

MOFFITT MOMENTUM®

PORTRAITS OF HOPE, INNOVATION AND TRIUMPH

MOLECULAR MARVEL

Meet the maestro of radiation

HOPE IN HUMAN FORM

The incredible Vikki Pinkos

FUELING THE FIGHT

The Rays 3rd baseman steps up



Alan F. List, M.D.
President & CEO
Moffitt Cancer Center

MOFFITT MOMENTUM®
VOLUME I, ISSUE 2

Dear Friends,

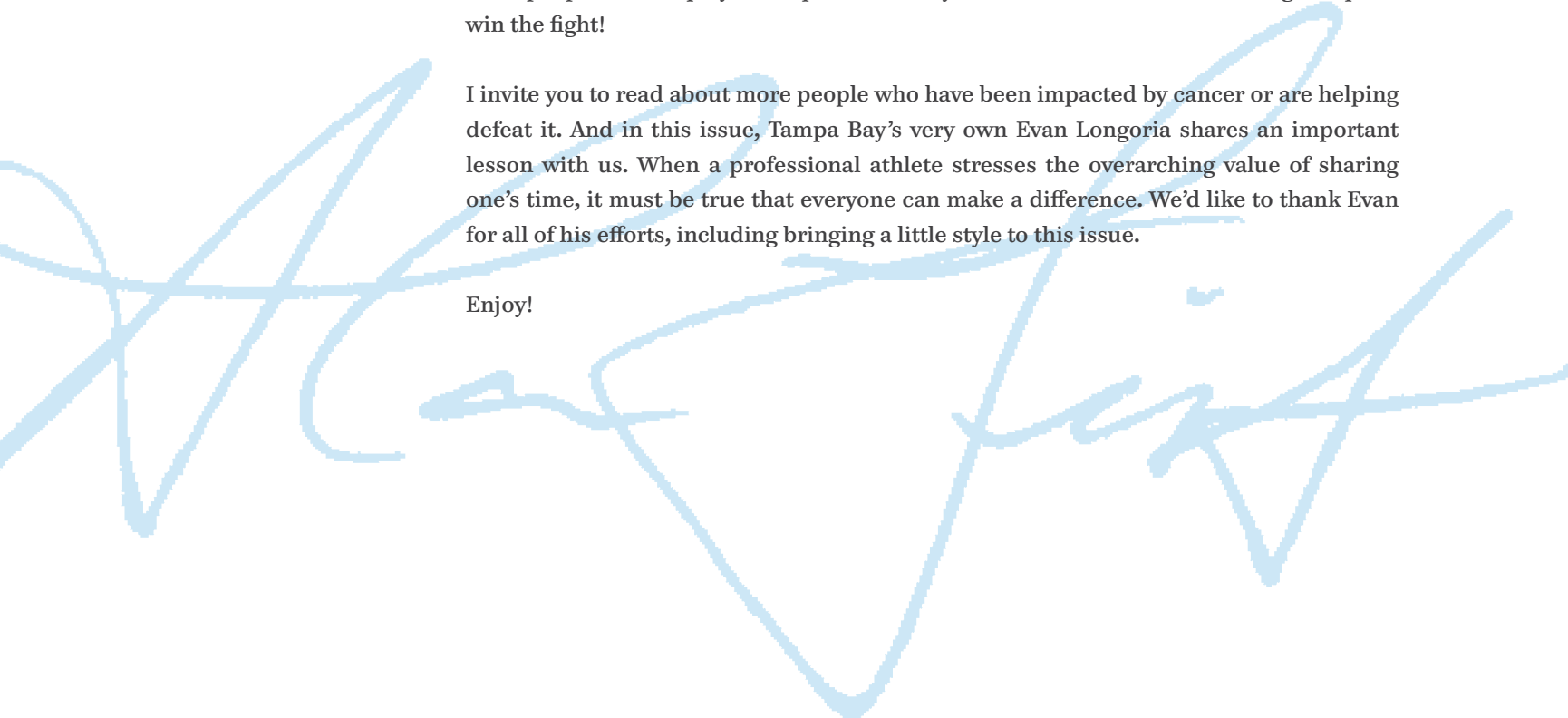
Our mission to contribute to the prevention and cure of cancer continues, and a lot has happened since the inaugural issue of *Moffitt Momentum*.

At this year's Magnolia Ball in May, \$3 million was raised for cancer research. And just one week later, the PNC Bank Miles for Moffitt community fundraising run/walk event added another \$600,000 to the fight. Moffitt is grateful for this incredible support. We're also honored to have established The Shula Fund with the generous gift of \$1.5 million from the Don Shula Foundation. Thanks to Coach Shula and his family, this fund will be designated exclusively for breast cancer and related basic science research.

But as you're about to see, philanthropic efforts are not the only stories to share. And if I can think of just one way to describe all of them, it's teamwork. Many organizations use this word. But when you consider that we're fighting cancer and how we bring teamwork to life on a daily basis, it becomes so much more than a word. From our physicians and scientists, to patients and survivors, to the volunteers, donors, staff and community members who help drive our mission forward, everyone is part of a great team. Each has a unique position to play and a personal story to tell. And all share the same game plan: win the fight!

I invite you to read about more people who have been impacted by cancer or are helping defeat it. And in this issue, Tampa Bay's very own Evan Longoria shares an important lesson with us. When a professional athlete stresses the overarching value of sharing one's time, it must be true that everyone can make a difference. We'd like to thank Evan for all of his efforts, including bringing a little style to this issue.

Enjoy!



4 **DOING IT HIS WAY**
The artistry of radiation therapy



6 **SPECIAL DELIVERY**
A nurse's story



16 **LOOK OUT, DARWIN**
Here comes Lloyd



27 **GOLD MEDALIST JOINS OUR TEAM**
Givers, take your mark



18 **A LIFE EXTENDED**
Reporter reports on self



23 **EVER AGGRESSIVE**
Cancer's met its match



10 **LONGO HITS IT HARD**
On and off the field

THE MOST IMPORTANT CONCERTO OF HIS LIFE

With music as his muse, Dr. Javier Torres-Roca is rewriting the rules for radiation therapy.

“In music, you learn how to play other people’s songs, then you learn to improvise around them. Or write your own. Ultimately, you learn how to play something in a way that no one has ever played it. That’s what I’ve tried to do my whole life.”



By his own admission, Javier Torres-Roca, M.D., a radiation oncologist at Moffitt, is a bit of a willful individualist. Always has been. Even as a child growing up in Puerto Rico.

“I didn’t want to follow any rules,” he recalls wistfully. “I just did not want to do what I was told.”

Of course, it’s one thing to ignore your mother’s pleas to make your bed, but another to turn a deaf ear to your father who’s begging you, now a full-fledged adult, not to drop out of medical school to follow the siren song of music and pursue a career as a classical pianist.

“But that was a pivotal moment. I decided to open up the creative juices by going back to music school. Looking back I was essentially saying that creativity is something that I have to feed in some kind of way – in whatever I do.”

And feed it he has. In his own characteristically willful and individualistic manner.

After completing two years of intense musical training, he returned to medicine and has spent his career since then taking, one might say, the neural path less traveled, developing a molecular diagnostic test to predict whether a cancer patient will respond to radiation therapy.

This, when most clinicians were focusing on the more traditional approach of administering radiation therapy without knowing or investigating ways to predict tumor response to radiation.

That may not sound radical, but hear him out:

“Depending on the cancer, radiation therapy can be curative. In some cases, it’s considered equal to or better than surgery because generally it has better functional outcomes. For example, before a treatment plan is devised, a patient might be told he has an equal chance of doing well with surgery or radiation. But that’s just based on the average. Not the individual. What our test does is help to identify the patients most likely to be cured with radiation.”

For oncologists, that’s big. If you give them genomic information on the specific tumor that they’re treating, they can better tailor a patient’s treatment.

After medical school, Dr. Torres-Roca spent five years as a researcher completing postdoctoral training in molecular biology and immunology at the Institut Pasteur, Unité d’Oncologie Virale in Paris, France, and Stanford University in California. He completed his clinical training in radiation oncology at the University of California, Irvine. Most notable was his time in the laboratory of Professor Luc Montagnier, co-discoverer of the AIDS virus and winner of the 2008 Nobel Prize in Medicine. “Incredibly eye-opening,” he says of his time there. Among other things, he was introduced to the idea of entrepreneurship. And this has led to his cofounding of a company called CvergenX to market the molecular diagnostic test. A physician-scientist for Moffitt since 2002, where he ran both an active laboratory and a clinic, he now directs his efforts

toward this commercial endeavor with Moffitt’s blessing and support. Moffitt co-owns the technology that enables the test, and CvergenX has an exclusive license for its commercial use.

“I came to Moffitt,” Dr. Torres-Roca remembers, “because they showed a great interest in being novel going into the genomic space and thinking outside the box. I knew if I came here nobody was going to tell me I was crazy.”

People telling him he’s crazy, then the good doctor proving them wrong, seems to be a recurring theme here.

Dr. Torres-Roca continues, “Radiation oncology departments are usually very conservative by nature, and I knew that what I wanted to do would not fit well in the majority of radiation oncology departments in the United States.”

Not surprisingly, he gives at least partial credit to whatever success he’s had to music. In a way, his career has played out like variations on a Beethoven theme: “I returned to medical school because I realized that you can be an artist in all walks of life.”

He keeps this metaphor close. Always handy. It explains him so well.

“In music, you learn how to play other people’s songs, then you learn to improvise around them. Or write your own. Ultimately, you learn how to play something in a way that no one has ever played it. That’s what I’ve tried to do my whole life.”

So then, let’s hear it for improvisation. And, of course, willful individualism. 🎵

CvergenX is one of Moffitt’s newest and most exciting startups. It was co-founded by Javier F. Torres-Roca, M.D., and Steven A. Eschrich, Ph.D., to market a game-changing molecular diagnostics test the two are developing. Using a proprietary algorithm to generate a radiosensitivity index derived from the expression of 10 specific genes, the test will enable oncologists to predict patient response to radiation therapy. In other words, says Dr. Torres-Roca, we will soon be able “to identify the patients most likely to be cured with radiation.”

Dr. Torres-Roca is a board-certified radiation oncologist at Moffitt and serves as chief scientific officer of CvergenX. Dr. Eschrich is an associate member of Moffitt’s Department of Biostatistics and Bioinformatics.

CHOSE ME

“I’m a survivor. That’s why I’m here. It helps me deliver better care.”



Vikki Pinkos couldn’t catch her breath. Her neck, webbed with lymphoma, had lost its shape. From the mass in her neck, fear grew. She was scared she would stop breathing.

But something else was growing, too. A baby girl, with the kicking power of an Olympic swimmer, grew inside her.

Pinkos remembers climbing up on the table for regular ultrasounds. And, when she was fighting for breath, she’d watch the screen, hope rising with her healthy daughter’s diaphragm, as she noted each organ: the brain, the kidneys, the heart.

Vikki Pinkos was diagnosed with Hodgkin lymphoma, a cancer of the immune system that starts in white blood cells (lymphocytes), when she was seven months pregnant. She spent her final trimester fighting for her own life and nurturing a new one.

“Of all the things that can go wrong in a normal pregnancy, with all the odds stacked against me and Catherine,” she says, “how can you not say it’s a miracle?”

She received four chemotherapy treatments while she was pregnant.

“My family was scared, but I had a sense of peace,” she says. “I believe that God grants mothers special graces and I knew that everything would be all right.”

Catherine was born on August 20, 2004 – just four days after Pinkos received chemo. She had an emergency C-section on Friday. An oncology appointment the very next Tuesday. She didn’t finish chemo until December 2004. Radiation started in February 2005 and lasted five weeks. Finally, she had a PET scan at her six-month follow-up in July 2005.

Positive.

“When I got the call from my doctor, I was devastated,” she says. “I just didn’t believe that I had cancer again.”

They discussed treatment options. The prognosis, plans, procedure. She learned that she would need a bone marrow transplant. She’d be launching into chemo once again, just one week after baby Catherine’s first birthday. But she would be at Moffitt, close to home.

Pinkos was a patient once again – which isn’t easy for a registered nurse. But life often runs in full circles.

This is her incredible story.

Her voice tells you that her heart is light and strong. It’s the way she sings things when she talks. It’s the way her laugh skips about like a pixie. But when she pulls a story up from its well in her memory, it echoes with the quiet confidence of someone who knows how it feels to measure a day in breaths and heartbeats.

She was the kid who loved Creature Features, the little girl who would lean in when something “a little freaky” flickered on the screen instead of flinching or shuddering. Her mom worked as a phlebotomist at a south Florida hospital and, as soon as she could, so did Pinkos. After she graduated from high school, she started working there full time.

“I had an opportunity to read the charts and talk to the insurance companies,” she says. “I would read all kinds of things and, when I didn’t understand what I was reading, I wanted to know what they were. So, I looked things up, I asked questions. I realized that I wanted to go to nursing school.”

But it was loss, a step back a few years later, that finally pushed her to take a step toward her dream career. Cancer snatched two of her grandparents. They were just 66.

“When my grandparents were first ill, I was a teenager,” Pinkos says. “I was so detached. So the loss really shook me. I wished I had spent more time on the caregiver level with them, been more involved with them. I knew that I couldn’t make a difference for them then, but I could make a difference in the future.”

That’s why she’s sure she didn’t choose nursing. “Nursing,” she says, “chose me. I had fleeting thoughts back then. Wouldn’t it be great if I could help find a cure for cancer? All kinds of things went through my mind. What if I could work for a cancer center? Wouldn’t it be great to have a center named after them [her grandparents]?”

So, after working in health care for a decade, Pinkos started a nursing program when she was 28. And she graduated when she was 31 – in 2001.

She spent several years working on a surgical floor, soaking up experience every day, healing with medicine and compassion. How could she know, as she scurried from patient to patient,



“I make it my personal mission to leave an everlasting imprint of hope.”



VIKKI PINKOS
SURVIVOR + MOTHER + NURSE

that she would soon need the very care she was sharing?

But that's when the nurse became the patient, diagnosed in the middle of her nursing career and first pregnancy.

A few months after her positive PET scan, when baby Catherine was just 11 months old, she met Ernesto Ayala, M.D., in the Bone Marrow Clinic at Moffitt Cancer Center. It was October 2005. He told her there was a 60 percent survival rate for patients with Hodgkin lymphoma who underwent autologous stem cell transplants. The procedure involves removal of one's own stem cells before receiving chemo or radiation treatment. The stem cells are stored in a special freezer and returned to the patient's body following treatment to regenerate normal blood cells.

Pinkos was 100 percent sure she would beat those odds.

"I had the will to live," she says. "I was faced with the challenge to muster up the courage to fight. It wasn't easy, to say the least."

First, it was high-dose chemo. Again. And, again, she looked ahead of the moment, ahead of the treatments, ahead to holding and playing with her baby Catherine.

On January 4, 2006, she received a lifesaving stem cell transplant. After that, sickness settled in. Nausea and fatigue overtook her. Anxiety raced against sanity through her veins.

"I wanted so badly to believe everything was going to be okay," Pinkos says. "But I was afraid I was going to go to sleep and not wake up. I didn't want to die."

It was all the life around her that charged her: "Heaven-sent angels." She credits her recovery, in part, to every single person who came into her room and shared a little time, a few hope-filled minutes that inflated her joy and pushed away the pain.

She remembers one such individual – a kind lady who came to clean her room each day, telling stories about her dog, a boxer. She would spend a few extra moments cleaning just to talk.

"It was a sweet escape," Pinkos says. "My mind wandered off to a happy place. Those five-minute increments helped me put one foot in front of the other and forge ahead." And she did forge ahead.

Fast forward to 2011. Pinkos began her career at Moffitt: a personal steppingstone, an intersection, a familiar path. She was now working in the same place that had worked to heal her. And, sometimes, she even pulls out her phone to share a picture of her time as a Moffitt patient – the one where she's bald, with a fatter face, and she thinks she looks just like Uncle Fester from *The Addams Family*.

"I'm a survivor. That's why I'm here. It helps me deliver better care," Pinkos says. "One of the things that people underestimate is that it's not just the medicine in the syringe that helps people – especially cancer patients. Sure, I give medicine to relieve pain and side effects, but the encouragement, support and patience – the importance of that should never be underestimated."

"I had the will to live. I was faced with the challenge to muster up the courage to fight. It wasn't easy, to say the least."

She works each day to share her own dose of hope.

Hope is feeling the fierce kicks of your unborn baby girl and living to see your nine-year-old daughter kick across the pool in a swim meet – your "beautiful, healthy, smart, strawberry blonde child." Hope is your husband waking you up to give you medicine, feeding your newborn and walking the dog while you sleep off the effects of chemo and then just sitting right beside you to calm the panic that quakes beneath your skin. Hope is recognizing the very fear you lived in your patients' eyes, meeting them where they are and never leaving them there, "holding their hearts and hands and cheering them on to the finish line, wherever that may be."

"I make it my personal mission," Pinkos says, "to leave an everlasting imprint of hope." 🍓

Marc Topkin, Guest Columnist, Tampa Bay Rays Beat Writer, Tampa Bay Times

STEPPING UP TO THE PLATE

For Tampa Bay Rays star Evan Longoria, helping Moffitt is an easy call.



“Hope is very strong. So if people have hope, they can battle through anything.”

THE DETAILS OF EVAN LONGORIA'S FIRST VISIT TO MOFFITT CANCER CENTER ARE FUZZY NOW, YEARS LATER, BUT THE IMPACT ON THE TAMPA BAY RAYS ALL-STAR THIRD BASEMAN REMAINS CRYSTAL CLEAR.

Longoria met several patients that day, but the one that stood out was a young man who had been actively pursuing a baseball career until being diagnosed.

Longoria didn't catch his name, or recall his specific type of cancer, but he will always remember how he felt.

"At that moment, it was just kind of like, man ..." Longoria says. "I guess when it's someone that does something that you do, whether they're 15 years old or 50 years old, it just feels like it's a lot closer to you."

"It struck me pretty deep. It hit me pretty hard to see that."

So Longoria joined the fight, lending his name, and his time, to help several Moffitt causes.

And while some athletes and celebrities may ask why they should contribute, Longoria saw the question as, why not?

"I think it's kind of doubly important for me," he says. "Not only is Moffitt a world-class facility with a world-class staff, but they are right in our backyard. So it's one thing to be part of an organization like that wherever they are, but to have that sort of facility right where we live makes it a real easy decision for me to be a part of it."



LONGORIA RAPS ON A WOOD PANEL IN THE RAYS clubhouse when acknowledging how fortunate he is to say that his family has thus far been cancer-free, one of his many blessings he is well aware of.

Raised by working-class parents in Southern California, Longoria was just another kid playing baseball – not even drafted out of high school – before blossoming into a future major-leaguer at Rio Hondo Community College and then Long Beach State University.

Under new management, the then-struggling Devil Rays made him their first-round pick in the 2006 draft, and the relationship has been quite a hit: a mutually beneficial arrangement that has paid off handsomely for both sides.

The Rays, as they rebranded to in 2008, have become one of baseball's most successful teams with Longoria as the centerpiece of their lineup, making four playoff appearances in the six years since.

And Longoria has become one of the game's top players as well as the face of their franchise, signing a long-term contract that guarantees him \$100 million, earning three selections to the All-Star team, winning two Gold Gloves for fielding excellence and appearing in several national television commercials.

Life, obviously, is good. He has a stunning fiancée,

model Jaime Edmondson, with plans for a January 2016 wedding, and a beautiful daughter, Elle, who turned one in February and keeps him plenty busy when he is not at the field.

Plus, he is a part-owner, and main menu planner, for a recently opened restaurant/sports boutique lounge in Tampa: Ducky's.

With all that going on over the grind of a 162-game baseball season (after six weeks of spring training, and, he hopes, before a month of playoffs), Longoria still finds time to help Moffitt causes in various ways.

He participated in his second Miles for Moffitt event in early May, made numerous appearances, donated hitting lessons and other items for the annual Magnolia Ball and made public service announcements in support of Moffitt.

"It's been great," he says. "I think I'm in a position where I'm able to make an impact. It's a responsibility. It's something that is needed, and I enjoy being a part of organizations like this."

The Miles for Moffitt event was particularly touching, Longoria says, because of the chance to meet both survivors and patients.

"Hopefully it was uplifting for the people that were there," he says.

"It's been great," he says. "I think I'm in a position where I'm able to make an impact. It's a responsibility. It's something that is needed, and I enjoy being a part of organizations like this."



Through his involvement with Moffitt and other charitable causes and appearances he has made around the Tampa Bay area, Longoria has met cancer patients of all ages. He is frank to admit that the younger ones can be the toughest for him, though he tends to end up finding the experience rewarding.

"We deal with little things every day that sometimes get blown out of proportion, whereas these kids are dealing with very serious life-threatening diseases and they live every day like it's a normal day and they're having fun and just enjoying being kids," Longoria says.

"If there's anything good you can take out of the experience, it's that those kids don't really quite understand what they're going through, and I think the fact that they don't gives them this sort of tremendously positive outlook on life.

"And I think that's something we all can, and that I, take out of it."

EVERYONE, UNFORTUNATELY, KNOWS SOMEONE WHO KNOWS SOMEONE DEALING WITH CANCER ISSUES.

For Longoria, his first real experience came in 2009 when a friend of a friend was diagnosed with cervical cancer and was being treated at Moffitt.

"It's something you never want to hear about someone you care about," Longoria says. "It took an emotional toll on her and on me. It's hard to watch someone go through that. It opened my eyes to the reality of life."

It was also what got Longoria involved in helping Moffitt, something he now says "was an easy decision" to make based on its reputation as a world-class facility.

And it also taught him that giving of himself – even more than giving of his money – was how to make the biggest difference in the fight.

"I don't think money is the thing," Longoria says. "Time is the most important thing."

During the offseason, Longoria read the Simon Sinek book, *Leaders Eat Last*, and was struck by some of the concepts on team success as the result of individual sacrifice by those in charge. He shared those with Rays manager Joe Maddon, and the book title has become something of a theme for the Rays this season.

And in a way, those same thoughts are the way Longoria looks at the opportunity to help Moffitt.

"It kind of goes back to the *Leaders Eat Last* book a little bit, in that people you're around that

feel drawn to you for whatever reason, or look at you as a role model, or as a person that has an impact in the community, whether it's me or anybody else, the most important thing is time," he says. "Because people value their time more than anything."

And that is how he tries to have the biggest impact.

"When you take time to do a fundraiser or go spend time with somebody in the hospital or go to somebody's house, whether it's a family member or the actual person, it seems to me, and, I believe, to pretty much everybody else, as a more significant gesture than just penning a check and sending it in. That's just more important."

In addition to the help he provides, Longoria encourages others to join the cause and help Moffitt help fight cancer.

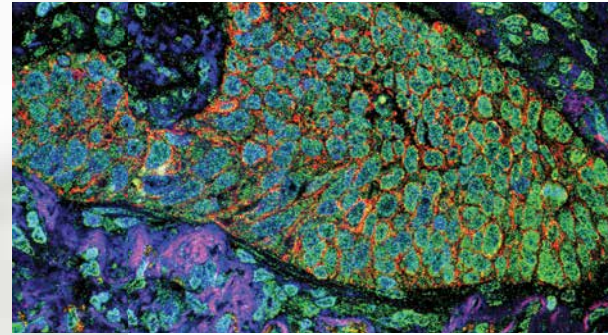
"I think it's important for everyone to get involved however they can."

"I think it's important for everyone to get involved however they can," he says. "The more we have supporting, the better chance we have of a better outcome."

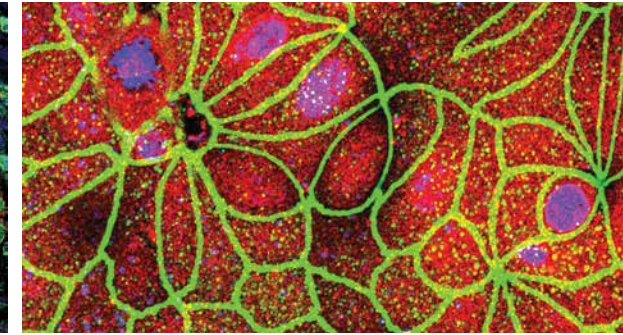
Whether it's giving his time, his money or his name, Longoria is pleased to do what he can to help in the fight, no matter what the currency.

"Hope is very strong," he says. "So if people have hope, they can battle through anything." 🍌

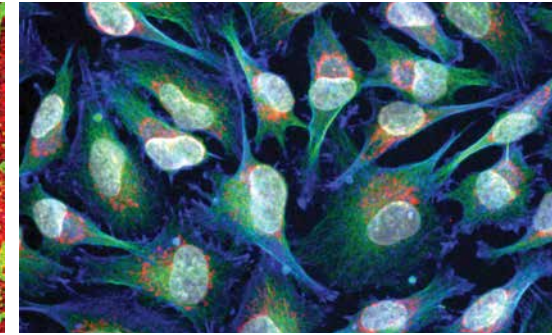
“I believe nature is our best teacher.”



PROTEIN INTERACTIONS
IN LUNG CANCER TISSUE
Haura Lab/Matt Smith



PREMALIGNANT
BREAST CELLS
Chellappan Lab/Wasia Rizwani



MELANOMA SKIN
CANCER CELLS
Smalley Lab/Jobin John

MICROSCOPY THROUGH AN ECOLOGIST'S EYE

Cancer as a species? How radical thinking has researcher Mark Lloyd on the right track.

The ecology movement has a new battlefield. Way down at the cellular level. Where cancer cells run amok, tearing into the landscape of a human life. And Mark Lloyd, M.S., staff scientist at Moffitt, has emerged as an impassioned leader.

In a move that places an exclamation point deservedly after the word innovation, even if the explanation of this new ecological movement leaves some scratching their heads, Lloyd, his mentors Robert Gatenby, M.D., and Joel Brown, Ph.D., and his team of researchers have begun to look at cancer as its own species. And how this particularly insidious species evolves to survive.

To one of the head-scratchers, Lloyd explains: “A landscape ecologist looks at satellite images of trees and habitats. How new construction, for example, affects those habitats. We’re looking at the exact same thing. Except we’re looking not from a satellite but through a microscope.”

Lloyd runs Moffitt’s Analytic Microscopy Core laboratory, providing researchers with valuable information related to intracellular trafficking, cell cycle progression, DNA repair and more.

When he and his fellow scientists peer deeply into their microscopes, they have their eyes peeled for the things cancer cells must do to survive. The sinister habits they must develop. The destructive tactics they must employ.

As if reading from Darwin’s playbook, Lloyd continues: “Imagine you’re a cancer cell and you’re struggling to survive in an environment very hostile toward you. One, you’re competing with fellow cancer cells. And two, the body’s immune system is battling you tooth and nail. So you need to find a way to be fitter than all those others to survive. You will evolve.”

The understanding of what’s driving that evolution, says Lloyd, can lead to a more effective treatment.

“I believe nature is our best teacher,” he maintains. If the predictable rules of selection and adaptation pertain to cancer cells, he believes we can use them to find more effective ways of treating cancer.

This is heady stuff. The kind of stuff that, even if you don’t understand it, leaves you feeling deeply grateful we have such inquisitive minds in our corner. Oh, and empathetic ones at that.

“To be a scientist,” claims Lloyd, “means not simply to ask important questions, but most importantly to have an impact on patients. My job is to ask questions that will ultimately translate to optimal patient care. As an example, I like to spend time once a week hanging out in the patient lobby. Just chatting with patients.”

He listens to their stories and takes these stories back to the lab. He wants his researchers to always remember the reason they stare into microscopes all day. And this, he vehemently postulates, is what’s great about Moffitt: “Moffitt encourages researchers to have that close relationship with both clinicians and patients. To stay focused on the right questions. It helps so much to collaborate with lots of different kinds of people. It facilitates the multidisciplinary approach that I crave. Sure, I can publish. I can get grants. I can get all the pats on the back from my research collaborators and feel good about myself, but if I’m not making an impact on patients, then I’m not doing the best that I can.”

In this last statement lies the sum of Mark Lloyd. A scary-smart guy who’s pioneering a method of studying cancer cells that has more in common with the method scientists use to study snow leopards and crayfish; a guy who continues to juggle a day job in Tampa (that would suck the life from most of us) with doctoral work in biological sciences at the University of Illinois in Chicago. And an entrepreneur who recently founded a clinical service company called 2DP that develops pathology solutions to more rapidly and accurately diagnose cancer, with the aim of improving patient outcomes. Best of all, it turns out he’s just a regular guy bent on relieving human suffering.

And maybe that’s his real brilliance. 🍷



A Modern-Day Miracle

The GIFT of HOPE

As told by Phil Jones

AS A CBS NEWS CORRESPONDENT FOR 32 YEARS, I REPORTED ON WARS, PRESIDENTS, IMPEACHMENTS, PRESIDENTIAL CAMPAIGNS, AND POLITICAL SCANDALS OF EVERY STRIPE. Little did I know that one day I'd be the one making news. I was the first 75-year-old Moffitt patient to receive a bone marrow stem cell transplant from an UNRELATED donor for MDS (myelodysplasia), and this was after another nationally renowned cancer center told me I was "too old" for the procedure. In effect, "Grandpa was pushed off the cliff." Or, perhaps it was a case of "age-biased medicine."

As they say on television, those are the headlines: now the details.

My journey began about two years ago while being checked for a blood clot. Doctors found I was anemic and my bone marrow was not producing healthy blood cells. I was told I had "very aggressive" MDS and it was "incurable." With my wife, Patricia, at my side, the local doctor handed us a page of his handwritten notes listing possible treatments that included "chemotherapy and clinical trials." We were told my MDS would lead rapidly to acute leukemia and then I would have six months to one year to live. There was one possible cure, a stem cell transplant. At our next appointment with a Naples, Florida, oncologist, I excitedly asked about a transplant. His curt response, "Not possible. You are too old." I quickly changed oncologists.

Fortunately, I was referred to a world-renowned specialist on MDS, Dr. Alan List, now President and CEO of Moffitt. Dr. List confirmed my diagnosis and put me on a chemotherapy cycle to see if the MDS could be managed. As expected, the chemo did not work. Without hesitation, Dr. List referred me to Dr. Claudio Anasetti, chair of Moffitt's Department of Blood and Marrow Transplant. Dr. Anasetti is recognized as one of the world's leaders in innovative approaches for transplanting older patients. With that expertise, I knew I was in good hands.

After going through a complete physical examination, Moffitt accepted me as a transplant candidate. My siblings were not compatible donors, but a "Perfect Match" was located from a list of more than 10 million donors at the National Marrow Donor Program.

As I awaited my scheduled Moffitt transplant, a friend urged me to get a second opinion. So we flew to another preeminent cancer

center in another state. After two days, that institution's Chief of Oncology proclaimed, "I will not recommend a transplant because you are *too old* and you should ask any doctor who will do it how many transplants he's done on 75-year-old patients." I returned to Moffitt and asked Dr. Anasetti that very question. His answer, "None. I don't have a crystal ball, but we've looked you over and you are in good health. We are prepared to do it if you want and if you don't, I understand."

Friends said I was brave, but since I was not ready to accept a six- to 12-month life sentence, going for the only "cure" was an easy decision.

I'll never forget my first night in the hospital. I was facing four days of heavy chemotherapy to wipe out my diseased bone marrow cells in order to reduce the chances of my donor cells being rejected. Maria Garcia, an oncology technician, walked up to my bedside and in a drill sergeant tone said, "I want you to listen to me. I'm going to tell you what you have to do if you expect to come out of here alive. You gotta do what you're told. You have to have sort of a kick-butt attitude." As she continued, Maria sounded more like a chaplain. "I'm not a Bible-beater," she said, "but I carry the church and my faith with me every day, I pray for every one of my patients." I felt like I was in Maria's and God's hands. And through it all, I remembered the words of another friend, "Phil, we're getting hernias pulling for you."

On July 4, 2012, a nurse appeared in my room carrying what looked like a blood transfusion bag. It was stem cells from a donor. I was told only that my donor was a 33-year-old man who lived in the United States. The actual infusion of the donor's stem cells took less than two hours. At my urging, a nurse drew a lighted firecracker on the white board in my room. There were no loud explosions, but it was still the biggest July 4th celebration of my life.

For the next three months I remained in Tampa so the Moffitt team could monitor for any evidence of rejection. I was physically weak, but psychologically strong. I felt as though "I was living a miracle." My doctors were more cautious. They constantly reminded me that I wasn't "out of the woods yet."



The GIFT of TIME

ERIC PRIEST IS AN ORDAINED MINISTER, A NAVY LIEUTENANT AND A LIFE SAVER. TO HIM, NONE OF THESE THINGS ARE JUST A JOB OR A TITLE. HE SEES THEM ALL AS HIS CALLING, HIS DUTY, HIS OPPORTUNITY TO SERVE.

In 1997, Eric walked across the stage to receive his high school diploma and he marched into boot camp one month later. While there, he learned he could sign up to be a marrow donor and didn't think twice when he put his name to paper.

"In 17 years," Eric says in a pure southern accent, "I'd gotten a phone call that I could be a match for someone twice before."

But it was never a perfect match. Until the phone rang that third time. The charm. Eric was stationed at the Naval Postgraduate School in Monterey, California, and studying mechanical engineering when he got a life-changing call.

"They did say I was the best match," Eric says. "I had to discuss it with my wife. We talked about what was best for us and for our family. It didn't take us long to decide that this was the best thing for us."

But Eric couldn't know anything about the recipient. He couldn't know a name or a face or hometown. He had no idea that Phil Jones, a 75-year-old man who had been rejected for marrow transplant by other doctors and given just a short time to live, was waiting for Eric's life-giving cells, through an unrelated donor transplant, a procedure rarely attempted nationwide with an MDS patient his age. All Eric knew was that someone needed him, he was a perfect match and he had an opportunity to serve.

"Everyone makes a big deal over you, but I was back to 100 percent a few days after the procedure," Eric says. "It wouldn't be right for me to take credit. The main thing I gave was my time - and a little marrow along the way - but it takes a whole team to be successful. A simple mistake on any portion of the process could have prevented the success."

Eric made the donation at noon Pacific Time on July 3, 2012. His marrow left from San Diego, California, and made it to Tampa, Florida, by 9 a.m. July 4. But Eric only received little tidbits about Phil. One week after the procedure, he got an update that the donation went well, but he didn't receive any health updates on the patient for another six months. And he still didn't know his name. Finally, finally, the two were able to connect the old-fashioned way, through letters, notes exchanged across several states. They were able to talk on the phone, now knowing each other's names, their wives' names, their individual stories. Phil and his wife, Patricia, had been praying with their church for Eric and his wife, Tina. And Eric and Tina and had praying with their church for Phil and Patricia.

On March 8, 2014, Eric Priest and Phil Jones, the men with now-matching marrow, were able to meet face-to-face.

"I was really excited to meet Phil," Eric says. "I felt like I knew him. I'll never forget seeing him for the first time walking up from the car. He looked so healthy. He did not look like a 75-year-old man who had been given a year and a half to live and had gone through the process that he went through. Seeing the success of his procedure was the most powerful thing."

They shared hugs and pictures and stories. And Phil gave Eric a pewter clock with this message: Thanks for adding time to my life. Its home is now on Eric's nightstand. And it serves as a daily reminder that there's good to do, good we can't do alone, but so much good that we can do. When he sees the clock each day, Eric prays for Phil.

"I really think this is much bigger than all of us," Eric says. "I believe God's hand has been in this from the beginning. Before Phil knew, before I knew, God was orchestrating it for us to be in the right place, the right time, with the right people. And it's great to be part of one of His miracles." 🙏

"Everyone makes a big deal over you, but I was back to 100 percent a few days after the procedure."

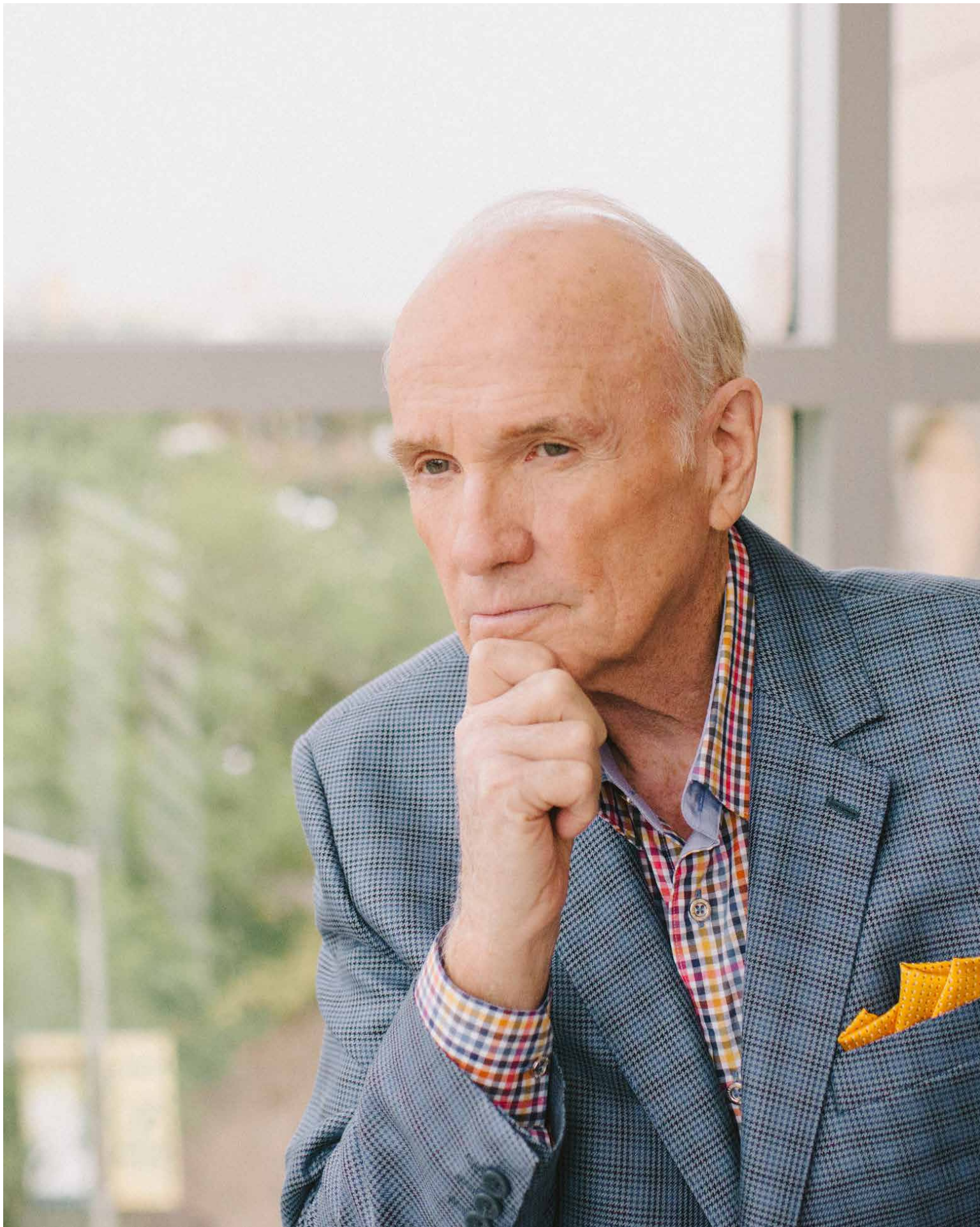


After one year donors and recipients are allowed to share their identity and in March of this year my wife (caregiver extraordinaire) and I went to Tennessee to meet the man who had given me a "gift of extended life." His name is Eric Priest, a Navy Lieutenant. It was an emotional meeting. I told Lt. Priest he had "given new meaning to serving his COUNTRY and MANKIND" and that I didn't know whether to salute him or hug him. So, I saluted and we hugged. We will be joined at the marrow forever.

Mine is a story of "MEDICAL HISTORY." Prior to August 2010, Medicare would not pay for MDS-related stem cell transplants. Under heavy pressure from the medical community, Medicare Services relented, and hundreds of MDS patients in their

mid-60s to their early 70s were transplanted. However, it was a much different story for MDS patients who had reached the age of 75. Nationwide, only FIVE 75-year-olds were given transplants from 2010 through 2012. In unpublished data collected by the Center for International Blood and Marrow Transplant Research, of those FIVE transplanted, two were still alive after one year. I am ONE of those TWO. Since my transplant, only one other Moffitt MDS patient age 75 and older has received a transplant — a 76-year-old woman. Doctors tell me, "I led the way."

I am now 77, in complete remission, 100 percent donor, with no evidence of MDS. Now this is a "MOFFITT MIRACLE." 🙏



PHIL JONES
SURVIVOR

“For somebody that’s always on the go,” Leonel says, “not being able to walk, to need help getting out of bed – I felt like the least important person in the world.”

JUST ONE MORE OPPONENT

A former kickboxer lays a counterpunch on cancer

WHEN *MOMENTUM* CAUGHT UP WITH LEON LEONEL, HE WAS GETTING HIS 2000 HONDA CIVIC READY FOR THE IMPORT ALLIANCE CAR SHOW IN ATLANTA. SO FAR, LEONEL’S SWAPPED OUT THE ENGINE AND MODIFIED THE TRANSMISSION FROM AUTOMATIC TO STANDARD. “IT’S ALL RIGHT,” LEONEL SAYS, “BUT I STILL HAVE A TON TO DO.”

Doing a lot on swapped-out parts is nothing new to Leonel. In 2012, when he was 21, Leonel had half his tibia, his knee and 10 inches of his femur replaced with metal prostheses. The culprit: osteosarcoma. A type of cancer that starts in the bones, osteosarcoma is the most common bone cancer in children. It also is common in people over age 60.

A runner, kickboxer and inline skater, Leonel thought at first that the swelling in his knee was just another torn ligament. By the time he started visiting doctors, the pain was excruciating, but no one would see him “without crazy amounts of money.” Then his dad, Rolando, took him to Moffitt – determined not to leave until someone saw his son. There, David Cheong, M.D., an orthopedic oncology surgeon, took one look at Leonel and said, “Be in my office at 6:30 tomorrow morning. We’re doing a biopsy and placing a port.”

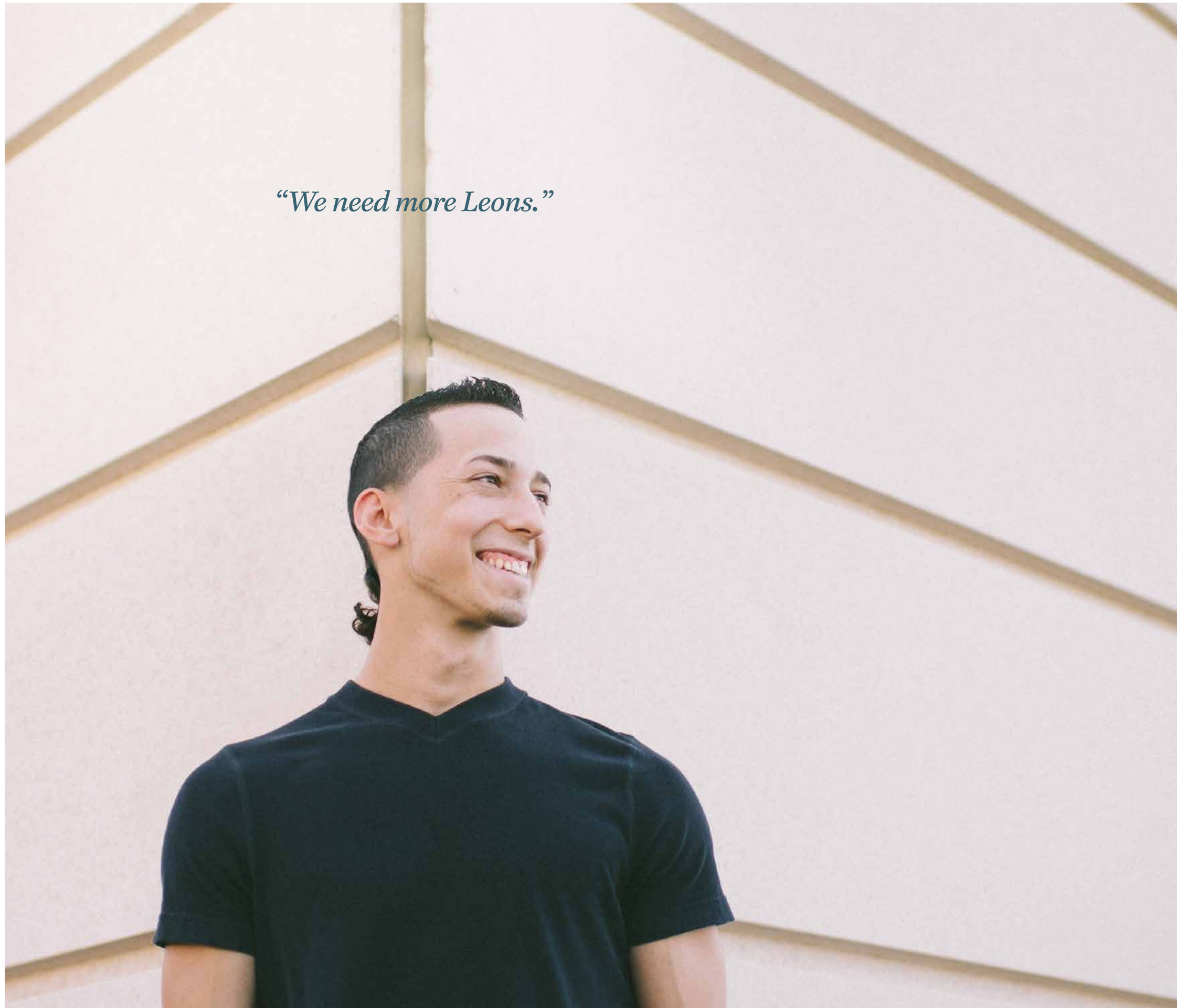
What followed was 18 months of surgery, chemotherapy and rehabilitation. There were the typical indignities – pointing children, people mistaking his missing eyebrows for a practical joke, the protective mask, the feeding tube – but worst of all was the feeling of uselessness. “For somebody that’s always on the go,” Leonel says, “not being able to walk, to need help getting out of bed – I felt like the least important person in the world.”

To overcome this, Leonel learned to “eat that pain.” The average time patients take to walk again after a surgery like Leonel’s is

six to eight months. Leonel ran in Richard’s Run – a cancer charity 5K in Ybor City – less than seven months after he got a new knee. “I didn’t care how much pain there was. The whole world deserves to be able to walk. So I put my mind to it and I ran.”

One of his nurses, Marris Smith, ran with him. She and the other nurses on Five North “were like family,” Leonel says. They talked to him at night when he couldn’t sleep. They laughed with him. They were positive. Six months after his treatment ended, Leonel stays in close contact with them. “They remind you of that tough time,” he says, “but they also remind you of how lucky you are to have met them.”

This level of personal investment is typical of the Adolescent and Young Adult (AYA) Program at Moffitt. Damon Reed, M.D., medical director of Moffitt’s Sarcoma Department, created the AYA Program in 2011 to address the age-specific challenges of having cancer while developing as a young adult. At first, Dr. Reed thought “we would get patients on clinical trials and get them talking about science and meeting the investigators.” Noticing a lack of enthusiasm for this among his patients, however, Dr. Reed and his team of medical and psychological experts in AYA care shifted gears to address the less tangible needs specific to AYA patients. Developmentally, they are seeking independence, training for their future careers and fostering relationships with their peers. Social interactions, which can be stressed by a cancer diagnosis, are critical to their well-being. One attempt at helping this vulnerable population navigate an unfamiliar medical (and emotional) maze that can seem overwhelming and unfriendly was creating Meet-Ups – “support groups that we don’t call support groups” – to bring AYA patients together and combat the loneliness pervasive among them.



“We need more Leons.”

It worked. The meetings, Leonel says, are “a place to go express yourself, if you have pain in you, if you want to talk to someone who’s been through what you’re going through.” Their common experience makes the advice and motivation the patients share ring true, and, in Dr. Reed’s view, it’s this identification that’s made the AYA Program such a success. Leonel and his nucleus of friends created an atmosphere that was inclusive and energetic. “Cancer is trying to destroy these young people,” Dr. Reed explains. “A natural human response to that type of threat is to withdraw, to make a shell around you. But Leonel didn’t do that. If you were getting chemo and Leonel was around, he was going to walk up to you and talk to you, maybe about having cancer and how much it sucks, or maybe about what you’re going to do after cancer. Whatever it was, you were going to talk together. It was probably therapeutic for him to talk to as many people as possible, but it was also therapeutic for them to share.”

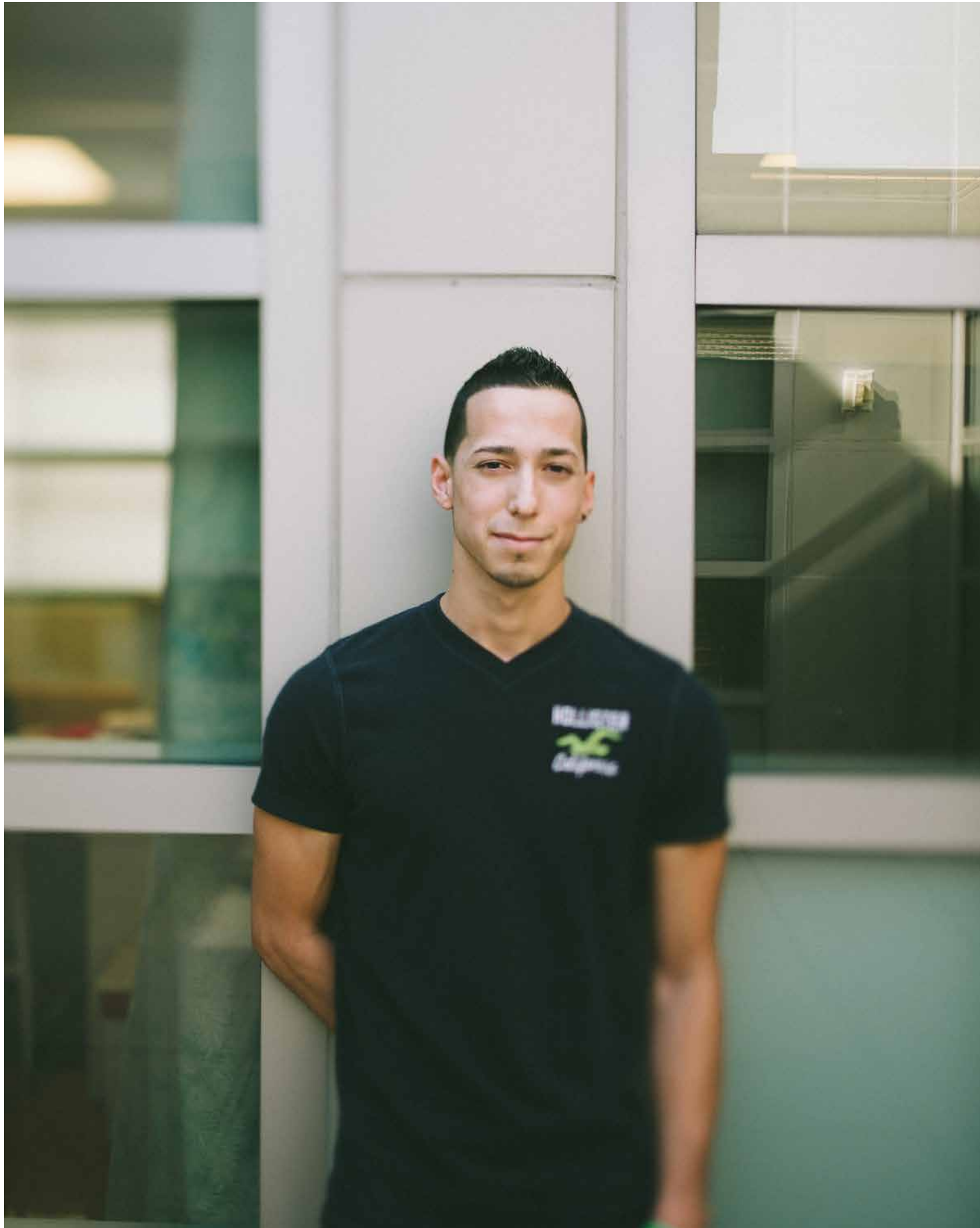
To that end, Moffitt is planning to build a lounge for AYA patients to foster the sense of community that Leonel helped create. But most of all, Dr. Reed says, “We need more Leons.”

Leonel does plan to continue being a part of the AYA Program and Meet-Ups. “A lot of them are survivors that are having my same problems,” he says of the group attendees. “A regular person is going to feel pity for you. But not them [in AYA]. They’re going to feel your pain because they’ve been through it. They’re the only people I can talk to about my experience.”

Aside from his quarterly checkups, prior to which he can get fairly nervous, Leonel’s biggest challenge is figuring out – and overcoming – his physical limitations. “I started kickboxing again for a few months after treatment, but realized it just wasn’t for me anymore. I had to think about the use of my leg.”

That doesn’t mean he babies the metal knee, though. “The doctors told me the only time I’m allowed to run is when there’s a fire. But I didn’t go through 18 months of hell to just sit around.” In fact, Leonel is constantly on the move. He still runs and enjoys inline skating – and sends his doctors pictures and video of him doing so. “Just to rub it in,” he says with a laugh. Metal prostheses can handle a finite amount of wear and tear, and Leonel’s active lifestyle will likely require they be replaced earlier than normal. “But,” Leonel says, “I’d rather have the surgery in 10 years instead of 20 and know that I enjoyed life.”

To Leonel, doing so remains straightforward. “The key is to surround yourself with really positive people, with a positive vibe. Giving up without a fight isn’t the right thing to do, because there is light at the end of that tunnel.” 🍷



LEON LEONEL
SURVIVOR

BROOKE BENNETT TAKES THE PLUNGE

The Olympian is going for gold in cancer research



With three Olympic gold medals to her name, Brooke Bennett knows just how far the right team can take you. Throughout her successful career – 14 U.S. Championship titles, handfuls of international medals, the International Swimming Hall of Fame – she’s never lost sight of how she got there. “Your friends and family and coaches,” she says, “we rely on those support groups, on the teams we put together.”

Bennett has applied this team mentality to everything she’s done, from sportscasting to personal training to the various charitable organizations she supports.

Among those organizations is Swim Across America (SAA). What started as a single swim in Nantucket in 1987 has grown to include dozens of annual swims across the country and has raised more than \$46 million for cancer research. Bennett did her first SAA swim 17 years ago and was integral in launching the Tampa swim in 2012.

In their search for a Tampa beneficiary, Swim Across America organizers hit upon Moffitt Cancer Center. “They described their developments in melanoma research, and because we’re in the Sunshine State and we’re an outdoor sport, it’s a perfect fit,” Bennett says. During the event, which is a half-mile, mile or 2.4-mile swim held at Clearwater Beach each May, Moffitt’s Mole Patrol® is out in force. The Mole Patrol includes doctors and nurses who set up skin screenings at community events around Florida to provide participants with melanoma prevention information and, if necessary, follow-up recommendations that can be taken to their primary physician or Moffitt Cancer Center.

Tampa’s first Swim Across America event in 2012 raised \$100,000. In 2013, attendance increased and donations jumped to \$150,000. The May 31, 2014 event broke last year’s record, and as this magazine went to press Swim Across

“Swim Across America gave me my passion to pursue what’s now an Olympic event.”

America presented Moffitt with a check for \$165,000. Because SAA only has four employees (located in Boston) and everything else is done via local volunteer committees, every dollar raised for the Tampa event goes straight to Moffitt.

A portion of these proceeds goes toward tumor-infiltrating lymphocytes (TIL) immunotherapy clinical trials being run by Moffitt’s own Amod Sarnaik, M.D., and Shari Pilon-Thomas, Ph.D., who participate in the SAA event each year. With SAA participants’ generous donations, Dr. Sarnaik says, Moffitt is “able to treat 18 patients who wouldn’t have been able to be treated through traditional funding mechanisms.” Without SAA, there would be no funding for the trial, and traditional funding mechanisms would not support this type of trial, adds Dr. Pilon-Thomas.

The investigators are studying the safety, side effects, and benefits of therapy with TILs in patients with metastatic melanoma.

The balance of the funds raised goes to the Adolescent and Young Adult (AYA) Program, which supports cancer patients who fall into a care gap between pediatric and adult age groups. Damon Reed, M.D., who established and directs the three-year-old program, says, “We wouldn’t be as far along today without Swim Across America. It almost immediately legitimized the AYA Program.”

For Bennett, Moffitt’s direct participation lends immediacy to the event and epitomizes the community aspect of Swim Across America. The latter is the rewarding part for Dr. Pilon-Thomas, too. While the money is certainly important, she says, it’s the energy of the event that “makes me want to come back to work and get this therapy going.”

Dr. Reed believes a lot of that energy comes from Bennett herself. “She brings a certain excellence to it,” he says. “It’s neat having someone who’s so clearly dominant in her sport and so clearly a fantastic personality wrapped into one.”

For Dr. Sarnaik, having adolescents, teenagers and their parents all come out for a fun-filled event adds a new dimension to raising cancer awareness. “It’s outstanding,” he adds, “the way Brooke’s leveraged her charisma and prestige as an athlete to give back to the community.”

This sense of giving back is stronger than ever for Bennett. She’s set her sights on the open water 10K at the 2016 Olympics in Brazil, bringing her involvement with Swim Across America full circle. The 10K wasn’t around when Bennett won her golds, but she’s been swimming in open water since 1997 – when she did her first SAA swim in Boston. “Essentially,” Bennett says, “Swim Across America gave me my passion to pursue what’s now an Olympic event.” Whether or not Bennett qualifies for Rio, her Olympic clout brings much-needed exposure to the fledgling event – which Bennett sees as an “opportunity to do something great for a sport that’s provided me so much.”

It’s that back-and-forth – that giving and receiving – that makes the partnerships in Bennett’s life so meaningful. Whether an individual is training for an Olympic race, or participating in a community event like SAA or receiving the next round of chemotherapy, Bennett stresses the importance of remembering we’re all in this together. Seeing survivors at Swim Across America events gives Bennett that “extra push” when the workout hurts or the race feels too hard; knowing that the inspiration goes both ways makes the partnership particularly rewarding. “If those watching the events see the love and the heart and the passion that we have to help them get better,” Bennett says, “then maybe when they feel like they have no fight left, they can find that fight through what we’re doing.” 🗨

“Maybe when they feel like they have no fight left, they can find that fight through what we’re doing.”





BROOKE BENNETT
OLYMPIAN

NOTABLE

THE DON SHULA FOUNDATION DONATED \$1.5 MILLION TO MOFFITT, and in a video shown at the 2014 Magnolia Ball, Don Shula challenged guests to match the gift, which establishes The Shula Fund. “Cancer has touched our family personally. And I know that the more we give to cancer research, the closer we are to finding a cure,” Shula said. “We want to make a difference in this fight, and we want you to be on our team.” He added that the fund encourages Moffitt scientists to begin promising pilot projects that will lead to improved treatments for cancer patients everywhere.

MOFFITT NAMED ITS PRECISION MOLECULAR DIAGNOSTICS LABORATORY AND NEW PATIENT AND FAMILY CENTER AFTER PHILANTHROPISTS CAROL AND FRANK MORSANI. The Morsani Molecular Diagnostics Laboratory, under the direction of Executive Director Anthony M. Magliocco, M.D., is revolutionizing cancer diagnostics by using the most advanced genetic testing tools available to reduce errors and improve patient care. The Morsani Patient and Family Center will be the heart of the new 200,000-square-foot McKinley Outpatient Facility scheduled to open next summer. The Morsani family have been longtime supporters of Tampa’s health care community, including contributions to Moffitt.

THE NEWLY ANNOUNCED ONCOLOGY RESEARCH INFORMATION EXCHANGE NETWORK (ORIEN) is a collaboration between two of North America’s leading cancer centers, Moffitt Cancer Center and The Ohio State University Comprehensive Cancer Center – Arthur G. James Cancer Hospital and Richard J. Solove Research Institute, with the goal to develop more precise ways to prevent, detect, diagnose and treat cancers. ORIEN will utilize a single protocol, Total Cancer Care®, to accelerate the development of targeted treatments, allowing researchers and clinicians to more quickly match eligible patients to clinical trials.

MOFFITT RESEARCHERS LAID GROUNDWORK FOR A REVOLUTIONARY COMBINATION THERAPY TO TREAT ADVANCED MELANOMA – melanoma that cannot be removed surgically or has spread to other areas of the body. The newly FDA-approved therapy, Mekinist (trametinib) in combination with Tafinlar (dabrafenib), is one of the biggest advancements in melanoma treatment in the last three decades.

NEWSWEEK’S MARCH 28 ISSUE FEATURED MOFFITT’S INTEGRATED MATHEMATICAL ONCOLOGY DEPARTMENT AS THE COVER STORY, “Solving Cancer: You Can’t Cure What You Don’t Understand.” Our brigade of mathematicians and oncologists hopes that by mathematically modeling cancer, we can “make its movements as predictable as those of a hurricane.” The program merges the fields of oncology and mathematics with the goal of using an integrated approach to better understand, predict and treat cancer. Moffitt is the only cancer hospital in the country to have such a program.

MEDICAL/SCIENTIFIC ADVISOR
Frank D. Vronis, M.D., M.P.H., Ph.D.

MANAGING EDITOR
Cathy Clark

H. Lee Moffitt Cancer Center & Research Institute, an NCI Comprehensive Cancer Center – Tampa, FL
© 2014 Moffitt Cancer Center. All rights reserved.

SHARE YOUR
THOUGHTS



EDITOR@MOFFITT.ORG

FLORIDA IS THE OFFICIAL PLACE OF BUSINESS FOR THE MOFFITT CANCER CENTER FOUNDATION. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING 1-800-435-7352 TOLL-FREE WITHIN THE STATE. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE. FLORIDA DEPARTMENT OF AGRICULTURE & CONSUMER SERVICES REGISTRATION NUMBER CH-4675. NO PERCENTAGE OF CONTRIBUTIONS ARE RETAINED BY A PROFESSIONAL SOLICITOR, 100% OF ALL DONATIONS ARE RECEIVED BY THE FOUNDATION.



12902 Magnolia Drive, Tampa, FL 33612

TO CONTRIBUTE TO THE PREVENTION AND CURE OF CANCER

MOFFITT.ORG | 1-888-MOFFITT