



thrive

Tina Reuben saw a clinical trial as a way to move knowledge of her rare cancer forward.

Empowered

Also: How to find your purpose; the impact of fundraising

thrive



THIS ISSUE'S THEME

Giving Back

We outline the diverse ways patients can contribute to the cancer community.



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by Leisa Thompson

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Elevating Care

The cancer center's already renowned prostate cancer care gets a boost from a generous gift.

By Mary Clare Fischer

University of Michigan Regent **Ron Weiser** has committed \$30 million to Michigan Medicine to elevate and optimize the health care experience for patients with prostate cancer and their families.

The Ronald Weiser Center for Prostate Cancer will invest in staff, infrastructure, technologies and education as well as research into the disease and its treatment.

"The goal is to make this center the easiest and best place to be treated for prostate cancer in the country, if not the world," says **Ganesh Palapattu, M.D.**, the George F. and Sandy G. Valassis Professor of Urology and the chair of the Department of Urology at Michigan Medicine.

The center will draw on the already immense resources of the Rogel Cancer Center's renowned prostate cancer program, including state-of-the-art urology, radiation oncology and radiology programs; multidisciplinary prostate cancer clinics; cutting-edge technology; highly sought-after training opportunities and a robust research program that seeks to improve the diagnosis, treatment and survivorship of prostate cancer.

"We have more than a critical mass of providers, investigators, educators and thought leaders in the field," Palapattu says. "This center is going to be the mortar that keeps all those bricks together."

A portion of the money will be used to recruit and retain more trainees and faculty, including those who are underrepresented in the field of prostate cancer. The gift will also fund advanced equipment and materials that will further the center's approach of using precision medicine to diagnose and treat patients.

"With this gift, we can increase timely and convenient access to the latest technology and treatments that will allow us to provide

a superior experience for our patients, regardless of means," says **Vikas Gulani, M.D., Ph.D.**, the Fred Jenner Hodges professor and the chair of the Department of Radiology.

Weiser, one of the university's top donors, was diagnosed with prostate cancer in 2019, and the experience caused him to reflect on how he could help combat the country's second-leading cause of cancer-related death among men.

"I'm grateful for the excellent care at U-M that has helped me fight the cancer that invaded my body," Weiser says. "But going through this has made me realize more could be done to support so many other men and their families who face this terrible disease, too."

Weiser will work with Michigan Medicine on fundraising efforts for the new center and encourages others to join him in supporting this transformational initiative. 

Resources

► Learn

rogelcancercenter.org/prostate-cancer

► Meet

rogelcancercenter.org/prostate-cancer/prostate-cancer-team

► Give

michmed.org/j8j9d

I've Been There

A cancer researcher reflects on his personal experience with cancer and its impact on his work.

By Mary Clare Fischer

When **Bradley J. Zebrack, Ph.D., M.S.W., M.P.H.**, was 25, he thought he might become a schoolteacher. Then he was diagnosed with Hodgkin lymphoma, a cancer that originates in the immune system. In an effort to cope, Zebrack went to a meeting of what would eventually become the well-known support network Cancer Support Community. He remembers being fascinated by the social worker who facilitated the group.

"I had this lightbulb moment," Zebrack says. "I could see myself doing that kind of work."

Decades later, Zebrack, a professor of social work at U-M, has served as not only a teacher and a social worker but also a researcher who studies the effects of cancer on the growth and development of adolescents and young adults. In a recent editorial, he outlined how his experience as a cancer patient has led to and influenced his work.

"I've always been very clear that I'm doing this work because I just want to help people with cancer," Zebrack says, "because I know that cancer sucks."

We spoke with Zebrack to hear more about the lessons he learned from his own cancer and how he's used them to redefine the health care experience for patients.

Q: What was a moment during your experience with cancer that affected how you think about your work now?

I go back to when I first started hearing the term "positive attitude."

The story I sometimes tell is I would go for chemotherapy, then afterwards get into bed and pull the covers over my head



and endure a couple of days' worth of nausea. (This was 1986, before Zofran.) After those initial waves would pass, I'd be able to lean over and turn on the radio. Eventually, I felt a little bit better, and I could walk down to the kitchen and get myself something to eat. Instead of worrying about what I wasn't able to do, I had to flip that and think about what I was able to do in that very moment. I had to reframe those experiences.

I think that translated into my work later to think about strength and resilience. How did I find that in myself? How do we elicit that in our work with cancer patients and their families to try to figure out, while you're going through this very traumatic experience, what resources do you have available to cope? How have you dealt with challenges in the past? If you've been successful in the past, how can you translate that into now successfully managing and adapting to cancer, so you can move forward in your life?

Q: Is there anything you remember a provider or family member saying to you during your cancer experience that was intended to be hopeful and helpful but wasn't?

I had an aunt who I loved very much. She was a big part of my life, before, during and after cancer. Sometimes, she would

Dr. Bradley Zebrack parlayed his experience with cancer as a young adult into research on the psychological, behavioral and social issues that arise for adolescents and young adults who are diagnosed with cancer.

come over and try to hustle me into a corner and say, “So, how are you really feeling?” as if she was trying to get the real story. It felt like more pressure to me, especially because I wasn’t hiding anything.

Where that experience played out in my work is an understanding of the emotional impact of cancer for young people. At 25 years old, you’re barely a few years into learning how to deal with the adults in your life as adults. You don’t have much experience managing your own emotions let alone having to carry the emotions of others. It’s difficult to figure out how to respond and to carry that burden when it gets unloaded on you, especially from people you love.

Q: In your editorial, you discuss the impact of meeting a man who’d had cancer at a young age, like you, and was doing well years later. Why is having a role model important for young people with cancer?

Particularly for a younger population, they’ve been having hopes and dreams and thoughts about what they want their future to be. To have cancer disrupts that; you’re then left as a young person with no vision of what your life might look like with cancer or after cancer.

But even people in their older years still have hopes and dreams for the future. They want to be around for their granddaughter’s wedding or to take that long-awaited vacation. Without a vision of a future reality, our brains fill in the gaps with information that tends to be negative, even catastrophizing. And that’s scary. So it’s important to seek out people who can serve as an example of who you could be after your cancer treatment. ☐

Resources

General

cancer.gov/types/aya

Michigan Medicine

► Patient care

michmed.org/AYQ9V

► Research

michmed.org/mVDZN



Additional Resources

American Cancer Society Michigan

cancer.org/about-us/local/michigan.html

Cancer Support Community Greater Ann Arbor

cancersupportcommunity.org/location/cancer-support-community-greater-ann-arbor

Gilda's Club

gildasclubdetroit.org

gildasclubgr.org

Leukemia & Lymphoma Society Michigan-Indiana

lls.org/mi-in

Michigan Breast Cancer Coalition

mibcc.org

Michigan Ovarian Cancer Alliance

mioca.org

National LGBT Cancer Network

cancer-network.org

Pancreatic Cancer Action Network - Michigan

facebook.com/groups/pancanmichigan/

Sisters Network Greater Metro Detroit Chapter

michmed.org/3AW3y

Teen Cancer America

teencanceramerica.org

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to get involved with:







Peer to Peer

Steve Keating's end-stage colon cancer means he has limited time left. He's using those days or weeks or months to share his knowledge of the cancer experience with other patients.

**By Mary Clare Fischer
Photographs by Erica Bass**

Steve Keating knows how it feels.

He knows what it's like for your hands to tingle from oxaliplatin. He knows the sensation of sweat pooling in every pore, the watering of the eyes, the running of the nose while irinotecan is infusing into your veins. He knows that providers tend to counteract those side effects with atropine, which makes the skin become dry and flaky, like you just walked through a windblown desert.

He knows how compassionate the nurses at the Rogel Cancer Center can be. He knows how hard the physicians will try to save your life.

Most of all, he knows how it feels to face your own mortality and to keep pushing, to keep giving, with the time you have left.

Steve is 46. He has undergone multiple surgeries and several different kinds of chemotherapy to treat his colorectal cancer. Despite the "wonderful nursing staff and doctors and overall fantastic human beings" at Rogel, Steve will likely die of his cancer or a related complication. He might be alive for a few more days or a few more years. It's difficult to know.

But Steve knows he wants to use that time, however long it is, to give back. He has recently joined the cancer center's Patient and Family Advisory Committee as well as its diversity, inclusion and justice group and hopes to become a peer mentor to, as he says, "offer straight talk from someone who's been through it."

"I want to inspire and help patients, particularly new ones," Steve says. "I don't know how much time I'm going to have, so I would really like to get moving and try to help some folks."



Steve's wife and two children have supported him through aggressive cancer treatment.

'I'm still here'

He found out because of a kidney stone.

That's why Steve went to the emergency room in March 2019. When his imaging showed a faint shadow on his colon as well, he scheduled what turned out to be a very short colonoscopy — as it was evident that Steve had a large, aggressive tumor. CT scans shortly afterward showed that the cancer had spread to his liver, too, despite his lack of symptoms.

Colorectal cancer has surged in younger adults over the past few decades: diagnoses under age 50 have more than doubled since the 1990s. Many of these people will live for quite some time after their treatment; in fact, one recent study found that the majority of those with early-onset colorectal cancer tend to live for at least a decade after diagnosis.

But that's only if their cancer is at an early stage when it's discovered. When the cancer has spread beyond its origin, like in Steve's case, patients often grapple with shortened lifespans.

At the beginning, though, there was hope. Seventeen days after his diagnosis, Steve had surgery to remove the tumors, followed by several months of chemotherapy for good measure. In December 2019, he was declared cancer-free, although he would need scans every three months to confirm the cancer hadn't returned.

"It was like, 'We've got this,'" recalls Lisa Keating, Steve's wife. "We're going to do exactly what they say, and you're so young, so this will be fine."

But by March 2020, the cancer had spawned in Steve's liver again.

Since then, it's been a cycle of hospital visits, chemotherapy sessions and operations, including one to implant a hepatic

artery infusion pump, which sends chemotherapy directly to the liver instead of infusing it through the veins.

John Krauss, M.D., the medical director of Rogel's Multidisciplinary Colorectal Cancer Clinic and Steve's oncologist, was honest with Steve and Lisa from the start.

"In terms of prognosis, I think you can't hit people over the head with it," Krauss says. "My message to the Keatings was, 'Our goal is to put you into remission but, in your case, we probably won't put you into remission, so you'll be on lifelong treatment.'"

The couple appreciated the transparency.

"I don't have enough good words to say about Dr. Krauss," Lisa says. "He really seems to care about the patients, but he doesn't sugarcoat it either. If there wasn't a solution, he told us that. There wasn't false hope given."

As Steve started meeting with his accountant and financial planner to make sure his family could access his life insurance and pension in the future, he felt comforted.

"It's difficult," Steve says. "There's lots of tears and downtime and decent dark spaces. But it's also been a boon for the most part because we weren't ready — who's ready for that to happen? And now it's all ready to go."

At the same time, it was important to Steve to keep living as normally as he could, while he could. He, Lisa and their teenage son and daughter continue to take vacations whenever possible, with Krauss weighing in on what's safe given the pandemic and the status of Steve's health.

And Steve is still working as a material flow engineering supervisor for Ford Motor Company, often texting and emailing



Steve and his family love to travel, and they continue to do so whenever their physicians sign off. Important family dates get the artistic treatment.

on his work phone from the infusion area.

“It can be done, for sure,” Steve says. “I’m still here.”

Surrounded by like minds

It began to occur to Steve that the nuances of his experience might be useful to share with other patients, particularly new ones. Once, when he overheard another man next to him at the cancer center “hemming and hawing” about the same chemotherapy regimen Steve was taking, Steve pulled the thick tan curtain separating them aside.

“If you have any questions, let me know,” Lisa recalls Steve telling the patient. “I’ve been through this before.”

The man, she says, was thrilled.

Get involved at Rogel

Apply to be on the Patient and Family Advisory Committee

What: A group of patients, family members, providers and staff convene via Zoom once a month for an hour and a half to develop education and communication materials for patients, generate new program ideas, enhance ongoing collaboration and cooperation among providers, patients and families, and more.

► If the time commitment is too much, e-advisers are also needed to review and comment on patient education materials and provide input on various topics through electronic surveys.

How: Call or email the Michigan Medicine Office of Patient Experience at 734-764-1202 or patient-experience@umich.edu for more information.

Become a peer mentor

What: Former patients receive extensive training to provide information and one-on-one guidance and emotional support to patients who have experienced a serious health issue. Current programs include bone marrow transplant, radiation oncology and head, neck and throat cancer peer mentors.

How: Email the relevant coordinator; find the list at michmed.org/zQgBg

“That gave Steve a real sense that he could use his experience in a good way,” Lisa says.

Steve inquired about how to volunteer and eventually became part of several cancer center patient groups, including the Patient and Family Advisory Committee, which focuses on improving the patient experience.

When he called into his first PFAC meeting, there were about seven other people on the Zoom call. Five or six had also been through cancer.

He described the sensation as akin to the first time he got off a plane in Ireland and realized that a good half of the people there had red hair like him. He no longer felt like the only red-head — or person with cancer — in the crowd.

“I knew the committee members truly understood,” he says. “Fortunately for them, they’re not facing early mortality like I am, but they understand the treatment and the trauma of being a patient. These are things you can’t know unless you know.

“That’s what I think I can help others with,” he continues. “People have enough going on with their cancer diagnosis. Knowing that someone’s been through it might give them an extra lift.” ☑





Do Unto Others

Adrenal cancer is diagnosed in one in every million people — and research studies to test new treatments for it are just as rare. But Tina Reuben was the first patient in one of the few clinical trials for the disease and hopes that her involvement can help other patients with adrenal cancer live longer.

By Mary Clare Fischer



When a doctor told Tina Reuben she had cancer, she was alone.

It was May 2020. Five days had passed since Tina had checked into the emergency department at University of Michigan Health-West, her potassium levels extremely low, her blood pressure so high she'd worried about having a stroke.

She had tested positive for COVID-19 and was in isolation, waiting as her providers investigated whether something else was going on with her body. The hospitalist on call had gone home for the night by the time the results of Tina's CT scan came through. But he came back in at 9:30 p.m. to tell her about the large tumor he'd seen on her imaging.

The mass was an adrenocortical carcinoma, a cancer in a gland on top of the kidney.

This cancer is so rare that it's diagnosed in about one in every million people in the country. Clinical trials — research that tests novel strategies and techniques to prevent, detect and treat disease — for adrenocortical carcinomas are scarce. And even if these tumors are treated successfully, the likelihood that they will recur is high.

Tina called her husband, Terence, over FaceTime to tell him what was going on. Visitors weren't allowed at the hospital, and it was frustrating that Terence couldn't hold Tina like he had through more than 20 years of marriage.

"It was a horrible experience to be by yourself to find this out," Tina says.

But, later that night, the Bible verse Jeremiah 29:11 came to her: "For I know the plans I have for you, declares the Lord. Plans to prosper you and not to harm you, plans to give you a hope and a future."

Tina wrote the scripture on the whiteboard that hung on her door. When her nurse, **Cassie McAlister, R.N.**, came in, she noticed the words. Tina works as a physical therapist at a U-M Health-West facility, and McAlister knew her as the PT who could always meet a patient on their level. McAlister walked over and erased every reference of "you" in the Bible verse, changing each one to "Tina."

"It's personal," McAlister told her. "He knows the plans he has for you, Tina, not just anybody."

A neighbor of Tina's eventually turned the personalized verse into a painting that hangs in

After more than a year of cancer treatment, Tina Reuben is back to her favorite hobbies, like cooking and spending time with her family, as well as her job as a physical therapist.



Tina's home in Grand Rapids. She looks at it often, marveling at how true its words have felt over the past two years.

Godsend after godsend has shown up for Tina — from thoughtful prayers to an opportunity to participate in a clinical trial at the Rogel Cancer Center — as she's persevered through treatment. She's determined to be one of the few people who can say they don't have adrenal cancer anymore. But she'd also like to make it a less elite club.

"There's not a lot of hope for some people with this," she says. "So if I get benefit out of the clinical trial, wonderful, but if it helps somebody else, even better."

Faith and science

Ryan Hop, D.O., had never seen anything like the tumor that was growing inside Tina. But the U-M Health-West physician thought that someone at the Rogel Cancer Center, two hours east, might have.

He was right. **Gary Hammer, M.D., Ph.D.**, the director of the endocrine oncology program at Rogel, is one of the preeminent experts on adrenal cancer in the world. The physicians connected and, with Tina's agreement, decided it would be best for her to continue her cancer care at Rogel — starting with surgery to remove the tumor.

The choice paid off: Surgeon **Barbra Miller, M.D.**, was able to remove Tina's tumor cleanly with no complications. She may have been aided by the prayers of the Reubens' minister, who drove all the way from Grand Rapids to Ann Arbor to walk around the medical campus during Tina's surgery after he said he felt called to do so.

There was more to be done. Unlike most adrenal cancers, Tina's tumor was diagnosed before it had broken through the thick capsule that encases the adrenal gland or spread to other organs. Yet it was also large and growing quickly, a sign that it could return even after surgery. So Hammer recommended further treatment to increase Tina's chances of staying cancer-free long-term.

Tina had a decision to make. She could receive radiation. Or she could participate in a new clinical trial at Rogel that was testing whether a combination of IV chemotherapy and a medi-

cation called mitotane was more effective than mitotane alone in treating adrenal cancer.

"There is very little research out there for rare cancers in which a trial develops that you can enroll a patient," Hammer says. "That's why we have built our program up to facilitate a research platform to get new therapies to patients."

Tina opted to be part of the trial.

"I believe in science," she says. "I wanted to be part of the trial, if not to help myself, to help someone else in the future, because this is a horrible, aggressive cancer."

Yet the trial hadn't started enrolling patients because of the pandemic, and weeks were passing quickly.

Hammer called a meeting of a Rogel tumor board, a multidisciplinary group of experts that weighs in on treatment plans for cancer patients, to confirm that Tina could wait up to 12 weeks after her surgery to start additional treatment.

But the urge to be proactive was becoming too strong for Tina to ignore.

She decided she was going to start radiation if she didn't hear about the clinical trial that very day. A few hours later, she received the call she'd been hoping for. She was going to be patient No. 1 on the trial.

"It's like everything fell into place the way it was supposed to," Tina says. "I don't really believe in coincidences, and neither does science. But I've been so, so blessed."

The empowered patient

Over the next few months, Tina drove from Grand Rapids to Ann Arbor to undergo several days of chemotherapy four separate times.

Clumps of her hair started falling out. Her brain turned foggy,

Resources

Learn: rogelcancercenter.org/clinical-trials

Find: rogelcancercenter.org/clinical-trials/find-clinical-trials

Call: Cancer AnswerLine at 800-865-1125



Tina has found support not only from friends and family but also from her dog, Milo.

her gut nauseous, but she kept going.

“She felt terrible, but she kept saying that if this clinical trial is going to help someone else, she was going to do it,” Terence says.

Amid the roiling side effects, Tina did research on her disease.

“I’m just one of those people that needs to know everything I possibly can do,” Tina says. “The numbers are the numbers. They don’t say which side you land on, and I’ve decided I’m going to land on the side that survives.”

She shows up to her Rogel appointments with a large pad of paper and a lot of questions. (“Tina worries that she asks too many questions,” says **Beth Hesseltine, N.P.**, an advanced practice nurse for the endocrine oncology program at Rogel, “but, in fact, I enjoy talking to her because she has such good questions.”) Terence keeps a spreadsheet of her lab tests, highlighting values that are outliers or trends.

“What I love about navigating the health care system this way is they’re open to this,” Terence says, noting that the couple’s experience with health care in South Africa, from which they emigrated, was very different. “They want to make the patient feel in control of their health.”

“Health care is more and more of a collaboration between a doctor and the patient,” Hammer says. “This is particularly true in rare diseases, where there are not many options available and where patients are appropriately empowered to be active partici-



pants in their care.

“And Tina does exemplify the empowered patient,” he adds, “who’s advocating not only for herself but for the very field and for all patients with adrenal cancer by spreading awareness.”

On Oct. 28, 2020, Tina celebrated her 50th birthday. A few months before, she wasn’t sure if she’d still be alive. Although she’ll be on mitotane for several more years, she’s currently cancer-free and back to working full-time. McAlister calls her a “walking miracle.”

“No evidence of disease today doesn’t mean there won’t be something tomorrow,” Tina says. “But I do believe God has a plan for me.” ☐

Finding Your Why

In response to tragedy, a U-M professor developed a toolset for creating a sense of purpose.

By Anna Megdell

When **Victor Strecher**'s daughter passed away at the age of 19, the U-M public health professor navigated his immense grief by committing to teach his students as if they were his own children.

He developed new habits and behaviors that helped him show up for his students in the way he wanted, like walking to work, eating healthfully, meditating, getting more sleep and taking better care of himself.

"Doing things with other people in mind, not just for myself, added a sense of meaning and connection," says Strecher, Ph.D., who's also the director for innovation and social entrepreneurship at the U-M School of Public Health. "That perspective gave me a new sense of purpose. It changed my life."

So much so that Strecher's work now focuses on the benefits of purpose, which he defines as a set of goals around the things that matter most in your life.

A strong sense of purpose helps maintain perspective, leads to a greater ability to change your own "emotional weather," as Strecher says, and can predict resilience and growth through difficult times. It also has real health benefits. Studies show that when you control for age, race, gender, income, education, health status and other factors, people with strong purpose simply live longer.

But purpose isn't something that either you have or you don't. Strecher says that a strong sense of purpose blooms from habits, behaviors and tools that can be created and developed. Here are three ways he suggests getting started.

1. Make a list of what matters most. Strecher says the list can be made up of anything — family, friends, causes, pets, etc. What matters is that it's important to *you*. "The act of taking stock and writing down what you value most is the first step of cultivating a sense of purpose," Strecher says. "Clearly knowing what you care about will help you create goals around how you want to spend your precious and finite life."

2. Talk to yourself in the second person. Visualize looking down on yourself with a soft, kind gaze. Tell yourself different phrases that a therapist or friend might say if they were trying to offer support, like "You're under a lot of stress," and "I'm here to help you." Be sure to use the second person, as if you're talking to yourself. Doing so allows you to become your own support system, which Strecher says helps you to see the bigger picture and cope with stress.

3. Think about your legacy. Nobody lives forever. Strecher says that embracing this fact allows us to live in ways imbued with purpose. "Instead of mortality being something we wall away out of fear," he says, "incorporating a worldview that life is finite makes for a more vibrant, fuller life experience." Ask yourself, "What do I want in the time I have left?" and "How do I want to be remembered?" Your answers will help accomplish your goals. ☑

Resources

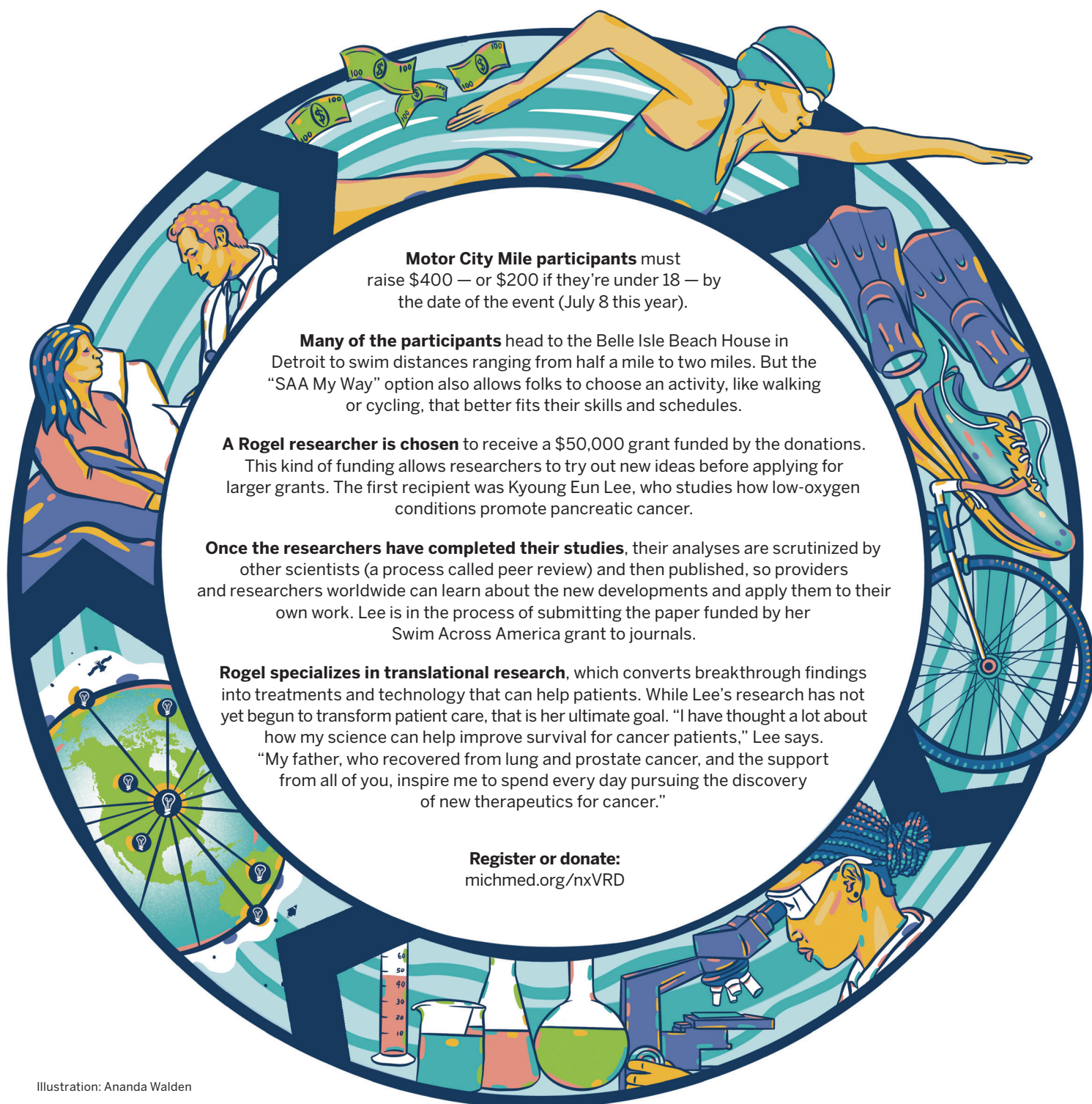
Read

- The graphic novel Strecher wrote after his daughter died: *On Purpose: Lessons in Life and Health from the Frog, the Dung Beetle, and Julia*
- His nonfiction follow-up: *Life On Purpose: How Living For What Matters Most Changes Everything*

Just Keep Swimming

Each summer during Swim Across America's Motor City Mile event, swimmers paddle through the Detroit River to raise money for Rogel cancer research. By funding work that aims to solve cancer's most puzzling problems, they're really investing in their own future. Here, we outline how their dollars (and dolphin kicks) could lead to life-saving results.

By Mary Clare Fischer



Motor City Mile participants must raise \$400 — or \$200 if they're under 18 — by the date of the event (July 8 this year).

Many of the participants head to the Belle Isle Beach House in Detroit to swim distances ranging from half a mile to two miles. But the "SAA My Way" option also allows folks to choose an activity, like walking or cycling, that better fits their skills and schedules.

A Rogel researcher is chosen to receive a \$50,000 grant funded by the donations. This kind of funding allows researchers to try out new ideas before applying for larger grants. The first recipient was Kyoung Eun Lee, who studies how low-oxygen conditions promote pancreatic cancer.

Once the researchers have completed their studies, their analyses are scrutinized by other scientists (a process called peer review) and then published, so providers and researchers worldwide can learn about the new developments and apply them to their own work. Lee is in the process of submitting the paper funded by her Swim Across America grant to journals.

Rogel specializes in translational research, which converts breakthrough findings into treatments and technology that can help patients. While Lee's research has not yet begun to transform patient care, that is her ultimate goal. "I have thought a lot about how my science can help improve survival for cancer patients," Lee says. "My father, who recovered from lung and prostate cancer, and the support from all of you, inspire me to spend every day pursuing the discovery of new therapeutics for cancer."

Register or donate:
michmed.org/nxVRD

Online: See how Michael Dudley transferred his discipline and focus from his triathlon training into his cancer recovery in our original video at michmed.org/mVNNG.

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