play again with his action figures. He was back to his baseline, and we really believed that was behind us at that point. I was hoping it was a benign tumor, something that we know he's going to get over and he's just going to live a normal life."

But the pathology results were grim. Zion had an atypical teratoid rhabdoid tumor (ATRT), a rare and highly aggressive childhood brain cancer. While Kosj had learned about this disease in his medical training, he committed it to memory but did not think much of it.

"I felt like the floor had fallen out from under me. I'm a doctor. I'm supposed to understand disease, to fight it, to control it, but here was my child, and the rules were completely different."

- Kosj Yamoah, MD, PhD



Kosj and his wife, Jaymi, explored every possible option for Zion's treatment. At the time, that meant traveling out of state, away from family and their support network.

'LIFE WAS TURNED UPSIDE DOWN'

The Yamoahs began an exhaustive search for treatment options for their son. Together they devoured every research article, every clinical trial, every protocol available. Kosj began leaning on the same mentor who taught him about ATRT for guidance on next steps.

"I had already worked with pediatric kids with brain tumors," Kosj said. "I started calling my friends and mentors saying, 'What can we do? I'm not coming to you as a physician colleague, but as a parent with a child with a brain tumor.' My life was turned upside down."

The best option for their son was out of state, far from home, away from family, support and everything familiar. Kosj's mentors recommended a newer clinical trial that was underway in Memphis, Tenn. It took nearly a month to go through the processing and testing to ensure Zion was eligible.

While his family packed up and moved to Memphis, Kosj began his orientation at Moffitt.

"I was living across three states," Kosj said. "I had my Philadelphia address, trying to sell our house, and I was renting a space in Tampa so I could work. And then I was traveling to Memphis to be with my family while Zion was getting his treatments. I was just trying to survive."

"I started calling my friends and mentors saying, 'What can we do? I'm not coming to you as a physician colleague, but as a parent with a child with a brain tumor.'"

Even with his expertise in radiation oncology, Kosj was thrust into unfamiliar terrain. A personal and professional limbo as a physician treating patients with cancer and a parent desperately seeking the best treatment for his child.

For more than four months, Zion underwent multiple rounds of chemotherapy infusion treatments in Memphis while Kosj lost precious moments with his son traveling in between.

"I felt like a failure in those moments," Kosj admitted. "I wanted to be a supportive husband, a father and a doctor, but there's no way to describe how much it feels like you're failing when confronted with something like this. Trying to practice medicine when there was nothing on this planet that could save my son. Trying to support my wife while she's handling everything on her own. That feeling of hopelessness was palpable."

ANOTHER PAINFUL REALITY

After the trial, Zion needed to begin radiation treatments. Kosj knew the best protocol for his son would be proton therapy.

Proton therapy is one of the most advanced forms of radiation therapy available. It uses hydrogen atoms and a massive cyclotron to accelerate proton particles to nearly two-thirds the speed of light to deliver radiotherapy to cancer cells. Unlike conventional radiotherapy, proton therapy delivers a powerful, highly focused dose of radiation directly to a tumor while minimizing exposure to surrounding healthy tissue.

The result is fewer side effects and, particularly for children, a reduced risk of long-term complications. For cases like Zion's, where the tumor is in a critical structure like the brain, this precision is crucial.

But, yet again, the best treatment for Zion wasn't available in Tampa where the family was living. They were left with no other option but to travel to Jacksonville.

By the end of October, five months into the battle, Zion's treatment was complete. For a fleeting moment, the family dared to breathe. They returned for more testing in early November to determine if Zion remained with no evidence of disease.

Kosj knew something was wrong at the next visit when Zion's oncologist, a former colleague, called him into the room to review his son's scans.

"I couldn't believe my eyes," Kosj recalled. "I thought to myself it had to be someone else's scans. I watched my son – this happy, carefree kid – running around, playing and laughing. But his scans showed that his entire spinal cord was filled with little white spots. The amount of recurrent disease I saw in my own son's scan was heartbreaking."

The scans had revealed a leptomeningeal spread, a sign that Zion's tumor had seeded the brain's membranes and spinal fluid. The prognosis was poor.

Kosj walked out of the room and delivered the news to Jaymi himself. The shrieking cry that came from her echoed through the halls and still lingers in his memory.

"That was the worst," Kosj said. "We were devastated, because I knew, and Jaymi knew, that this was bad."

'GIVING TIME TO LIVE'

The family immediately sought secondary proton treatment for Zion's recurrent disease. He was still eligible for proton treatment, but yet again, the best treatment was far from home. This time the family would travel back to Philadelphia.

By the time they arrived the following year in January 2016, Zion's condition had severely deteriorated. ATRT is characterized as a highly aggressive cancer due to its fast growth throughout the brain, resulting in headaches, vomiting and balance issues. Zion was confused, almost in a state of paralysis.

At this point, Zion couldn't walk. He'd gone from that little boy who was running around laughing after his first proton therapy treatment to now needing a wheelchair. Kosj could tell disappointment was weighing on Zion as his world became more limited.

By March 2016, the secondary proton treatment was working. They watched their son's spirit return. Zion gradually regained mobility. He even danced and sang on stage at the family's church.

"Seeing him regain his strength, getting off the wheelchair and getting to dance again, getting to be on stage with his friends," Kosj remembered, "I watched proton therapy working in real time, to give us back our son."

By April 2016, Zion was able to be a normal kid again. Proton therapy gave Zion and his family nearly four months of grace and normalcy where he could simply live.

"If you think about a child's life of barely four years, that is 25% of his life in normalcy," Kosj reflected. "Giving time to live – even weeks or months – is monumental. For kids, those moments out of the hospital are precious, and when you give them the chance to live fully, you sometimes give back half of their life. That's something we can give to our community, our city, our state and around the world."

THE MOST DIFFICULT DECISION

A few months later, ATRT's aggressive nature began to deteriorate Zion's condition once again. And once again, the family was referred to another out-of-state facility – this time in Boston.

At this point, Kosj and Jaymi were forced to make a decision that no parent should be confronted with. Their discussions shifted from curative to palliative.

"We had been through it all," Kosj recalled. "We knew how the disease could steal away from the quality of time that Zion had left with our family. And that was what he really needed. He needed to enjoy doing the things he loved at home, and we don't regret that decision."

Despite the best care, Zion died on July 7, 2016.

"In spite of the struggle, my family held it together," Kosj said. "And it was really Zion who saw our family through it all. Through our faith and seeing our son's love for life, we persevered."

Zion's love for life touched everyone he knew. His parents have made sure his legacy lives on, through nonprofit initiatives and Kosj's own work to bring lifesaving proton therapy to Moffitt.

A FATHER'S PROMISE

In the time following Zion's passing, the Yamoah family began to lay groundwork for new purpose. Out of the tragedy emerged two nonprofit initiatives, one offering creative arts camps and support for children with medical needs, and another focusing on the rare ATRT community providing support and research collaboration for families.

Kosj also began channeling his professional energy into another goal: bringing proton therapy to Moffitt Cancer Center.

Finding the right treatment for Zion had highlighted the stark difference between what is possible in principle and what is possible in practice. Kosj saw firsthand how the absence of certain technologies locally, like proton therapy, can leave patients and families scrambling, uprooted and under stress.

"Even as a Moffitt physician and oncologist at a top cancer center, when my son needed that resource, I had to leave the state," Kosj said.

Confronting his own painful experience as a father and a physician, Kosj became committed to ensuring that patients in the region would not face the same hurdles his son did. Most importantly, Kosj wanted to give those families back time and quality of life.

With support from Moffitt leadership, its board and a generous $15 million philanthropic gift from the Richard M. Schulze Family Foundation, his promise has become a reality.

INVESTING IN HOPE AT SPEROS

In the years following Zion's passing, proton therapy technology has made major advances, and the landscape of what's possible has changed. The formerly massive machines have shrunk in size. Imaging and radiation beam capabilities have increased targeted accuracy. Treatment planning for advanced cases has improved, and novel technologies have become widely available.

At Moffitt, the cancer center launched a new real estate development large enough for a state-of-the-art proton therapy center to finally be built. The cancer center broke ground on Speros, a 775-acre campus in neighboring Pasco County, in January 2023.

The sprawling campus is designed to be an epicenter of life sciences and innovation, a place where proton therapy and other advanced cancer modalities converge with research and clinical care.

At Speros, the Tampa Bay area's first proton therapy center will begin treating patients this summer. Initially, Moffitt will be treating adult patients and young patients who do not require anesthesia, with plans to expand access for more pediatric patients in the future.

After a year of difficult treatments, the Yamoahs made the decision to prioritize Zion's quality of life. "He needed to enjoy doing the things he loved at home, and we don't regret that decision," Kosj said.

The first 75 acres of development at Speros include the Moffitt Speros Outpatient Center, which includes the proton therapy vault housing the ProteusONE, and the Moffitt Discovery and Innovation Center, a 250,000-square-foot research facility.

"We're transforming the spirit of discovery into purpose at Speros – a name that literally means hope," said Josh Carpenter, DPhil, president of Speros. "We're building a campus intentionally designed to accelerate cures and carry forward Moffitt's legacy of healing. It's where science and humanity intersect to provide a future where patients and families can access the very best care, right here in our community."

With a focus on proton therapy, radiopharmaceuticals and immunotherapies, Speros aims to compress the timeline from concept to cure – giving patients and families better access to lifesaving drugs and treatments.

The vision for Speros includes a fully integrated campus where families live near care, research feeds clinical trials, technology evolves and every piece is aligned with Moffitt's mission of prevention and cure.

For Kosj, the initiative is both personal and mission critical. It ensures patients and families no longer need to travel across the country for the best care and embeds proton therapy access into Moffitt's clinical and research mission.

"Bringing proton treatment to Speros is more than providing a service," he explained. "It's a promise. Speros is where that promise becomes reality."

A LEGACY FORGED FROM LOSS

Sitting in his office in Tampa, Kosj keeps a portrait of Zion smiling above his desk. It's a reminder of the child who sang, danced and drew joy from life even under the weight of treatment.

While Kosj doesn't tell every patient the story of Zion – "I always want to center the patient," he said – the memory of his son fuels his daily work as a physician and a scientist.

Moffitt's proton therapy center serves as a symbol of his promise kept. It is a legacy forged from loss. Because for every child who will one day access proton therapy locally rather than traveling afar, Zion's story becomes one of impact and not just sorrow.

For Kosj, when the first pediatric patient walks through the doors of the proton therapy center, Zion's story will live on in every life touched, every family comforted and every child granted more time to laugh and dream.

"Bringing proton treatment to Speros is more than providing a service. It's a promise."

After his final radiation treatment, Jimel Smart was with his wife, Brittany, when he started to feel faint. Minutes later, he went into cardiac arrest.

BEATING THE ODDS

First cancer, then cardiac arrest – Moffitt's ICU team rushes to save a man who's 'truly as rare as they come'

By Megan Myers | Photos by Nicholas J. Gould

When Jimel Smart's wife, Brittany, began planning his 48th birthday party, the theme came to her instantly: peacocks.

A peacock may symbolize many things in life, depending on whom you ask. For Brittany and Jimel, the bird possesses rare qualities and represents divine protection and strength.

It's what Brittany sees when she looks at her husband. He's a man who not only beat a rare cancer but also survived multiple catastrophic health emergencies.

"He is truly as rare as they come," Brittany said. "He has beaten the odds time and time again and has shown immense strength in every situation thrown his way."

'A GUT FEELING'

The story behind the peacock-themed birthday began a year earlier in June 2024.

Jimel was getting ready for the day with his usual morning routine. As he began shaving, he felt an unusual lump in his neck.

"In that moment, I had a gut feeling that something was wrong," Brittany recalled.

A visit to Jimel's primary care doctor revealed that the lump was a swollen lymph node. A biopsy led to a diagnosis of adenocarcinoma at the base of his tongue.

Adenocarcinoma is a cancer that begins in the glands that line the organs. It's typically found in the lungs, breast, pancreas and colon. Adenocarcinoma in the tongue is rare.

Jimel turned to Moffitt Cancer Center for treatment. He underwent seven rounds of chemotherapy and 35 rounds of radiation.

"His treatment days were very long, and it was really hard on Jimel's body," Brittany said. "After being an electrician for more than 20 years, he had to stop working, and I took time off to take care of him."

Jimel received his final radiation treatment on Nov. 18, 2024. It's a date the couple will never forget. A day that's typically a celebration quickly took a terrifying turn.

"I remember that he was up walking and talking, acting fine, and then he started to feel faint," Brittany said. "I went out to the nursing station to see if I could get him some juice, and when I came back into his room, he was gasping for air and unable to speak."

This was the first time Jimel went into cardiac arrest.

Jennifer Cox, MD, from Moffitt's Intensive Care Unit, worked to treat Jimel's saddle pulmonary embolism. When his condition worsened, she called in gastrointestinal surgeon Ji Fan, MD.

"He is truly as rare as they come. He has beaten the odds time and time again and has shown immense strength in every situation thrown his way."

- Brittany Smart

LIFESAVING TEAMWORK

Jennifer Cox, MD, was the attending physician in Moffitt's Intensive Care Unit (ICU) that day. Moffitt's ICU is a place where patients go to receive care that cannot be done elsewhere in the hospital, such as vasopressors to bring up blood pressure, mechanical ventilation to support the lungs, continuous renal replacement therapy for kidney failure and frequent lab draws due to organ failure.

Nov. 18, 2024, is a day that Cox also remembers vividly.

"There was a call to the ICU team for a patient who was in urgent care under observation status – Jimel," Cox said. "We came down and he was awake and talking, and we left. Within just a few minutes, we were called back for a code blue – meaning the heart or the lungs have stopped – and that is when we start CPR."

Jimel required nearly an hour of CPR before he stabilized enough to transfer to the ICU.

The ICU team determined he had suffered a massive saddle pulmonary embolism – a large clot lodged in the main pulmonary artery that blocks blood flow to both lungs.

In the ICU, Jimel experienced two additional code blues, requiring another 24 minutes of CPR.

As doctors treated the saddle pulmonary embolism, Jimel remained in Moffitt's ICU for six weeks. However, his condition worsened. His kidneys began to fail. His bowels stopped functioning. His abdomen was hard to the touch and distended – signs that demanded urgent intervention.

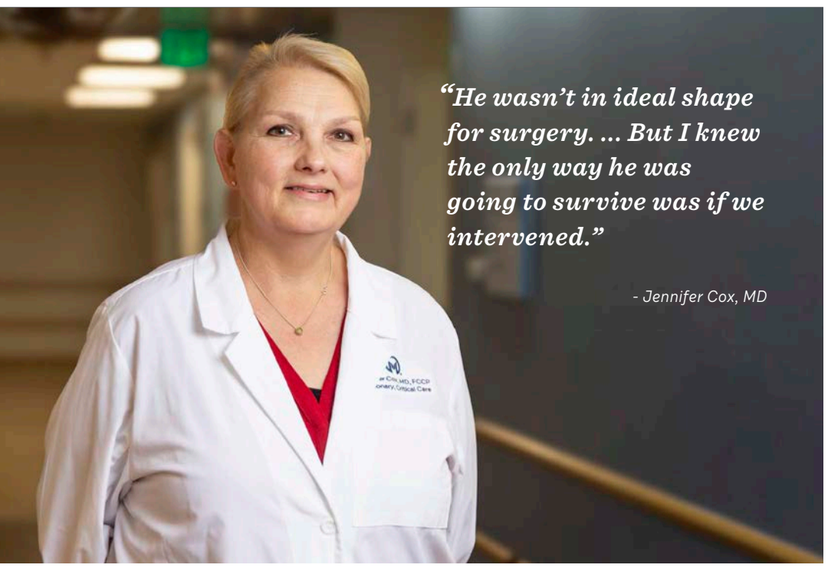
"He wasn't in ideal shape for surgery," Cox said. "We questioned whether he would make it through. But I knew the only way he was going to survive was if we intervened."

Cox made the call to gastrointestinal surgeon Ji Fan, MD. Fan serves in a unique dual role – specializing in both complex cancer cases while also responding to urgent surgical needs.

"His wife was a very strong advocate for him, and so was Dr. Cox. After careful consideration, we made the decision to move forward with abdominal surgery, although it was a risk," Fan said.

In the operating room, Fan and the surgical team found extensive bowel dysfunction and a large leak. Fan removed the damaged bowel and performed an ileostomy – creating an opening in the abdomen that diverts waste into an external pouch.

"This surgery ultimately saved his life," Brittany said. "If it wasn't for Dr. Cox first and then Dr. Fan and their teams, Jimel wouldn't have survived. Watching the communication and teamwork between different teams at Moffitt is incredible to see."



Cox and her team performed nearly an hour of CPR on Jimel before he could be transferred to the ICU.

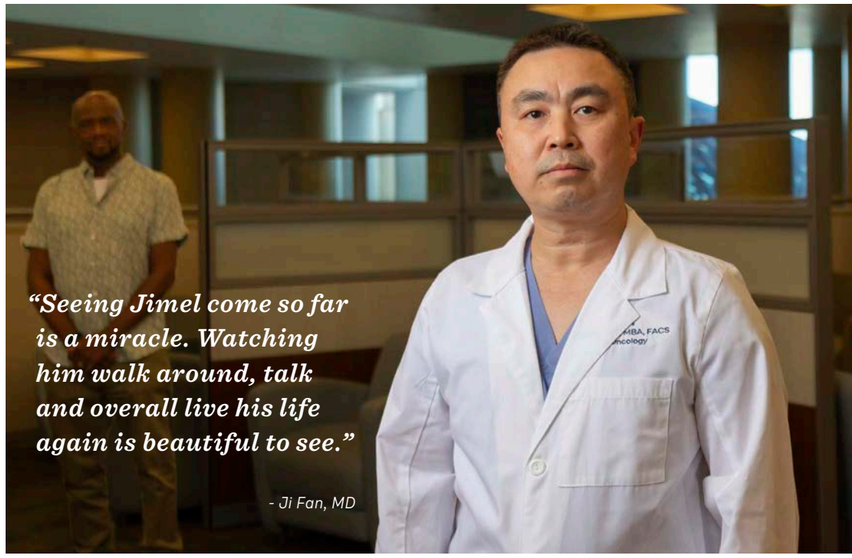
'ANOTHER MIRACLE'

On Jan. 1, 2025, Jimel was discharged from Moffitt's ICU.

Jimel's recovery journey was long and rigorous. He was in a wheelchair. He was unable to form a full sentence. He couldn't complete basic tasks on his own.

"For the amount of time Jimel was under CPR, it was expected that he likely would have had irreversible damage to his brain," Brittany said. However, the damage was limited, and his brain is expected to recover some functions over time.

In the operating room, Fan and the surgical team found that Jimel had extensive bowel dysfunction and a large leak.



"It is really shocking and, once again, another miracle," she said.

Jimel spent months undergoing physical therapy, speech therapy and occupational therapy, all with Brittany by his side. It was part of the promise the two made to one another when they married in 2021: to stick by each other's side in sickness and in health.

"It was a difficult time," Brittany shared. "Through hard times, I will always be by his side. In our relationship, we not only love each other, but we also genuinely really like each other and like to be together. He is so unique and unlike anyone else I know."

A RARE RECOVERY

Nearly a year later, a lot has changed for Jimel.

He is able to walk and doesn't need a wheelchair. He can have full conversations. He completes daily tasks like shaving and getting dressed without assistance.

"He is able to do normal things every day without a problem," Brittany said. "He just can't complete complex tasks because it becomes overwhelming."

In August 2025, Jimel reunited with Fan for an ileostomy reversal, allowing him to go to the bathroom normally again.

"Seeing Jimel come so far is a miracle," Fan said. "Watching him walk around, talk and overall live his life again is beautiful to see."

Jimel says he is taking things day by day, thankful to be present.

"Overall, I feel good and blessed," he said. "I couldn't have gotten through all of this without my faith and without the support of my wife."

To Brittany, Jimel has not only remained her partner through sickness and health, but he's truly a peacock in her eyes.

"His cancer was rare. Surviving a saddle pulmonary embolism of that magnitude was rare. The fact that he did not receive a permanent brain injury is rare," Brittany said.

For Cox, Jimel's story is also a reminder of why the work matters.

"Before they left the ICU, Brittany gave me a gift – a paperweight with a peacock on it," Dr. Cox said. "I keep it in my office. I look at it often. It reminds me of Jimel – and why we do what we do."

These days, if Jimel is asked to describe himself, he'd say he's a husband, a son, a father, a believer, and with a chuckle and a smile, he'd include a peacock.

Brittany gave this peacock paperweight to Cox as a thank you gift. Cox keeps it in her office as a reminder of Jimel and the crucial work of the ICU team.

"This surgery ultimately saved his life. ... Watching the communication and teamwork between different teams at Moffitt is incredible to see."

- Brittany Smart

NO TIME *to* WASTE

GIVEN JUST WEEKS TO LIVE, A YOUNG MOTHER WITH LEPTOMENINGEAL DISEASE TURNS TO A DENDRITIC CELL TRIAL

By Corrie Benfield Pellegrino

Photos by Nicholas J. Gould

Heather Curley started with a stack of 18 birthday cards. Her daughter was 3 at the time, and Heather was planning ahead for all those big milestones. Her first year in kindergarten. Learning to drive. Graduating high school. Heather poured her love for her daughter, Palmer, into those sweet birthday wishes and sealed them for the years to come. Years that Heather feared she wouldn't be around to see.

Just weeks earlier, Heather had been feeling optimistic. The 32-year-old hairdresser and her husband, Dennis, had taken their daughter on a summertime family vacation to Mexico to mark what she thought was the tail end of her breast cancer journey. She had been diagnosed in December 2022 with stage 4 HER2-positive invasive ductal carcinoma and completed 12 weeks of chemotherapy. Afterward, she had settled into a regimen of immunotherapy and hormone suppressants.

"My scans showed shrinkage of all my tumors and all my metastases in my body," she said. "I was feeling good. My hair was growing back. We just got back from this amazing vacation."

HEATHER CURLEY
Cancer Survivor

Heather was sitting on the couch with Palmer at their Clearwater home on Aug. 10, 2023, getting her precocious preschooler ready for the day, when she got a call from her doctor at Moffitt Cancer Center.

Heather had been to the hospital the day before for a follow-up MRI. The results revealed the worst-case scenario.

The cancer had metastasized to the spinal cord fluid around her brain, a condition known as leptomeningeal disease (LMD). Heather's doctor asked her to come in immediately and cautioned her: Do not Google it.

"Of course I did. I hung up, I looked it all up," the young mom said, remembering the shock of the prognosis. "It said two weeks if you don't treat it, a couple months if treated. I immediately went into fight or flight."

OUT OF NOWHERE

Leptomeningeal disease is an aggressive and poorly understood complication of cancer in which tumor cells spread to the coverings of the brain and spinal cord fluid. The disease most commonly stems from breast cancer, lung cancer and melanoma.

Women who are diagnosed with leptomeningeal disease are typically young, like Heather. She was 29 and pregnant with Palmer when she first felt a lump in her breast in 2019. Her gynecologist told her it was normal, likely caused by hormones.

But even after giving birth, she felt odd. Her body felt off. She went to an endocrinologist, a dermatologist and then back to her gynecologist. No one suspected cancer. She had no family history, and she was below the recommended screening age for a mammogram.

Still, she was concerned about the changes in her breast. She had started to notice what looked like rippling, and then in October 2022, she felt the lump again. Her gynecologist sent her for a mammogram. By December, she had her diagnosis.

"The cancer had spread within practically my whole entire body," she remembered.

"The cancer had spread within practically my whole entire body."

The diagnosis was terrifying, but Heather seemed to respond well to treatment. After chemotherapy, her scans painted a positive picture. Her oncologist had also arranged for her to join a brain MRI clinical trial in February 2023 to monitor for potential metastases. That scan was clear.

As she continued on immunotherapy and hormone suppressants, the outlook got better. She was starting to see the light at the end of the tunnel. Then came the follow-up brain scan.

This type of silent progression is common for breast cancer patients diagnosed with LMD, says Peter Forsyth, MD, a neuro-oncologist at Moffitt and a world-renowned expert in the field.

"For reasons that aren't understood, breast cancer really likes the brain and tends to go there. It's like a sanctuary site where the tumor cells can hide," Forsyth said. "It usually happens when everything else in the body is quiet. So you went to see your oncologist, the bone metastases are fine, the tumor in the breast is gone. You have a clean bill of health. And then you start getting headaches. It's particularly heartbreaking because once it gets in the brain, that's usually what kills patients."

'I WANT TO FIGHT THIS'

Heather knew time was not on her side. She immediately met with her team of doctors at Moffitt, with Forsyth walking her through the treatment options.

She remembers he told her: "This is very serious. There are not a lot of trials or research geared toward leptomeningeal disease, but this is something that's close to my heart that I've been researching."

The standard treatment for LMD is radiation and intrathecal chemotherapy, which is delivered directly through a port in the skull. But even with treatment, the prognosis is only two to four months.

Forsyth recommended that Heather start with proton therapy, a type of precision radiation therapy that targets cancer with minimal damage to surrounding tissue. He also told her about his first-in-human phase 1 clinical trial that uses a person's own dendritic cells, a type of immune cell, to fight the disease. There was only one person on the trial at the time. Heather would be the second.

"I said yes. I want to do everything and anything that I can do. I want to fight this. I want to try," she said. "I have a 3-year-old at home, I'm not ready to give up."

Heather completed 10 rounds of proton therapy at a hospital in Baltimore and then returned to Moffitt to join Forsyth's dendritic cell trial. She started by having surgery to install the intrathecal port toward the top of her skull, which would allow the dendritic cell treatment to be injected directly into her spinal fluid.

Heather Curley enjoys some family time with her daughter, Palmer, and husband, Dennis. When Heather was diagnosed with leptomeningeal disease, her prognosis was only two to four months.

"This was the first surgery I had ever had in my entire life. I had never had anesthesia for anything," she said. "So brain surgery was my first surgery."

Next, Heather went in for apheresis, where blood was collected to extract white blood cells that would be used to develop her own personalized dendritic cell vaccine. During the production of the vaccine, the dendritic cells were grown in a lab and trained to recognize, remember and attack cancer cells, specifically with HER2 and HER3 proteins, which can drive aggressive forms of the disease.

Forsyth likens dendritic cells to a familiar historical figure.

"The dendritic cells are the Paul Revere of the immune system. We're growing them in a dish and training them to recognize the enemy," he explained. "So all the Paul Revere cells are like, OK, this is what the enemy looks like. If you see these proteins, get really angry and really excited. The dendritic cells run around and say, the cancer is coming, the cancer is coming. So it's just educating our immune system, making it angry and turning it on."

'A HELPING HAND'

Once her personalized dendritic cell vaccine was ready, Heather came to Moffitt weekly for treatment. Being patient No. 2 on the trial, she didn't know what to expect. Initially, she experienced excruciating migraines, back pain and vomiting in the first three days after the injection.

Forsyth explains that the dendritic cell vaccine triggers a type of aseptic meningitis, causing these side effects.

"We used to think that leptomeningeal disease was a whole bunch of tumor cells floating around in this watery spinal fluid. But when we look at all the cells in people with leptomeningeal disease, 90% of them are immune cells. So it turns out it's an inflammatory disease. These immune cells are fighting it just a little bit, but not enough," he explained. "That raises the obvious strategy of helping the good cells to fight it better and trying to fight the bad cells that might interfere. This dendritic cell vaccine gives a helping hand to your body to fight that. So when we put in the dendritic cells, we get this aseptic meningitis, with headache and neck pain."

The meningitis inflammation indicates the dendritic cells are doing their job. They are recognizing the cancer cells, getting angry and fighting back.

Heather developed her own routine to temper the side effects. She ate a light breakfast and drank a caffeinated hot tea before the vaccine was administered. Then she would take antinausea and pain medication to control the headache and back pain afterward.

As part of the trial, she came to Moffitt every Monday for 12 weeks to receive her dendritic cell doses. Although the treatment itself took only about 15 minutes, she typically spent the entire day at the cancer center, getting lab work done and waiting for the vaccine to be prepared for that day's injection.

At the end of her 12 weeks on the trial, her care team informed her she had enough personalized vaccine left for four more rounds of treatment. They gave her the option to continue.

Her daughter drove her decision.

"As hard as the vaccine was, I was like, if I say no, I'm going to regret it," she recalled. "I just have to say yes. I've done it for 12 weeks. What's a few more?"

'UNCHARTED TERRITORY'

After completing the dendritic cell treatment, Heather's scans showed significant signs of improvement in the leptomeningeal disease. She also had no evidence of disease in her body from the neck down. However, her breast cancer had metastasized to the brain itself. She went back on chemotherapy to target the brain tumors.

With her dendritic cells now supercharged and trained to keep fighting the leptomeningeal disease, Heather also worked with Forsyth to join a phase 1/2 clinical trial led by radiation oncologist Kamran Ahmed, MD. The trial uses intrathecal trastuzumab and pertuzumab, two antibody therapies, to improve survival for patients with HER2-positive breast cancer that has led to leptomeningeal disease. She started on the trial in March 2024, seven months after her LMD diagnosis.

At best, Heather had originally been told, she had four months to live. By this point, she felt like she was in "uncharted territory."

'A MAJOR UNMET NEED'

Forsyth has now treated 14 patients with the dendritic cell vaccine, and he's aiming to treat a total of 15 during the phase 1 trial. In October 2025, he was awarded a $22.4 million grant from the U.S. Department of War to open two new trials targeting LMD. The first, expected to open in September, will be the phase 2 trial for the dendritic cell vaccine. It will combine the dendritic cells with targeted antibody therapy and checkpoint inhibitors to treat patients with LMD stemming from HER2-positive and triple-negative breast cancer.

The second trial funded by the grant will combine the dendritic cells with a sugary protein called alpha-galactosylceramide to boost the immune response to LMD.

"The puzzle is that nobody really understands leptomeningeal disease in terms of the biology," Forsyth said. "This grant is important because it allows us to open clinical trials that we think are going to give meaningful results to change that as well as tons of basic research so we can understand the disease better and try to find better treatments."

Moffitt will also be expanding treatment options for patients with LMD with the opening of its Speros proton therapy center in Pasco County over the summer.

Peter Forsyth, MD, a world-renowned expert in leptomeningeal disease, was recently awarded a $22.4 million federal grant to explore new treatment options for patients like Heather.

> ***"The dendritic cells are the Paul Revere of the immune system. We're growing them in a dish and training them to recognize the enemy."***

"Leptomeningeal disease is a major unmet need, and it's a real problem. But Moffitt has one of the top programs in the world," Forsyth said. "This huge immune component just opens up a universe of new treatments."

He credits Moffitt's breakthroughs to the collaborative mission of its physicians and scientists, particularly the work of Brian Czerniecki, MD, PhD, who has pioneered research into dendritic cell vaccines for breast cancer patients.

"In order to make discoveries and improve care, you need a team," Forsyth said. "Nobody has the full view of the elephant. We're all working in the dark. Moffitt's great because everybody gets it – we need each other to succeed."

Forsyth also works closely with the few other experts in the field from around the world. He points to a promising trial at Memorial Sloan Kettering exploring iron depletion as a means of starving tumor cells in the cerebrospinal fluid. There's also research into the use of radiopharmaceuticals, which use radioisotopes to deliver radiation directly through the patients' intrathecal port.

At the forefront of it all, for Forsyth, is Heather.

"I always want to have an option for Heather. I never ever want to look her in the eye and say, oh, we don't have anything for you," he said. "I can't see these young women without having another option."

'THERE IS HOPE'

For Heather, she's happy to be shattering statistics. She is still on weekly chemotherapy and is undergoing radiation for the brain metastases, but her last scan showed no evidence of leptomeningeal disease.

"It's just such a miracle," she said. "I just want to spread awareness and let people know that these statistics aren't the normal anymore, that there is hope."

Over the course of the past three years, Heather has thought a lot about the core memories she wants to make with her daughter. They've gone on family vacations to Disney and taken a cruise. She has written letters and recorded herself reading storybooks. She even made a book with her voice singing the happy birthday song.

Perhaps better than anyone, Heather knows that tomorrow is never promised. So she lives for the hugs and the smiles of today.

In October, Palmer turned 6. The family went to a trampoline park to watch the bubbly kindergartener bounce around in celebration. Back at home, Heather marked the milestone in another way. She took out the birthday card she'd written to Palmer for the occasion so many months ago. She didn't open it, didn't read it. Instead, she tore it up, threw it in the trash and held tight to her growing girl.

Senior research specialist Vincent Law examines a sample under a microscope in Forsyth's lab. Researchers are working to better understand how leptomeningeal disease works and how to boost the immune response to it.

MONITORING *for* METASTASIS

The National Comprehensive Cancer Network Guidelines do not currently recommend routine brain MRI screening for stage 4 breast cancer patients. However, research suggests brain MRI surveillance could help detect asymptomatic metastasis earlier. Heather Curley's leptomeningeal disease was diagnosed in the early stage as part of a phase 2 clinical trial using brain MRI surveillance in stage 4 breast cancer patients. The trial, led by Kamran Ahmed, MD, was funded by the Florida Breast Cancer Foundation. Subsequent funding from the Florida Department of Health will support the next phase of the brain MRI surveillance trial. Ahmed hopes this research will shape changes in current guidelines and open the door for routine brain MRI surveillance in late-stage breast cancer patients.

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

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