

MOFFITT

Volume 6, Issue 2

MOMENTUM[®]

A SURGICAL FIRST

And a child's arm is saved

RESEARCHERS' BRAINCHILD

Fueled by a common enemy

DETECTING GENE FUSIONS

Test results give treatment
guidance



Message from the President & CEO



Alan F. List, MD
President and CEO, Moffitt Cancer Center

Dear Friends,

Since 1986, our single focus has been to contribute to the prevention and cure of cancer, and the dedication to that mission is illustrated throughout this issue of Momentum magazine.

The story of Josalyn Kaldenberg and her family is especially heartwarming. At age 8, Josalyn faced the likelihood of losing her arm due to a sarcoma diagnosis. Douglas Letson, MD, was able to replace the child's entire humerus bone, a first in the United States. Josalyn returned to playing piano and this year, at age 16, she delighted guests at the 2019 Magnolia Ball with a surprise performance.

Moffitt pathologists are using next generation genetic testing to provide better diagnosis and treatment options for patients like Constance Kihm. Moffitt STAR, the 170-gene panel that looks for changes in RNA, provided data about her unique genetics that allowed her to be matched to a new lung cancer clinical trial. With renewed quality of life, Kihm is dancing again.

Moffitt is committed to reducing health disparities and is working toward closing gaps in health care outcomes. In this issue Clement Gwede, PhD,

MPH, RN, describes progress made in eliminating disparities in colorectal cancer. Additionally, Moffitt created a new position to help better understand and address our community's cancer needs through engagement, ongoing dialogue and partnerships. Susan Vadaparampil, PhD, MPH, is Moffitt's first Associate Center Director of Community Outreach, Engagement & Equity.

The first Miles for Moffitt event in 2006, held on the University of South Florida campus, drew 1,200 participants and raised \$55,000. Since its inception the race has grown to 5,800 loyal participants who helped raise \$1.1 million in 2018. This issue describes some of the research accomplishments made possible through the Miles for Moffitt awards. You also will learn why brothers Marco and Luis Echeverry started Team DrivenFit and why they are so motivated to this cause. The 2019 Miles for Moffitt event will be held in downtown Tampa on Nov. 23.

We hope you enjoy reading these and other stories in this issue, which share our growing scientific research initiatives, innovative new treatments, commitment to our community and more.

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United
Nothing Unites Like A Common Enemy



More Than A Label
Spearheading research



Miles For Moffitt
Participants Run, Walk, Jog in 2018 event



JOSALYN KALDENBERG
Cancer Survivor

GRASPING THE CHANCE

with both hands

Eight years later, family thanks Moffitt surgeon for saving daughter's arm

By Ann Miller Baker

Parents proclaim they'd stop at nothing if their child's life was on the line.

Would you have the strength to allow surgeons to amputate your daughter's arm if it might save her?

Heidi and Norm Kaldenberg have faced that unthinkable decision. Their eldest child, Josalyn, was then a seemingly healthy second-grader with a passion for the piano. Heidi had played to her while she was still in the womb and began teaching her when Josalyn was just 6.

"Usually, a piano teacher will give you a certain number of songs for each week's lesson," Heidi explains. "Josalyn would have those songs memorized in two days. She would sit for hours at the piano, any time of the day."

That all changed in October 2010, shortly before Josalyn's eighth birthday. She'd been complaining of a sore right arm, not enough to worry her mom until a tickle battle between Josalyn and her little sister Myra. "All of the sudden, Josalyn cried out in pain. She literally went from laughter to tears because her arm got bumped. And I thought, that's not right."

Weeks of tests and biopsies revealed that the humerus bone in Josalyn's right arm was riddled with cancer from shoulder to elbow. Chemo started just four days before Christmas at Blank Children's Hospital in Des Moines, Iowa. But experts around the country agreed the strong drugs wouldn't be enough. They recommended amputation.

"When you hear the word cancer, your mind goes right to a dark place, wondering if she'll survive," says Heidi. "But for some reason, in my mind, it was always about the arm."

"I remember watching her at the piano and thinking, 'God, You know she loves to play. Why would You take her arm?'"

THE GOLDEN TICKET

When it came to saving Josalyn's arm, Heidi was not going to concede easily. "I couldn't stand not knowing what the options might be, but nobody could tell us."

"When you hear the word cancer, your mind goes right to a dark place, wondering if she'll survive. But for some reason, in my mind, it was always about the arm."

Norm wasn't surprised when she resorted to Google research. "I call her the nerd of the family," he says, "and that's a good thing." It led her to what they call the "golden ticket" article. Titled "Extensible endoprotheses of the humerus after resection of bone tumours," it appeared in the May 1999 issue of The Journal of Bone and Joint Surgery. The article detailed the experience of 18 patients in Birmingham, England whose humerus bones had been replaced with an expandable device created by Stanmore Implants. Further searching linked an American surgeon working with Stanmore on such implants, Dr. Doug Letson of Moffitt Cancer Center in Tampa. An orthopedic oncologist, Letson is a renowned expert in expandable implanted devices.

"It was in print! They saved this girl's arm with an expandable implant," says Heidi. "I thought I must be crazy because all these doctors are saying that's not a thing. Then I looked closer and saw that the medical journal was from England. And I thought that must be why. They don't do it here. They only do it there."

Still, she printed it out and took it to Josalyn's oncologist appointment, four days before surgery. They'd already signed



Photography: Nicholas Gould

Josalyn's orthopedic oncology surgeon, G. Douglas Letson, MD, is involved in the design of instrumentation for minimally invasive reconstructive surgery.

consents for amputation, so this appointment was one last chance to discuss the plan.

"We were pretty resigned to it," Heidi recalls. She almost forgot about the paper, showing it to the doctor at the very end of the appointment. "I said, well, this is what I thought they could do. But I guess they can't. And he said, let me see that."

Within minutes, their doctor came back to say he'd phoned Letson, who thought he could help Josalyn.

"And right then, everything changed," says Heidi, "by the grace of God at the last minute."

A SURGICAL FIRST

A thousand miles away, Letson was finishing up another surgery when he got the call about Josalyn. The inquiry itself didn't surprise him. "One focus of my work in orthopedic oncology has been designing implants, trying to prevent amputations in children – whether it's an arm or a leg – to improve their quality of life," he explains.

But the extent of Josalyn's cancer did give him pause. "She had an unusual tumor because her entire bone had a malignancy in it," says Letson. "Removing a whole bone and

replacing it with an expandable prosthesis, those are difficult cases that we do very, very rarely."

At that point, replacing a child's entire humerus bone would be a first in the United States.

But once he saw Josalyn's scans, Letson says, he had no doubt they'd be able to remove the tumor and reconstruct her arm. "I couldn't wait to be able to help her out," Letson recalls.

Josalyn couldn't wait very long, either.

With the cancer still in her arm, she would begin another round of chemo aimed at limiting its growth while Letson prepared for this surgical first. Since Moffitt does not provide care for pediatric patients, that would mean enlisting the help of a hospital capable of handling orthopedic surgeries in children. Letson approached Shriners Hospitals for Children in Tampa, where he performed pediatric operations. "Once they understood the need, they opened their doors and said we will absolutely let you use our facilities without any cost, anything that we can do to help."

Then there was the matter of what would replace Josalyn's cancer-riddled bone. Letson had long consulted with Stanmore Implants in Great Britain on the design of custom, expandable devices to replace bones in children. "We'd been working on developing these prostheses that we could lengthen as the child grows," explains Letson.

"We'd been working on developing these prostheses that we could lengthen as the child grows."

In Josalyn's case, this would entail annual follow-up outpatient surgeries performed through an incision the size of a pencil eraser. A special screwdriver would be inserted into the device to turn gears in the telescoping prosthesis, increasing its length a few millimeters at a time. Josalyn would need these lengthening procedures until she was fully grown. Letson and the engineers at Stanmore worked from Josalyn's scans to design the implant, which the company provided at reduced cost. With countless updates and coordination over the phone and email, the process would take six weeks.

And then, patient, family and surgeon would finally meet.

WORRYING ABOUT WHAT-IFS

For Josalyn, the trip to Tampa would be a first airplane flight and a trip to the beach. The surgery part wasn't tops on the 8-year old's list. "I didn't care if it was going to help me, I just didn't want to have surgery, period," she recalls with a laugh.

“One focus of my work in orthopedic oncology has been designing implants, trying to prevent amputations in children — whether it’s an arm or a leg — to improve their quality of life.”

She had already been through so much in just the previous year. Ten months before she was diagnosed, cancer had claimed her Uncle Nathan. “I remember when my mom told me I had cancer, the first thing that went through my mind was I’m going to die, too,” Josalyn remembers. Small wonder, then, that Josalyn’s parents never mentioned the word “amputation” to their daughter. “Being innocent is good, because then you don’t think about all the ‘what-ifs,’” she says.

Josalyn left those worries to her parents and her surgeon, who met face-to-face the very first time on the day before

her surgery. “It was straight to hugs,” recalls Heidi. “Looking back, that was a lot of trust. But at the time, we were just so hopeful about the situation that we felt it was going to work out.”

Among the surgical risks they discussed, Letson had to remind them that amputation was still a possibility. If the tumor had spread beyond the bone to encase any of the blood vessels or nerves necessary to maintain function of the arm, he couldn’t risk leaving any cancerous tissue behind.

On April 26, 2011, Letson and his surgical team began the tedious process of freeing muscle, nerve and blood vessels from the bone in Josalyn’s arm. All would have to be examined for any trace of tumor and preserved in place for reconstruction of the arm. The entire bone would need to be removed in a single piece, leaving no trace of tumor behind. Then, rebuilding Josalyn’s arm could begin. Artificial shoulder and elbow joints would hold the expandable prosthesis in position, and a vascular sleeve on the device would provide a place for muscles to be reattached and eventually grow to enable it to function.

“Being innocent is good, because then you don’t think about all the ‘what-ifs.’”

Eight hours later, Josalyn and her parents were reunited in the recovery room. The operation, Letson told them, couldn’t have gone any better. “But once my part was done,” says Letson, “she had a lot of hard work left to do.”

HALF A LIFETIME AGO

Fast forward eight years and a different thousand miles to Carlsbad, New Mexico. A teen with long, brown curls tends to a handful of goats and more than a dozen chickens outside the family home, while two large dogs keep a watchful eye.

This is Josalyn’s happy place, among her precious animals. Cuddling one goat in her lap, she reaches out to smooth another’s coat. “I just love my animals,” she says. “They always



Photography: Kevin Kirby

“Cancer doesn’t just happen to one person,” says Josalyn’s mom Heidi. “It happens to the whole family.” Pictured, left to right, top row: dad Norm, siblings Isaiah and Myra, mom Heidi. Front row, brother Wesley, Josalyn and sister Layna.

“I just love my animals. They always cheer me up just like the therapy dogs did when I was at the hospital.”

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In some ways, those post-surgery months of continued chemo and grueling physical therapy seem to her like a lifetime ago. After all, the eight years she’s lived with her new “bionic” arm are half of Josalyn’s lifetime.

But in other ways, the memories remain close. “Whatever I’m doing, I do it with all of my heart,” she says. “Something as simple as holding Theodore the goat, working on my sketches or playing the piano is very precious to me – so much more so with both arms.”

Now 16, Josalyn is back to being the “leader of the pack” of her four younger siblings. “She’s the one who comes up with the ideas for games and projects,” Heidi says. “Cancer doesn’t just happen to one person, it happens to the whole family. And when you have a lot of little ones whose big sister is sick, that’s a journey for everyone.” Thankfully, with eight cancer-free years behind her, that journey is in the rearview mirror.



Photography: Kevin Kirby

In those years, Josalyn has also nurtured her artistic talents. She’s returned to playing piano, practicing daily on the one in her family’s living room. Her drawings, especially of animals, are remarkably lifelike. She’s shared special animal portraits along the way, including one of a beloved German shepherd owned by Tampa restaurateur and Moffitt Foundation Board member Richard Gonzmart. He became a family friend through the Kaldenbergs’ return trips to Tampa as Josalyn’s “bionic” arm was regularly lengthened. “He really took Josalyn under his wing,” says Heidi. Josalyn still has the medals he sent her from his participation in various running events to encourage her to keep going in treatment and therapy. “He’s been a blessing to our family,” adds Heidi. “It’s so nice to have friends when we go back to Tampa.”

MUSICAL THANKS

On one of those return trips for an outpatient lengthening procedure, Josalyn decided to offer thanks to her surgeon by playing the piano in Moffitt’s lobby. “I spent months preparing that song,” says Josalyn. “I was so excited!

“I just really wanted to show Dr. Letson that this is what you allowed me to do by saving my arm.”

Letson admits it was hard to keep back the tears as he watched her play. “It was a huge effort for her to rebuild that arm and she was able to do it,” says Letson. “And I’m just so proud of her.”

“I don’t think there are enough words to thank Dr. Letson,” says Norm. “I’d rather give him a hug.”

To Heidi, Letson personifies Moffitt. “It’s not just a matter of saving lives, but what are these lives going to be like? For us, Moffitt means we have music in our house on any given day of the week. It means that the world has the gift of Josalyn’s art and her music and all the other things that she can do with that arm. And it means that a lot of other kids in the United States will get that chance, too, because of Dr. Letson’s work.”

“Every day, something similar like this is happening at Moffitt,” Letson says humbly. “Whenever there is a patient need, our faculty always go over and above, whatever it takes to help that patient out.”



“I really wanted to show Dr. Letson that this is what you allowed me to do by saving my arm.”

Photography: Ray Reyes

A video testimonial of Josalyn’s story was shown at the 2019 Magnolia Ball, where Josalyn surprised guests with an in-person piano performance. View the video at <https://youtu.be/zlZXa6vAThw> or by scanning the QR code with your smartphone.



Magical Moment As Magnolia Ball Raises \$3.5 Million

Imagine being part of the team that helped to save young Josalyn Kaldenberg's arm, and being thanked with Josalyn's own two-handed gift: her performance on the piano.

Guests at the 2019 Magnolia Ball to benefit Moffitt's Foundation didn't have to close their eyes and dream. Immediately after viewing a video version of Josalyn's story, they heard and saw her perform live in the ballroom of the Tampa Marriott Water Street.

It was an electric moment for a signature event that has raised more than \$46 million throughout the years for Moffitt's cancer-fighting efforts. And it was completely fitting, as Magnolia Ball donors are part of the Moffitt team, helping to underwrite research of new treatments that benefit patients like Josalyn.

Moffitt's Magnolia Ball got its start in 1994. The first gala, held at the Tampa Yacht Club, raised \$80,000 for the Hope Lodge Program aimed at assisting out-of-town patients. Since then, the ball's beneficiaries have broadened to focus on Moffitt's research and treatment efforts.

This year's sold-out event raised \$3.5 million, thanks in large part to generous donors who accepted the challenge to match a \$1 million gift from event co-chairs Lesa France Kennedy and Bill Christy. The International Speedway Corporation CEO and her health care entrepreneur fiancé have been Magnolia Ball mainstays ever since Kennedy became part of Moffitt's national Board of Advisors in 2012. In addition to their \$1 million match challenge this year, the couple helped to boost the ball's auction income by donating an

exclusive NASCAR experience package and a getaway to their Snowmass, Colorado, vacation home.

Foundation special events coordinator Liz Flach says ball chairs bring more than generous gifts. "It's really that personal touch from them; sharing their passion for the cancer center and specifically for this event to help it grow." By sharing their enthusiasm within their personal network, chairs bring new attendees into the Magnolia Ball fold. Flach adds that they also bring new elements to the event, like this year's lively after-party fun.

Guests of the black-tie event arrive to a cocktail hour, mingling as they check out silent auction items and a Mystery Wine Wall with numbered corks for a \$25 purchase that match bottles on display. After dinner, they're treated to an inspiring program of speakers and a patient testimonial before the live auction gets underway with spirited bidding. Then it's dance time, while nationally known musical acts like this year's guest performers Kool & The Gang put on an hour-long show. Afterward, this year's attendees could grab a quick Krispy Kreme from the doughnut bar to fuel more dancing at the after-party with a DJ spinning hits. That meant some of this year's 700 guests who arrived at the Marriott Water Street at 6 p.m. didn't leave until after midnight.

No doubt they left tired, but Flach hopes they also left inspired. "They are a key part of something that's huge," she explains. "Moffitt Cancer Center is doing so many incredible things, and it's amazing for everyone in that room to feel that they are making a difference."



Photography: Ray Reyes



A Passion for HEALTH EQUITY

*Dr. Clement Gwede
Works to Eliminate Cancer
Health Disparities*

By Cathy Clark

Clement Gwede, PhD, MPH, RN

Photography: Kevin Kirby

“If you look back historically, health disparities or health inequities have been here in the United States for a long time.”

Ask someone to describe health disparities or health inequities, and the response could be inequality or difference. Someone else might describe the term as the lack of similarity of equality or inequality. Still others might suggest less positive descriptors, such as injustices, discriminations, biases, disproportions or imbalances.

Whatever the words used to describe them and wherever they may exist, health disparities are clearly and quickly recognized by Clement Gwede, PhD, MPH, RN. Gwede grew up in Zimbabwe when the south-central African nation was called Rhodesia, before the country had become independent Zimbabwe. In 1984, Gwede completed his nursing diploma program in the capital city of Harare, where he worked as a hospital staff nurse for the next two years.

Gwede’s primary motivation for coming to the U.S. in 1986 was to pursue higher education. “We had only one university in Zimbabwe during the era of the early 1980s, and I wanted to continue my education in health.” He also was inspired by “the desire to identify the unjust factors that are keeping the health of some groups down.”

“I’ve always been aware of the need to create health equity, even when I was in Zimbabwe, but the dynamics are a little different in the United States,” said Gwede, senior member of Moffitt Cancer Center’s Division of Population Science. He is well aware the dynamics of and the reasons for disparities

might be different among countries, but inequities – along with their adverse consequences – exist, nonetheless.

“If you look back historically, health disparities or health inequities have been here in the United States for a long time,” said Gwede.

In 1985, a U.S. Department of Health and Human Services task force released a comprehensive study of the health status of minorities, known as the Heckler Report. The report elevated minority health to the national stage and served as a driving force for changes to advance health equity at all levels of government.

Earlier, in the late 1960s, the following statement was attributed to Martin Luther King Jr., and proponents of quality health care use it frequently: “Of all the forms of inequality, injustice in health care is the most shocking and inhumane.” The actual documented quote conveys what many might consider an equally strong message: “Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in death.”

CHALLENGES COUPLED WITH HOPEFUL RESULTS

“For the past 50 years, we have seen a strong consciousness of the need and importance of health equities, and yet startling disparities remain,” said Gwede. “The not so good news is that they are persistent and we are not doing enough in terms of intervention and, in some cases, we still don’t know why they exist.”

U.S. death rates from all cancers combined are at least 25% higher among blacks than whites. Gwede takes prostate cancer as a case in point. “We are still trying to find whether the biology of the disease is different or if prostate cancer is a result of genetics or other influences. Is it more lifestyle, behavioral or cultural issues that we need to address? We think it is a combination,” Gwede said. “We haven’t quite hit the sweet spot, and, therefore, we are still struggling in some areas.”

Another challenge is triple-negative breast cancer, an aggressive subtype of cancer that is difficult to treat. For reasons that remain unclear, individuals of African American and Hispanic descent tend to develop triple-negative breast cancer more often than Caucasians and Asians. African American women with this subtype of cancer are known to have worse clinical outcomes than women of European



Photography: Kevin Kirby

descent. This indicates a need to improve access to genetic services among such high-risk individuals, and those so identified should be encouraged and meaningfully supported to undergo known and beneficial cancer prevention options.

Despite the challenges, there is good news in that much has been learned in the past few decades. “One part of the good news is that we can identify and describe the disparities. We understand quite a bit about how they have come to be, and we are committed to do something about it,” Gwede said. “We are doing interventions to eliminate the disparities when we know the causes or sources and solutions.”

One such area of hope, opportunity and challenge involves eliminating disparities in colorectal cancer.

“Colorectal cancer is a cancer for which we have well delineated screening modalities that we know work very well. Colorectal cancer is the most preventable, most detectable and most treatable if it is found early. We have a paradigm of a cancer that we can find, remove, prevent and treat,” said Gwede. “Yet we are not achieving the elimination of colorectal cancer.”

Gwede and his colleagues are tackling the problem of health disparities, particularly in the area of colon cancer, through research, education and partnerships. It is in this area Gwede and his team have had the most achievements and where he is most professionally gratified with the accomplishments. They spend a good deal of work educating patients about the importance of screening, early detection and prevention.

“Knowledge is power, and patients and unaffected community members need to know that screening is necessary and that it is something we can easily and, for the most part, conveniently do. Not everyone has that knowledge, and the most important barrier for patients and the general public is the means and courage to get the screening done.” Anyone who has health insurance must know how and when to use it for age and risk appropriate screening. For those who are uninsured, help is often available for them to get access to the screening tests, but sometimes courage is needed as well.

80% SCREENING IS ACHIEVED

Gwede and his team are focused on helping people get screened for colon cancer through the use of an easy at-home stool test, called the FIT, or fecal immunochemical test. FIT looks for hidden blood in the stool, which can be an early sign of cancer. “If the test result is abnormal, we can help navigate patients to get a colonoscopy.” A colonoscopy allows doctors to view the entire colon, identify cancer or abnormal growths or precursors of cancer (polyps), and remove them before they turn into cancer. However, this specialized and thorough test is often not readily accessible for many.

Despite FIT’s simplicity and ease of use, there are barriers to overcome. “Many times we hear patients say they will not undergo screening because they feel well or are not experiencing any symptoms. Some say ‘I know my body; I can tell when something is wrong,’” said Gwede. “That is not exactly true. We think we know our bodies, but cancer often grows quietly without causing any symptoms, and by the time it causes any symptoms – whether minor bleeding or aches and pains – it may be too late.”

Gwede has led four studies in which over 80% screening was achieved for colorectal cancer, meaning that over 80% of people who received the FIT kits returned them. “From that perspective, I feel it is one of the highest accomplishments research can do when we demonstrate effectiveness.”

About 7% of people who did the FIT test had an abnormal result. Of the abnormal findings, Gwede’s team helped them to get additional testing with colonoscopy and three cancers were found. Three people had cancer of the colon or rectum, one had two additional cancers: bladder and kidney cancer. “They all got treatment at Moffitt as a result of the simple screening; those are success stories.”

Of the four FIT studies, one was done among blacks in nonhealth care settings, such as churches, barber shops and culture centers and programs – places where the individuals who participated were not seeking health care. The other three studies were performed in collaboration with Tampa Bay area community clinics, also called federally qualified health centers. These centers provide care regardless of one’s insurance status or ability to pay.

PARTNERSHIPS SUPPORT HEALTH EQUITY

Three partnerships in particular involving Moffitt have done a great deal to address diversity and health disparities and to improve health care access to our communities.

Tampa Bay Community Cancer Network was funded by a National Institutes of Health research grant (2005-2017) to develop an academic partnership with community organizations. The collaborative network is made of local federally qualified health centers, nonprofit organizations, faith-based groups, adult education, advocacy groups, literacy groups, and Moffitt Cancer Center. The network’s unified goal is to create and implement sustainable and effective community-based interventions to impact cancer disparities in the Tampa Bay area. Since 2017, Moffitt has continued supporting the Tampa Bay Community Cancer Network, which benefits underserved communities, regardless of race or ethnicity.

Another research collaboration, the Ponce Health Sciences University – Moffitt Cancer Center partnership, is enhancing

health disparities research at Moffitt, and cancer research and cancer care in southern Puerto Rico. Intended for Hispanics/Latinos in Florida and southern Puerto Rico, this research is providing more data about the behavioral aspects and genetics of cancer to know how to best improve screening, early detection, diagnosis and treatment of cancer. The partnership led to creation of a unique Hispanic/Latino Biobank, the first functional, centralized Hispanic cancer-related biobank in Puerto Rico. Representation of all groups is essential to research in preventing and treating various forms of cancer.

“I think the initial paradigm, no matter what sort of research we are doing, should always ensure equitable representation. In that way, everybody can benefit from new discoveries,” said Gwede. “What has been happening is that studies often are done with majority populations. After we find that something benefits that population, then we start asking ourselves whether it also could benefit minority groups. This incremental approach results in potentially harmful delays in which the knowledge and new discoveries are not immediately benefitting all the groups. So we are now trying to design studies upfront with adequate representation so beneficial findings can immediately translate to direct benefit for all.”

Another key partnership initiative is the Moffitt Program for Outreach Wellness Education and Resources (M-POWER), under Moffitt Diversity. “Those efforts are not research fueled; they are service-fueled, and equally pivotal to bring evidence-based interventions to communities,” said Gwede. “This means that the people involved with M-POWER are going out to educate and benefit the community, and they have developed numerous partnerships to achieve what is known as best practices to promote health and provide necessary linkages to cancer care.”

The benefits of working collaboratively are evident, noted Gwede. He is pleased to say he has seen strong commitment to address cancer health disparities at Moffitt for nearly 26 years.

“The institutional prioritization and awareness for addressing cancer health disparities is tremendous including broadening charity care, by financially supporting research that addresses cancer health disparities, and through work in the cancer

center’s catchment area to benefit our communities. There also has been a tremendous focus on understanding diversity within our staff, patient population and within our community, and addressing disparities with a very clear commitment of financial and leadership support,” said Gwede.

THE TIME IS NOW

Gwede’s life may look like the fulfillment of the American dream. Since coming to the U.S., he completed his bachelor’s, master’s in Public Health and doctorate degrees. After coming to work at Moffitt in 1993, he gradually rose in ranks to become a senior member, and he is a professor at the University of South Florida. His wife of 31 years, Itai, also completed nursing school in Zimbabwe. She has worked as a registered nurse for 26 years on a surgical oncology floor at Moffitt. She is now a new manager of her inpatient unit. The couple have two grown children. Their son is in medical school in Chicago and aims to become an oncologist. Their daughter completed a bachelor’s degree, works in the health and wellness field in the Tampa community, and is the mother of their first grandchild.

But Gwede is not one to sit back and rest and enjoy the good life. He is well aware that much work remains to be done, and he believes the commitment and means to achieve health equity is here.

“We are fortunate to have Moffitt leadership’s strongest commitment and support for diversity and health equity in every aspect. We have internal pilot grant mechanisms that aim to eliminate health disparities. We have transdisciplinary groups that are meeting to better understand and address disparities. There’s a prostate cancer group and others focused on health disparities research. We have a critical number of researchers that are now asking health disparities and health equity questions,” said Gwede. “We have all the momentum necessary, but clearly, not all the results. Not yet.”

So he and his team keep working during what he calls exciting times for health disparities research.

“I think there is a time to understand and address health disparities to achieve health equity; that time is now.”

“I think there is a time to understand and address health disparities to achieve health equity; that time is now.”

*Cancer survivor Greg Feldman
with his wife, Melissa Seixas*



Photography: Jeremy Peplow

UNITED AGAINST A COMMON ENEMY

By Ann Miller Baker

NOTHING UNITES LIKE A COMMON ENEMY.

Just ask participants in a tour of the Moffitt Cancer Center research lab run by Karen Mann, PhD, assistant member of the Department of Molecular Oncology. “Our focus in my lab is specifically to identify how pancreatic cancers become so aggressive,” Mann explains.

Her tour guests have been living with it. Greg Feldman is a pancreatic cancer survivor. His wife, Melissa Seixas, has been his primary caregiver throughout the seven-year battle. “When I tell people my husband was diagnosed with

pancreatic cancer,” she tells the lab personnel, “they assume I’m a widow. I have to jump in and say no, he’s fine! He’s been treated at Moffitt.

“I spent many hours here at Moffitt, but never on the research side,” says Seixas. “You’re kind of like the wizards behind the curtain, working to find treatments and cures.”

The couple came here for hope; to learn more about what Moffitt researchers are doing to advance the understanding, diagnosis and treatment of their common enemy. But their presence has a definite impact on those who work here.

“That’s the motivation that gets us going every day,” says postdoctoral fellow Suman Govindaraju as he takes a moment from his work at the lab bench.

PATIENT EMOTION BECOMES RESEARCHERS’ FUEL

The tour is part of a new program called the Patient Researcher Forum. It was the brainchild of another Moffitt researcher, Eric Lau, PhD. An assistant member in the Department of Tumor Biology, Lau and his research team center their work on melanoma and breast cancer. He was introduced to a young melanoma patient by his partner, acupuncturist Dr. Liem Le, and offered to show her the research work being done on her type of cancer in his lab. “We thought this would be an opportunity for my trainees to break down in layman’s terms what it is that they do,” says Lau. “But she turned the tables on us.

“For almost 20 minutes in my lab, she basically told us about everything in her life; from the day she woke up feeling sick to her diagnosis with metastatic cancer in the brain that same week. And it was very emotional, for the patient and for us. We provided an emotional reception that was very different from what she had experienced.”

The emotional release that proved helpful for this young patient became fuel for Lau’s research team. “It really motivated and brought a new perspective for everyone in the lab. That change in energy and the way people approached their work was very tangible.”

But beyond the benefits to young researchers, Lau says, “It is our social obligation to report back to the people who we serve, and those are the patients. And honestly, I don’t think there’s enough of an opportunity to do that.”

It was clear to Lau and Le that this experience and perspective needed to be shared with as many researchers as possible. Over the next few months, Lau and Le worked with Anne Bidelman, who manages Moffitt’s Patient and Family Advisory Program, and her predecessor in that role, Kim Amtmann-Buettner. Together, they designed a two-hour experience to replicate that original exchange between patient and researchers. Every month since July 2018, they have been identifying and recruiting patients who would be willing to share their experiences with lab personnel.

Lau says that he and most of his colleagues got into cancer research “because we were gung-ho about doing something to make a difference for cancer patients. But I can remember very clearly back when I was a grad student working in a lab. I reached a sort of mid-grad career crisis, wondering what on earth I was doing. I was under such pressure to write my thesis and ace whatever exam was on the horizon. You kind of lose focus and perspective of why you started this journey in the first place. And I think this kind of forum is really helpful in reminding – especially the younger trainees – why it is that they’re doing this and what they should be aiming for.”

CLINICAL CRASH COURSE

It’s also an opportunity for the researchers to gain a greater understanding of the clinical side of whatever type of cancer the tour patient is facing. While the patient and their guests tour the lab, forum researcher participants hear from a Moffitt physician who specializes in the diagnosis with a clinical “crash course.”

In Feldman’s case, his surgeon Pamela Hodul painted a bleak picture. The American Cancer Society estimates over 56,000 Americans will be diagnosed with pancreatic cancer in 2019 and, Hodul added, almost all will die from the disease. By the time patients go to the doctor for symptoms like abdominal pain, weight loss or jaundice, she said most will be diagnosed with cancer that’s spread beyond the pancreas. Out of every 100 newly diagnosed patients, only 20 have potentially curable disease. “I send 80% of my new clinic



Photography: Rafael Cardona

WHERE IT ALL STARTED – Patient Danielle DeCleene (center) was the first to share her story and inspire Moffitt researchers in an informal visit to the lab of Dr. Eric Lau (far right). Danielle was being treated by acupuncturist Dr. Liem Le (second from right) for pain related to her melanoma and expressed interest in learning about Moffitt’s melanoma research. Le arranged her visit to husband Lau’s lab, and the resulting emotional exchange became the basis for monthly Patient Researcher Forums. Moffitt’s Patient and Family Advisory Program Manager Anne Bidelman (far left), and her predecessor in that role, Kim Amtmann-Buettner (second from left), help to identify and connect patients to participate in the forums.

patients straight to the medical oncologist because I can't do anything from a surgical perspective," says Hodul. "And right now, surgery is the only chance for a cure." Patients like Feldman are the exception, said Hodul, with barely 8% surviving five years after diagnosis.

Hodul's colleague, medical oncologist Dae Kim, told the gathered researchers that all pancreatic cancer patients will receive chemotherapy at some point in their care, but only two chemo regimens are available. What's holding back progress, both agreed, is inadequate funding for pancreatic cancer research.

FIRSTHAND ACCOUNTS TRIGGER NEW THOUGHTS

Statistics can't match the impact of a firsthand account from the patient. Feldman shared that his only symptom was weight loss, something he wrote off to getting older and his active lifestyle. It wasn't until he had to have his tuxedo altered for a formal event that the extent of his weight loss hit home. "The tailor asked if he'd had gastric bypass surgery," wife Melissa told the researchers. "I've been known to have some colorful language, and by the time we got to the car in the parking lot, I told him in no uncertain terms he had to go see a doctor."

"I'm just thankful that there are bright, young dedicated people working on this thing still. They're improving the odds for future patients."

"We ended up at Moffitt and I had my pancreas, my gallbladder, my spleen, part of my stomach, part of my duodenum removed," said Feldman. "About the time I recovered, I got the fun of chemo. At the beginning, you don't realize what the journey's going to be and they don't really tell you. When I look back at it now, I realize they don't tell you because you don't really have any options. What point would it be to put more fears in it?"

Psychosocial effects were an unexpected aspect of the disease for both of them. Feldman became a type 1 diabetic as a result of the surgery and had to rethink everything about his diet. He also found himself coping with depression for the first time in his life, and sought help from Moffitt's Supportive Care program.



Photography: Jeremy Peplow

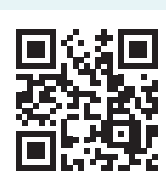
For Seixas, who likened the role of caregiver to "putting on my flak jacket and being ready for battle," the challenges came when her husband passed the two-year post-op mark without any signs of disease. "When I knew he was going to come out the other side of this, it was tough for me to transition back to being a wife because I was not going to let my guard down."

Hearing these firsthand accounts of cancer's effects can inspire researchers to pursue new questions, says Lau. "We've had forums in which we actually see patients experiencing things like chemo-brain, which causes people to get disoriented or lost. As researchers, most of us don't really know what that is. But once we see some of these side effects right in front of us, it can help to motivate people to think about how their current research might help to mitigate these side effects, or even sprout new ideas to investigate." Both Feldman and Seixas told the gathered researchers they'd most like to see progress on a way to detect pancreatic cancer before it has a chance to spread, and further development of targeted therapies that would have fewer side effects than chemo.

"I felt a lot of camaraderie in that room," says Seixas. "To help them make that connection, to know that on the receiving end of anything that they are doing is a family that is struggling for answers – truly it's a privilege to be able to do that."

"I'm just thankful that there are bright, young dedicated people working on this thing still," adds Feldman. "They're improving the odds for future patients."

Scan this QR code with your cell phone to view a video of Greg Feldman and Melissa Seixas touring a Moffitt Molecular Oncology research lab.



*“We need to bring
the community to the table.”*



Photography: Jeremy Peplow

Susan Vadaparampil, PhD, MPH

Engaging Moffitt’s Community Against Cancer

New leadership role for Dr. Susan Vadaparampil
oversees community outreach, engagement

By Ann Miller Baker

Amazing advances are being made almost daily in cancer prevention and treatment. But are they meeting the needs of, or even reaching, people throughout our community?

Moffitt created a new leadership position in late 2018 to help us better understand and address our community’s cancer needs through engagement, ongoing dialogue and strong partnerships. Susan Vadaparampil, PhD, MPH, is Moffitt’s first associate center director of Community Outreach,

Engagement & Equity. She has spent more than 15 years at Moffitt, researching cancer health disparities and participating in community projects that will serve as a solid foundation for the work ahead. While the National Cancer Institute (NCI) defined the community outreach and engagement portion of her title, Vadaparampil added Equity in light of how imperfectly cancer advances make their way through all segments of society, and reflecting Moffitt’s core value of Inclusion.

Enhancing Scientific Mission

“Throughout the nation, only about 50% of Americans receive what we already know works in terms of recommended clinical care,” Vadaparampil notes. “And if you look at who benefits from new advances, you see disparity and inequity.” She adds that disparities are defined not only by race or ethnicity. Your risk of developing or dying from a given cancer might be higher simply because of your gender or even where you live in the U.S. All the more reason, Vadaparampil says, for centers like Moffitt to understand and address what’s needed in our own backyard.

It’s an issue that has gained the attention of the NCI, which designates Moffitt as the only Comprehensive Cancer Center in Florida and one of only 51 nationwide. NCI designation comes with grant dollars (see story, page 20). As part of those grants, all such NCI centers now must demonstrate how knowledge gained from their research benefits the communities they serve. Moffitt Center Director Tom Sellers, PhD, MPH, who serves as the principal investigator for the Cancer Center Support Grant, says our community outreach and engagement effort is now a written and scored component of the grant. “The NCI Office of Cancer Centers has analyzed recently renewed centers and assessed that this addition is the second most important criteria affecting the overall score.”

For Vadaparampil, it’s an acknowledgement of our responsibility to those we serve closest to home. “We need to bring the community to the table,” says Vadaparampil, “to tell us what the most pressing needs are, and to help us understand how to shape solutions that fit our community. That is our mandate as an NCI-designated Comprehensive Cancer Center.”

So what exactly is Moffitt’s community? The NCI defines it in terms of a “catchment area,” a descriptor that outlines a geographic area surrounding the cancer center that is home to a majority of its patients. For Moffitt, it’s a 15-county block of west central Florida that is home to more than 70% of our patients. In actuality, our community extends well beyond immediate surrounding counties to all of Florida, the U.S. and beyond.

“It’s important to make sure that we’re doing research on the cancers that affect the population within our 15-county catchment area.”

Within our catchment area, we already have developed lasting partnerships and outreach programs. “We already have a strong history of engagement with our community,” notes Vadaparampil. These include efforts in:

- **Community outreach education such as Moffitt Diversity’s M-POWER program**
- **Clinical partnerships including Moffitt’s work with BayCare’s Morton Plant Hospital and Moffitt’s developing facility at AdventHealth Wesley Chapel**
- **Research partnerships like the Moffitt-led Tampa Bay Community Cancer Network and the Florida Academic Cancer Center Alliance**
- **Philanthropic efforts such as Moffitt’s George Edgecomb Society, which fundraises to accelerate Moffitt research in disparities affecting African Americans and blacks**

There are a multitude of other examples throughout Moffitt that Vadaparampil is in the process of inventorying and examining for potential to leverage further across our catchment area. Through collaboration with the Florida Academic Cancer Center Alliance, some of these strategies may even extend across the state. But Vadaparampil says her first order of business has been to engage with stakeholders from these efforts and throughout the community to gain their thoughts on what’s needed – in research, education, prevention, treatment and access.

“It’s important to make sure that we’re doing research on the cancers that affect the population within our 15-county catchment area,” says Vadaparampil. “But we also must prioritize the needs of our broader community, in terms of their cancer screening, education and access.” We need to identify and understand barriers to access as well, says Vadaparampil, to ensure stakeholders like payers and policymakers are also at the table to craft solutions.

“I don’t pretend to have all the answers for what our priorities should be. But I am listening to those who have been doing this work, to hear what is important to our stakeholders. Then, using secondary data from sources like the Florida Cancer Registry, we can better understand what our needs are. The next step will be to bring that information back to our community partners so we can prioritize and develop an action plan that really involves stakeholders from across the cancer center and catchment area to maximize Moffitt’s impact in our community and beyond.”



L-R: Lowell Smith, MA; Tom Sellers, PhD, MPH; Brian Springer, MHA

Photography: Nicholas Gould

More Than a Label

As a National Cancer Institute Comprehensive Cancer Center, Moffitt is spearheading research to drive a cure

By Ann Miller Baker

IT'S AN ELITE GROUP.

Only 51 centers nationwide have met the rigorous standards set by the National Cancer Institute (NCI) to be called a Comprehensive Cancer Center. Another 21 cancer centers have successfully achieved NCI designation, but lack the breadth, depth and integration of basic, clinical and population science research to achieve comprehensive status. Moffitt is the only NCI Comprehensive Cancer Center based in Florida.



In this case, *comprehensive* is a word with very specific meaning. The NCI outlines the attributes required for comprehensive status (language adapted from the NCI website):

Comprehensive Cancer Centers demonstrate depth and breadth of cancer research activities in three major areas: basic laboratory; clinical; and prevention, control and population-based science. They also have substantial transdisciplinary research, translating scientific advances into better health care. Robust clinical trial activity and accrual are critical. These Centers effectively serve patients in their self-defined region (“catchment area”), as well as the broader population, through cancer research. They integrate cancer training and education into programmatic efforts to enhance the scientific mission and potential of the Center.

Moffitt attained comprehensive status in 2001 at a remarkable pace, just three years after achieving NCI designation and 15 years after first opening its doors. NCI designation confers funding in the form of the Cancer Center Support Grant,

Enhancing Scientific Mission

or CCSG. Contrary to what one might think, the CCSG is not a largesse that underwrites all the work being done by Moffitt researchers. Far from it: At around \$3 million per year for Moffitt, CCSG dollars only partially support the structure needed to create the collaborative environment where great cancer research can take place. The faculty must still compete for external grant monies to cover their salary, hire staff, purchase supplies, and pay for use of the shared resources. But designation conveys a level of credibility that far exceeds the monetary value.

Tom Sellers, PhD, MPH, Moffitt's center director and executive vice president, says most of the money goes to support shared resources called core facilities. Sellers, who also serves as principal investigator for Moffitt's CCSG grant, explains that these provide access to high-tech instruments and experts crucial to success in the competitive world of cancer research. "It's beyond the means of any single researcher to afford, so we pool our pennies and then everybody gets access to the equipment or that expertise." In addition to cores, a substantial component of CCSG funds is devoted to clinical research activities, such as management of the 240+ members of the team, scientific review processes and quality review infrastructure.

Top-notch research requires faculty leadership to coordinate collaborative team science. Some of the CCSG dollars provide protected time for faculty outside of their laboratory or clinic to facilitate research program activities that lead to world-class innovative science. The remaining CCSG funds support continuous review and evaluation processes, and developmental funds for pilot research projects, recruiting new investigators or developing new shared resources.

Once attained, NCI comprehensive status and CCSG dollars are not assured permanently. At least every five years, centers must apply to renew their grant and status. "This is not a popularity contest," explains Sellers. "This is a formal, written, peer-reviewed grant application that is very data-driven, followed by an intensive in-person review by a site visit team."

It's also one with real consequences. Designation and CCSG dollars can disappear with an unsuccessful effort. With renewal, the strength of a center's research effort is reaffirmed. "It perpetuates a path of success in science," Sellers adds, as the majority of the federal budget that funds cancer research studies goes to NCI-designated and/or Comprehensive Cancer Centers. "Having NCI designation means we're doing relevant, impactful research, and we're attracting the best talent in many roles throughout the organization to make it successful."

Moffitt's last application, filed in 2016, weighed in at over 2,100 pages. NCI-selected experts in the types of research conducted at Moffitt spent one day on campus reviewing core

facilities, research programs, administration and leadership. It's a tight schedule, says Brian Springer, MHA, vice president and associate center director of Research Administration. Each research program typically gets just 10 minutes to tell its story. "That may be the life's work of 25 people in the program," Springer explains. "Imagine assembling all they're doing into a 10-minute talk or 12 pages of a report. If you don't get the point across, you can wind up not being evaluated as highly as you'd hoped."

When it comes to the CCSG, the quality of patient care is not directly reviewed. "The evaluation is solely based on the scientific impact," says Lowell Smith, MA, senior director of Research Administration for Moffitt's CCSG. "Clinical activities and care are not directly evaluated, except for clinical research activity that is considered the gold standard for the most advanced care. However, indirectly, it's been shown through outcome data and other statistics that patient care is better at designated centers. Quality research means better outcomes."

"It's really 6,500 Moffitt team members doing things every day that translate into the grant, because research is part of our DNA."

Susan Vadaparampil, PhD, MPH, Moffitt associate center director of Community Outreach, Engagement & Equity, says our patients contribute to our research mission in several ways. "Some participate in research studies aimed at improving cancer prevention, treatment and survivorship," she says. "Others participate in advisory panels, support groups and forums that allow researchers to quickly connect with the patient and their experiences and infuse those perspectives into research. These contributions add to the synergistic relationship between Moffitt's quality cancer care and its innovative research." (See story, page 18.)

And in that way, says Springer, Moffitt's CCSG is not just a research effort. "It's really 6,500 Moffitt team members doing things every day that translate into the grant, because research is part of our DNA."

"We all contribute, directly or indirectly, whether we realize it or not," adds Sellers. "If the invoices don't get filed for the clinical trials or the equipment isn't ready to see the patients or there's not a margin on the hospital's bottom line – all of that impacts our ability to do world-class research."

"Every single one of us contributes to the research success here. Every single person, no matter what they do."

Behind the MICROSCOPE

Pathologists – the ‘doctor’s doctor’ – are using next generation genetic testing to provide better diagnosis and treatment options.

By Sara Bondell



*Dr. Theresa Boyle (left)
with molecular technologist Liang Nong*

Constance Kihm discovered her passion for dancing in her mid-60s. On a friend's suggestion, she enrolled in a tap-dancing class, purchased her first pair of tap shoes for \$75 and took a deep breath. She told herself she had better like this new, and what seemed at the time expensive, hobby. She ended up more than liking it. She fell in love with the group of women she danced with, the glittery costumes and performances. Those shoes became her favorite pair.

But in fall of 2018, at age 72, Kihm lay in a hospital bed, wondering if she would ever dance again.

Earlier that year, severe joint pain brought Kihm to an urgent care center near her home on Anna Maria Island, Florida. She was sent for a chest x-ray, and while doctors told her cancer was a possibility, it wasn't likely. Kihm wasn't convinced. "On both sides of my family, everyone died of cancer," she said. "My dad died of testicular cancer at a young age and my mom died of lung cancer."

Tests confirmed Kihm also had lung cancer. She was diagnosed with a rare genetic driver of non-small cell lung cancer in the ERBB2, or the HER2 gene, which causes less than 5% of all lung cancers, mostly in women who have no history of smoking. HER2, a protein called human epidermal growth factor receptor 2, promotes the aggressive growth of cancer cells.

Kihm underwent four rounds of chemotherapy but had no response to the treatment. She was then enrolled in a clinical trial. While the treatment was effective at the start, it came with debilitating side effects and eventually stopped working.

Still, Kihm was well enough to take a previously planned trip to South Africa. But while on the trip, every day found her more and more short of breath. Eventually, she was admitted to a hospital there.

"They took a chest x-ray and the cancer had come roaring back," said Kihm. "I thought I was going to die in South Africa."

After 10 days in the hospital, Kihm was medically transported back to the United States and began another round of chemotherapy. She was at her weakest point, struggling to breathe and dropping to under 100 pounds. The treatment worked, but doctors knew they needed to find a better, less-toxic long-term option.

The search was on to find Kihm a new clinical trial that would give her the best chance at survival.

NEXT-GEN TESTING

When it comes to technology, we long for the next generation, the next big thing. We want the newest smart phone, the highest-resolution television, the most advanced car.

The completion of the Human Genome Project in 2003 was health care's version of next generation technology. The project ushered in a new era of genomic analysis called next generation sequencing. Pathologists now could sequence millions of DNA molecules at the same time and investigate numerous different genes simultaneously, a process that in the past would have been too expensive and too time-consuming to be clinically feasible.

Since then, Moffitt Cancer Center has been continuously improving diagnostic molecular testing and using next generation sequencing to help provide the best patient care possible. It was this work that paved the way to a new treatment option for Kihm.

In 2018, Moffitt debuted a new investigative lab test, known as an assay, for solid tumors. This new test changed the game when it came to diagnosing and creating personalized treatment plans. Moffitt STAR is a 170-gene panel that not only looks for changes in tumor DNA, like other conventional next generation sequencing tests, but it also investigates changes in RNA, the shorter, single-stranded cousin of DNA. If DNA holds the body's blueprint, RNA converts that information into the body's building blocks.

"RNA testing opens up a whole new field and we are making discoveries that just haven't been seen or investigated before," said pathologist Theresa Boyle, MD, who helped build the new technology from the ground up. "When we make a diagnosis, we can be sure we've investigated the patient's genes for any changes that lend themselves to known treatments. We also have enough information about the patient's unique genetics to match them to a targeted therapy or to a Moffitt clinical trial aimed at those genetic findings."

The FDA has approved certain treatments for tumors if a patient has a fusion in certain genes that can be identified. In the past, it was almost impossible for a lab to detect those fusions at the DNA level. Moreover, the fusions occur in such a small percentage of cases that it was hard to justify the time and cost of performing a separate lab test. Moffitt STAR can detect the fusions at the RNA level, and the results can give clear guidance to doctors on whether a patient would benefit from the treatment.

If DNA holds the body's blueprint, RNA converts that information into the body's building blocks.

*“RNA testing opens up a whole new field
and we are making discoveries that just haven’t been
seen or investigated before.”*

Moffitt STAR results not only can guide therapy, but also confirm diagnoses and, on a few occasions, have even overturned a wrong diagnosis. As the first institution to develop an integrated DNA- and RNA-based test, Moffitt has been a leader in this area and is helping other cancer centers develop a similar assay.

FASTER TURNAROUND

After looking at all the options, Kihm’s physician thought he found the best fit for her: an investigational drug that is designed specifically to turn off the HER2 gene. But to qualify for the clinical trial, Kihm had to have a positive test in the cancer tissue, not just in her blood, which was how she was originally diagnosed.

That’s where Moffitt STAR came in. The test can be run immediately after a tissue sample is collected because the test is done in-house at Moffitt.

This not only saves time but gives Moffitt physicians and researchers a better opportunity to analyze the data. On average, it takes about two weeks to get results and the team is working on making the turnaround time even faster.

Kihm’s physician told pathologists exactly what he was most interested in and how quickly he needed results. That fast-

tracked Kihm’s case; the pathologist confirmed the result that was needed before taking the time to review the entire case with a fine-tooth comb.

The new approach also instills even more confidence for pathologists. Known as the “doctor’s doctor,” pathologists spend most of their time behind the curtain. They know the work they are doing behind the microscope is making a bigger impact on patients than ever before.

“I think it may be encouraging for patients to know when they’re seeing their doctor that a whole team of care providers are assisting the doctor to come up with best patient care based on their individual situation,” said Boyle.

That collaboration landed Kihm on the trial quickly, and more than four months later her tumor had shrunk 35%. She is considered stable, and says the few side effects like fatigue are very manageable.

“Of all the treatments, this is the best in terms of quality of life,” she said.

*“Of all the treatments, this is the best
in terms of quality of life.”*

NEEDLE IN A HAYSTACK

Since the Moffitt STAR’s launch in February 2018 and July 2019 when this article was written, the test has been used in more than 800 cases. Moffitt has hired additional lab staff to run the test and has plans to develop automation and purchase a new sequencer with greater capacity to process more samples. Right now, the lab can process about 16 samples a week.

Moffitt pathologists are also rolling out another new assay this year that is similar to STAR. The myeloid action panel, or MAP, is a comprehensive 98-gene panel for blood and bone marrow cancers. While Moffitt STAR is used for solid tumors, MAP will be used for liquid ones and has the potential to be one of the best assays in the malignant hematology field.

“This is everything in one go, which is relatively unique,” said pathologist Mohammad Hussaini, MD. Before Moffitt MAP, pathologists had to do one expensive next generation sequencing test and then send out the sample for parallel



CONSTANCE KIHM
Cancer Survivor

Photography: Nicholas Gould



Mohammad Hussaini, MD

testing to make sure they weren't missing anything. "That's added cost and time and now, with Moffitt MAP, we don't have to do that anymore," Hussaini said.

Identifying these mutations quickly and easily will help pathologists make a diagnosis, determine prognosis and help develop a more tailored treatment strategy. "Starting off on the right foot with the right test makes all the difference," said Hussaini. "You can't treat unless you have the proper diagnosis."

All of the Moffitt STAR's results go through Moffitt's Personalized Medicine Group for further interpretation that is specific to each patient. The data is also kept for future research.

"As pathologists, we are stewards of the data and the samples, so it's really important we get it to the researchers," said Boyle. "It's not just about patient care today, but the research to make things better in the future."

With hundreds of cases run through Moffitt STAR, researchers have already started to see patterns emerge, specifically in advanced kidney cancer cases.

Epidermal growth factor receptor, or EGFR, is a protein that is amplified in cancer cells. It is most commonly found in lung cancer, and patients identified to have an EGFR mutation are eligible for certain targeted treatments. However, EGFR has never been significant in kidney cancer. All that changed once Moffitt STAR gave pathologists a look at RNA; they noticed a trend after running three kidney cancer samples.

"What we are finding is that it's not at the DNA level that we are finding changes in EGFR in kidney cancer, but at the RNA level," said genitourinary oncologist Brandon Manley, MD. "Only in kidney cancer cells is EGFR getting spliced at an abnormal rate way too often to just be a coincidence."



Brandon Manley, MD

Manley says this discovery is like finding a needle in a haystack. Now that they know what to look for, researchers can validate their finding and begin expanded studies. Manley has been recommended for a U.S. Department of Defense grant for additional research, and believes this could lead to important advancements in kidney cancer, the most lethal of all genitourinary cancers.

"Given the fact that this is so unique to kidney cancer,



Photography: Nicholas Gould

the next question is: Is there some way that this helps the cancer survive, grow or spread?" Manley asked. "And more importantly, can we use this against the cancer? Can we use this to better monitor patients, screen patients, follow treatment outcomes, or even the Holy Grail: can we develop a specific drug to exploit this?"

DANCING AGAIN

Constance Kihm, almost two years since her diagnosis, said she finds it incredible how far cancer treatment has come in the last decades. Rather than the generic "one size fits all" chemotherapy treatment, doctors now have the ability to identify specific mutations that can dictate certain FDA-approved treatments or clinical trials. "They've come so far since my dad died of cancer in 1947," said Kihm about the father she never got to know because cancer claimed his life.

Kihm has also come far since landing in that hospital bed in South Africa. With her renewed quality of life, she is back to dancing. She started slow, taking a hula class which brought her back to the stage for her first performance in over a year.

In July, Kihm took yet another step forward—literally—lacing up those \$75 tap shoes for her first tap class in eight months. "I was grinning from ear to ear," she said. "I made it the entire class without having to sit down. It was the best feeling ever."

A woman with blonde hair, wearing a vibrant purple suit, stands in a brightly lit room. She is smiling warmly at the camera while holding a large, polished brass bell with a white rope handle. Her left hand rests on her hip. The background is a blurred interior space with large windows and a yellow wall. A semi-transparent pink box is overlaid on the left side of the image, containing the title text.

THE CALL
for
COURAGE
BELL

*Stephanie Stanfield
boldly celebrates each day.*

Photography: Kevin Kirby

For patient Stephanie Stanfield, bell ringing ritual celebrates continuation of life, little victories

By Sarah Garcia

The moment is short but sweet. The sound is rich, resonating and recognizable.

A symbolic bell, placed at various locations across Moffitt Cancer Center's many campuses, often marks the celebration of the end of treatment. "Victory" over cancer as many might call it.

We have come to realize that message and purpose may not ring true for every patient who walks through our doors. As diverse as our patients and the diseases they face, so too should be the reasons to take part in this tradition.

A SOBERING SILENCE

Stephanie Stanfield stood by her mother's side throughout her battle with lung cancer at another institution, and distinctly remembers hearing patients ring the bell. It's a common ritual at cancer centers across the nation.

For some it's a joyous sound and cathartic experience; for others it can provoke a sobering silence within.

Stanfield recalls crying as she and her mother watched numerous families celebrate the end of treatment.

"We knew my mom would never ring that bell," she said. In the summer of 2017, she lost both her mother and brother-in-law to cancer.

THE UNEXPECTED

That December, Stanfield began experiencing back pain. Before her mother's passing, Stanfield had promised her she would still light up the house up for Christmas, and figured she had pulled a muscle decorating. But a routine mammogram in January 2018 revealed suspicious findings. "I think I knew right then I had cancer," she said. She was no stranger to the disease. "I had prepared myself to be a warrior as I thought I would be scheduled for a double mastectomy. I picked out a wig. I was ready."

After a series of tests and scans, Stanfield and her husband met with her surgeon. "When we walked in, my surgeon was crying. We sat on the couch you never want to sit on and she said, 'It's worse than we thought, and surgery is not an option.' We thought, 'How could it be worse?'"

Stanfield was diagnosed with inoperable stage 4 breast cancer. The disease had spread to several locations, including her spine. The diagnosis was terminal.

LIVING LIFE WITH CANCER

Known to always be a source of positivity to her two grown children, other family members and those around her, Stanfield calls herself lucky.

She recounts her blessings: "I didn't have to go straight to intravenous chemotherapy. I didn't lose my hair. I didn't have the fatigue many people manifest from treatment. And I'm stable."

"I had prepared myself to be a warrior as I thought I would be scheduled for a double mastectomy. I picked out a wig. I was ready."

For those with a terminal diagnosis, cancer may have no true "end" in sight. But due to medical advancements, patients like Stanfield are living with cancer much longer.

Although her body will never be cancer-free, there are effective treatments to keep the cancer in check and keep her stable. Her current treatment plan includes hormone therapy to inhibit the growth and spread of the cancer, as well as oral chemotherapy to slow the progression.

"They told us the average effectiveness is 22 months," she said. When this story was written, Stanfield was on the treatment 21 months. "You go into it knowing that the medicine is going to stop working. When it does, we'll try something else."

Working with her doctors, Stanfield has taken steps to improve her immune system as much as possible while undergoing continual treatment. She's radically changed her diet, eliminating sugar, dairy, meat and refined foods. She juices every morning. "I joke and say I'm the healthiest terminal person you'll ever meet. I really am thriving."

A SHIFTING PARADIGM

Every three months, Stanfield visits Moffitt's Richard M. Schulze Family Foundation Outpatient Center for treatment with Zometa®, an IV infusion drug she receives to help strengthen her bones and inhibit further metastasis.

When she came out after completing her first cycle, she told the staff at the Infusion desk, "I'm going to ring that bell."

Staff and other witnesses began congratulating her on completing her treatment, but she quickly interjected, "No, that's not why I'm ringing this bell. I'll be on treatment for the rest of my life. But every month that I start another treatment cycle is a celebration for me."

"The sound never gets old."

Stanfield once thought the bell was out of reach for patients like her mom, herself. Now she wants others to recognize it is a celebration of life, in the present.

"It's this shift of a paradigm that I really want people to think about," she said. "It [the bell] is not just reserved for those moving on from cancer. You can ring it for any reason, at any stage or to mark any moment you want to celebrate, big or small."

Stanfield continues to celebrate every opportunity to enjoy life. She and her husband made one of their dreams a reality when they recently took a trip of a lifetime to Bora Bora.

SPREADING THE WORD

Mayelin Torres, a registered nurse in Moffitt's McKinley Infusion Center, is helping to spread the same message. Being in infusion, she hears the bell day in and day out. "The sound never gets old," she says.

Both in her career and personal life, Torres has experienced the full spectrum of a cancer diagnosis and its impact on an individual and their loved ones. Her mother was treated at Moffitt for lymphoma, and like Stanfield, her cousin is battling terminal breast cancer.

Torres wants all patients to know that the tradition of ringing the bell is accessible, regardless of their cancer stage or where they are in treatment and whether their disease is curable or not.

In a true outpouring of the heart, Torres authored a piece titled "The Call for Courage Bell," now displayed at each bell

The Call for Courage Bell

I ring this bell as a symbol of perseverance

It takes a great deal of strength and dedication to walk through these doors and accept this journey as the new normal.

I ring this bell for my fellow patients

For those who have walked, are walking or will walk the journey of a cancer diagnosis.

I ring this bell in celebration of the little victories and the big victories

Receiving good news, reaching that milestone at the end of treatment or just celebrating that today is a good day.

I ring this bell to say thank you to my family and friends

It is not alone that I could have done this, or continue as such. It is coupled with the love and devotion that my family and friends have provided through this often very difficult journey.

I ring this bell in appreciation of the staff

It takes a special team to provide care to patients during this time. The medical and ancillary staff has been constant in their care delivery throughout the process.

I ring this bell as a symbol of acceptance and faith

I cannot control what the future holds but I am thankful for today.

Author: Mayelin Torres, MKC Infusion RN

across all of Moffitt's campuses. "I had my mom and all of my patients in mind when I sat down to write this," she said.

The piece embodies just what Stanfield wants to share with the world around her. "I have a terminal diagnosis. But I'm going to celebrate every day or every month I'm given."

"Maybe this is long term, but every day you sit in these chairs, you have the strength to do that," Torres adds. "That bell can bring forth some freedom. Understand that every day is a victory."



Jukka Rasanen, MD

Photography: Nicholas Gould

INESTIMABLE GRATITUDE

Medical Missions Trips Alter Life Focus

By Cathy Clark



Photography: Nicholas Gould

David Thrush, MD (R), with Dr. Rasanen

A SIMPLE FAVOR CAN UNEXPECTEDLY TURN ONE’S LIFE FOCUS. IT HAPPENED TO JUKKA RASANEN, MD, WHEN A COLLEAGUE AT MAYO CLINIC ASKED RASANEN TO FILL IN FOR HIM BACK IN 2004.

“Randy Flick [Randall Flick, MD], who is now the director of the Mayo Clinic Children’s Center, was working with Smile Network International. He was signed up to go to Querétaro, Mexico, and couldn’t, so I went in his place and have been going [on medical mission trips] ever since,” said Rasanen.

It seems relevant that Rasanen’s early volunteer outreach service was with Smile Network, as he originates from and earned his medical degree in Finland, named the world’s happiest country in 2019. During his work with Smile Network, he was among those providing life-altering reconstructive surgeries and related health care services to impoverished children and adults in developing nations. Many of the surgeries were to correct cleft lips or cleft palates. Now vice chair of Moffitt Cancer Center’s Department of Anesthesiology, Rasanen formerly served at Mayo Clinic in numerous capacities within the Department of Anesthesiology.

Since that first unexpected trip to fill in for his colleague,

Rasanen has been on numerous medical mission trips – one or two per year – and served as medical director for Smile Network International from 2007 to 2010. Another life-altering event took place, ultimately as a result of going on that first trip. He met his wife, Gina, through Smile Network when she was the mission coordinator. She now works remotely for Mayo Clinic.

‘NOW I CAN KISS!’

When asked about especially touching moments during his mission trips, Rasanen reflected, “Well, it’s all touching.” After a short pause, he continued, “There was a lady in her 60s who had a cleft lip for all her life. And then she got it repaired and she said, ‘Now I can kiss!’ ”

Recalling another patient, Rasanen described how a mother walked for a full day with her 2-year-old son before arriving at the hospital where he was working on one of his trips. The child had a cleft lip and a cleft palate. “We just had a cancellation due to infection in a patient, and so we were able to just take that patient. He had not had anything to eat, so he could be anesthetized and both his cleft lip and cleft palate could be fixed within a day,” Rasanen

said. “It all fell into place.” In the western world, all kinds of paperwork must be completed in advance, so a surgery like that just doesn’t happen within one day, he noted. “This was in Peru, and the mother was as amazed as we were.”

Over the years, Rasanen has volunteered primarily with three medical missions organizations. In addition to Smile Network International, he traveled through a program at Mayo Clinic in which he went on seven surgical missions to Hanoi, Vietnam. Currently, he has planned most of his medical mission trips on his own to Kenya, where he has gone almost every year for the past eight years.

While the Smile Network involved surgeries to correct cleft lip and palate, this condition is less prevalent in the African population. In Kenya, Rasanen’s work has focused primarily on treating older children and adults with burns. A substantial proportion of the population of people treated through medical missions there live in substandard housing where cooking typically is done over an open fire, resulting in many burns. Open cooking areas pose a danger for children playing and running nearby, and even for adults, he noted.

“There is little appropriate care for burn patients,” said Rasanen. “They don’t have much money, so they end up with these contractures requiring special care.”

“There was a lady in her 60s who had a cleft lip for all her life. And then she got it repaired and she said, ‘Now I can kiss!’ ”

CARE FOR BURN PATIENTS

Scarring after serious burns can lead to a contracture in which the normally elastic tissues are replaced by fiberlike tissue that does not stretch. Contractures often are painful and they impair normal movement in the affected area.

Basic requirements, such as the availability of blood products, certain medications and sterilization equipment, are essential to safely administer anesthesia or perform surgery. But “not necessarily air conditioning. That is a luxury,” Rasanen said.

PRECAUTIONARY DETAILS

Rasanen cautions anyone considering going on a medical mission trip for the first time. “Be careful who you go with. Make sure that the organization or the people who arrange the trip know what they are doing, that they have done their homework, and that it is a safe place and they have the proper equipment.” After those precautionary details are dealt with: “Just go!”

Gina has accompanied him on most of the trips to Kenya. David Thrush, MD, chair of Moffitt’s Department of Anesthesiology, has gone with Rasanen to Kenya, as has

“It’s a real privilege to be able to participate.”

Robert Gabordi, MD, a breast surgeon with St. Joseph’s Hospital-Tampa (Dr. Gabordi is married to Moffitt certified registered nurse anesthetist Tracie Gabordi). Rasanen said on average 10 participants accompany him on the week-and-a-half-long trips to Kenya, and these volunteers pay all their own expenses.

“Dr. Rasanen does an amazing job of planning and organizing the trip; it makes it easy,” said Thrush, who helped with the education of students studying medicine in Kenya. “It’s a real privilege to be able to participate.” Thrush says he was amazed at the dedication of all the students and medical staff in the hospital. Additionally, it was meaningful to have been part of a mission to help severely burned patients. “It’s also a very rewarding trip with unforgettable memories. Lastly, Africa is beautiful.”

Having staffed many such trips, Rasanen has drawn some conclusions about the people who commit to such volunteer work.

“There are people who will say no when you ask them. And that’s fine.

“And there are the people who say yes but don’t really want to go; they think they are supposed to say yes, and they come up with an excuse two weeks before it is time to go. That is the most difficult group to handle because then you have to replace the person with short notice.

“And the next group of people are the ones who go once and they think they’ve seen it all, and they don’t want to go again.

“The next group of people go more than once but only to a place they haven’t been before; they are the ‘tourists.’

“And then there are the ones that go on one trip and they can’t be without it. They always go back.”

Clearly, Jukka and Gina Rasanen, along with many of those who accompanied them, are among the last group of committed supporters.

The inestimable fulfillment recompense from the work itself is what most attracted Rasanen to this volunteer outreach work. “It helps you understand that the skills you have are invaluable. When you get a paycheck, it puts a price on your work. But there you see that the patients and their families are grateful, immensely grateful. They don’t give you money. They give you their gratitude, and that’s [worth] more than the money that you get with your paycheck.”

“It helps you understand that the skills you have are invaluable. When you get a paycheck, it puts a price on your work. But there you see that the patients and their families are grateful, immensely grateful.”

MILES FOR MOFFITT IS FOR EVERYONE!



2019 Participants Run, Walk to Help Cancer Research and Raise Awareness

By Cathy Clark

THOUSANDS OF RUNNERS AND WALKERS will make their way through downtown Tampa for the 14th annual Miles for Moffitt presented by AutoNation on Saturday, Nov. 23. Their common goal? To inspire courage and beat cancer. They will help Moffitt Cancer Center researchers take the next step toward new discoveries in cancer research.

Participants and supporters of the first Miles for Moffitt event in 2006 raised \$55,000. The proceeds that first year funded the work of two researchers, each with a \$27,500 grant. From its humble beginnings through today, all proceeds continue to go directly to cancer research at Moffitt.

The first event, held on the University of South Florida campus, drew 1,200 participants. By 2018, the race had expanded to 5,800 loyal participants who helped raise \$1.1

million. Last year, the race moved to downtown Tampa to accommodate the growing number of people who come out each year to enjoy the family-friendly community event.

The Miles for Moffitt 2019 goal is to draw 7,500 participants, noted Maria Muller, executive vice president, chief philanthropy officer and Foundation president.

“I think the race is important, not just because of the money raised, but also the awareness of cancer among the public, and the opportunity to highlight prevention and actions people can take,” said Muller.

Muller joined Moffitt in late 2018, and Miles for Moffitt was her first cancer center event. She noted the event is important because it enables people to make gifts at a wide range



“It allows Moffitt to fund cutting-edge research studies that may not otherwise receive funding independently.”

Photography: Donald Klotz



Maria Muller

of levels that result in funding lifesaving research.

“I think the progress is about time and money. It’s about enabling scientists and clinical researchers to have the time to do their research and money to support that,” said Muller. “The more money we are able to raise,

the more we are able to help our researchers so diligently searching for the next new treatment and cure.

“Anyone who is thinking about making a donation should not underestimate the importance of their single gift because in aggregate, it actually has such a huge impact. If everybody in Tampa Bay, Florida and beyond contributed, we could have an even greater impact. We can make real headway in the prevention and cure of cancer with everyone’s support.”

The money raised through Miles for Moffitt funds multiple pilot research studies annually. It allows Moffitt to fund the cutting-edge research studies that may not otherwise receive funding independently. “That makes it especially valuable because the money raised through this event supports research priorities throughout multiple disciplines, making it very impactful,” said Muller.

WHERE THE MONEY GOES

From 2006 through 2017, 56 pilot research studies have been awarded totaling more than \$3.8 million. Project funding from the 2018 race proceeds will be awarded in October 2019. This funding helps researchers gather preliminary data and develop their discoveries into a proposal that has greater potential to be funded by grant agencies that generally look to fund more established projects. Over the past 13 years, these Miles for Moffitt pilot studies have gained more than \$18 million in additional grant agency support, all set into motion by our participants, sponsors and donors.

Below is a sampling of some of the research accomplishments since the initiation of the first Miles for Moffitt event. It is sobering to imagine what lifesaving findings might not have been discovered without this funding. And it is encouraging to imagine what these and other grant recipients will discover in the years to come.



Jong Park, MS, MPH, PhD, a recipient of one of the first awards in 2006, says the \$27,500 award funded his research to find genetic biomarkers to predict individual risk for prostate cancer and to determine treatment plans based on predicted prognosis.

“This award helped me to obtain promising preliminary data, which led to a large National Institutes of Health-supported epidemiological study for prostate cancer,” said Park. The award also led to 78 published papers on biomarkers of prostate cancer.

“Most prostate cancer progresses relatively slow. Therefore, a long period of patients follow-up is critical for epidemiological studies,” said Park. “This award helped to build a large prostate cancer patient cohort, which allows us to follow patients’ clinical history for a long time.”

For **Stephanie Schmit, PhD, MPH, and Christine Pierce, PhD, MPH**, the \$100,000 awarded in 2016 from the 2015 event provided seed funding to get a new collaboration between the two junior Moffitt investigators off the ground.

Schmit and Pierce now are expanding their Miles for Moffitt-funded pilot study on “Microbes in the tumor microenvironment: bacterial influences on host immunity and prognosis in colorectal cancer” through funding from an external collaborator as they generate and analyze the rest of their data.

Their study was designed to understand more about the relationship between colorectal cancer cells, immune cells and bacterial cells residing in and on the tumor microenvironment, with the aim of evaluating whether the presence and abundance of certain bacteria impact patients’ prognosis.



Ultimately, they hope to learn how altering the bacterial landscape could contribute to slowing the development and progression of cancer as well as to modifying response to immune-based cancer therapy.

“The funding climate is difficult right now, and sometimes the higher risk but potentially high reward projects are challenging to get funds to conduct,” said Schmit. “Miles for Moffitt allows for investment in our local researchers who have exciting and out-of-the-box ideas to pursue that may not be easily funded through other mechanisms.”

Eric Lau, PhD, says the \$100,000 Miles for Moffitt award granted in 2015 for the research project “Roles of fucosylation in melanoma: immune cell biology” allowed him to hire a doctorate student and a research associate, significantly expediting the research. Lau and his team proposed to determine the specific type of immune response that fucose, a naturally occurring sugar, triggers to suppress melanomas, as well as to identify how this happens at the molecular level.



“In the long term, our goal is to determine how fucose can be administered as a new, safe and affordable anti-melanoma therapeutic agent,” said Lau. “Together, we have discovered that fucose modifies one type of cell surface protein in melanoma cells. The decoration of this protein with fucose triggers a very specific type of T cell-mediated tumor-suppressing immune response. In addition, we have developed a new technique for visualizing specific sugar-modified proteins by microscope – a previous technical challenge for the field of sugar biology.”

Since completion of the award, Lau’s team has made major molecular and cellular findings that have extended beyond the initial scope of the project proposal. “Our findings have been featured on the international stage at the 2018 International Congress of the Society for Melanoma Research.”

Basic biomedical research funding is extremely competitive at the state and federal levels. “Most funding applications require significant data, and thus, it is very difficult to find funding for pilot/starting projects, such as our project when it first began,” said Lau. “Miles for Moffitt funded our at-the-time pilot project, which helped it to quickly grow into a large-scale project that was awarded a five-year National Cancer Institute grant.”



“The Miles for Moffitt grant was integral to my success in obtaining federal funding for ongoing research.”

Photography: Donald Klotz

A \$40,000 award granted in 2012 from the 2011 event allowed **Katarzyna (Kasia) Rejniak, PhD**, to develop a mathematical model that laid the foundation for a new area of research: micropharmacology.

“This concept allows for investigating how chemotherapeutic agents distribute within the tissue and how they interact with tumor cells,” said Rejniak, about the collaborative project between her dry lab and Damon Reed, MD.



Using mathematical modeling, the investigators simulated combination treatment of two drugs that target different cell-cycle checkpoints. “We showed that in three-dimensional in silico culture, the incorrect order of

administered drugs may result in tumor regrowth, when in the Petri dish experiments in this order showed no adverse effects. This showed the importance of testing drug effects in the cultures that resemble clinical tumors,” Rejniak said.

As a result of the research performed due to this funding, Rejniak published two papers in collaboration with Reed and additional papers related to micropharmacology principles with Moffitt researchers David Morse, PhD, and Robert Gillies, PhD. Additionally, the micropharmacology model was employed in several funded awards, including a National Institutes of Health-funded U01 Physical Sciences Oncology Project grant.

“The Miles for Moffitt award allows researchers to try high risk, high reward ideas and to collect data for external funding,” said Rejniak.

In 2014, a \$100,000 Miles for Moffitt award for a project called “Survivin vaccine for multiple myeloma” allowed **Frederick Locke, MD**, to initiate a 10-patient clinical trial utilizing a Moffitt-created vaccine against a target called survivin.



When survivin is found in myeloma cells, it is predictive of worse outcomes, resistance to chemotherapy and shorter survival. The hope was the vaccine against survivin could potentially improve the outcomes of myeloma patients by administering it in conjunction with an autologous stem cell transplant.

After treating the first two patients, the trial was expanded based on the early results. “We have treated 14 patients on the trial, and we now are finishing the manuscript describing those results,” said Locke.

In 2015, Locke received a five-year National Cancer Institute grant that is allowing continuation of the work. “Getting the NCI grant was built upon doing the trial,” said Locke. “The Miles for Moffitt grant was integral to my success in obtaining federal funding for ongoing research.”

That initial work with the survivin vaccine, a cellular immunotherapy, also helped lay the foundation for Locke to continue research in cellular immunotherapies. More recently, Locke has been doing much work with CAR T, another cell-based therapy. “Although the Miles for Moffitt grant was not centered on CAR T, the funding helped to build momentum in order to continue research in cellular immunotherapies.”

Additionally, Locke received the National Cancer Institute's 2016 Cancer Clinical Investigator Team Leadership Award in recognition of outstanding contributions to the NCI clinical trials program. The award was based upon work with the survivin vaccine and CAR T.

"I think the Miles for Moffitt event is hugely important to the advancement of cancer research," said Locke. "It brings together people from Moffitt and the community, including employees, patients, their families, and their social circles, to celebrate our unity and singular focus on the fight against cancer. Importantly, the event raises awareness and the money necessary for the Miles for Moffitt awards to support early research."

HONORING A BELOVED AUNT SPURS MOTIVATION TO HELP FIND CURES

Ever since brothers Marco and Luis Echeverry started Team DrivenFit 11 years ago, they have participated in Miles for Moffitt. So far, their team has raised \$13,333. Their goal for the 2019 race is to raise \$10,000 and double the 25 team members from last year.

Why do they do it? "While raising money for cancer research is important to us, participating in Miles for Moffitt has always been about raising awareness of this great cause," said Marco, team captain.

In 2008, Marco and Luis moved to Tampa from New York to start their business, Driven Health and Fitness Services, also known as DrivenFit. That same year their beloved Aunt Frances was diagnosed with cancer and admitted to Moffitt. "Unfortunately, she passed away from the cancer, but our experience at Moffitt made a lasting impression," said Marco.

Luis reflects on that time. "We were new to the area, but we got to know Moffitt really well through what we were dealing with regarding our family. At the same time, we were trying to start a business, and I had just gotten out of the military. We wanted to find a way to cope with what we were all going through, as well as to share with some other people who maybe were impacted by a similar experience with a family member."

"When we learned about Miles for Moffitt, we knew we had to participate and give back to the cause," Marco said. "It helped us to grieve, but it also motivated us to do our small part to help find a cure so that, hopefully, no one else would have to face cancer like our aunt."

Since then, the Echeverry brothers have experienced the loss of their grandfather to cancer, and more recently, their stepfather was diagnosed with throat cancer. They are happy to say their stepfather now is cancer free, following

chemotherapy and radiation treatment at Moffitt. "Everyone there from the valet to the front desk, nurses to doctors, all treated us like family," said Marco.

In the business of fitness, which aims to help people achieve their best, the brothers could be described as encouragers. And they seem to find their own encouragement in seeing cancer survivors at the event and in getting their clients and the community involved in the race. "We offer several donation-based boot camps and fundraising bake sales leading up to the event. And new this year, we are creating a fun field day event with all proceeds benefiting Moffitt," said Marco.

They appreciate connecting with others who understand what it's like to lose a loved one to cancer or who has fought a personal battle with the disease and won.

"While raising money for cancer research is important to us, participating in Miles for Moffitt has always been about raising awareness of this great cause."

"On the turnaround they had last year, you'd see people you know or you'd see people cheering you on," said Luis. "It felt good, and we could almost feel the spirit of our aunt." Because of Miles for Moffitt, they feel closer to both their aunt and grandfather. "We are determined to do everything we can to continue to support this great cause."

They encourage their team to reflect a bit the night before the race on why they are participating. "If they are running for anyone and dedicating the race to anyone, we encourage racers on our team to take a marker and write the name on their wrist or arm somewhere so that while they are running they can have something to look at and reflect upon so they can push a little extra," said Luis.

NOT A RUNNER? NO PROBLEM.

The message they want to convey is that Miles for Moffitt is for everyone.

"You can walk, run, or jog, but the most important thing is being out there with everyone," said Marco. There are options to be a virtual runner or to support another person who is running or walking or to support one of the teams. "Cancer unfortunately does not discriminate. But being out there with cancer patients, cancer survivors and families is a way to lift people's spirits and also honor those affected by cancer. And we will never forget those who we've lost."

“You can walk, run, or jog, but the most important thing is being out there with everyone.”



Brothers Marco (left) and Luis Echeverry

Courtesy of Marco and Luis Echeverry



Photography: Chris Zuppa

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Join us at the 2019 Miles for Moffitt
Amalie Arena's Ford Thunder Alley
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For registration information, visit
www.MilesForMoffitt.com

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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.

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To contribute to the prevention and cure of cancer

VISION

To transform cancer care through service, science and partnership

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Notable

The Kay Yow Cancer Fund granted \$100,000 for ovarian cancer research to Moffitt immunologists Paulo C. Rodriguez, PhD, and Jose R. Conejo-Garcia, MD, PhD. Conejo-Garcia, who chairs Moffitt's Department of Immunology, voiced the expectation that research funded by this grant ultimately will result in the first FDA approval of a CAR T therapy for solid tumors, thus making the immune system more effective in ovarian cancer patients as well as resulting in increased effectiveness through better targeting strategies. New therapies for ovarian cancer are needed because the disease often is diagnosed at an advanced stage.

Moffitt and AdventHealth are expanding cancer care in the Tampa Bay area and will open a new Moffitt outpatient center on the campus of AdventHealth Wesley Chapel in Pasco County. The new center opens in fall 2020 and will provide medical and radiation oncology services and is designed to accommodate 20 exam rooms, 22 infusion stations and two linear accelerators. Cancer screenings and survivorship programs geared toward patients who are post-treatment and in remission will also be available.

Once again Moffitt Cancer Center is No. 8 on U.S. News & World Report's Best Hospitals for Cancer rankings. The ranking solidifies Moffitt as the best cancer hospital in Florida and top ranked in the Southeast. Moffitt has been included in the annual Best Hospitals list for 20 years in a row.

Moffitt moved up in the ranks to No. 3 on DiversityInc's 2019 list of Top Hospitals & Health Systems. This is the fourth year in a row that Moffitt was recognized by the organization and the highest the cancer center has ever ranked on the list.

Visit [MOFFITT.org](https://www.moffitt.org) to find out about our upcoming events

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