

SPECIAL ISSUE

FALL 2021

# MSKNews

MEMORIAL SLOAN KETTERING CANCER CENTER

## WHEN YOUNG PEOPLE *Get Cancer*

Cancer is on the rise in adolescents and young adults. Through a groundbreaking new center, MSK is helping patients like Desiree Allen, diagnosed at 31.

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Memorial Sloan Kettering  
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## Dear MSK Community,

Getting diagnosed with cancer at any age is a blow, but it's particularly hard for someone who had just gotten started in life, only to be forced to put their dreams on hold.

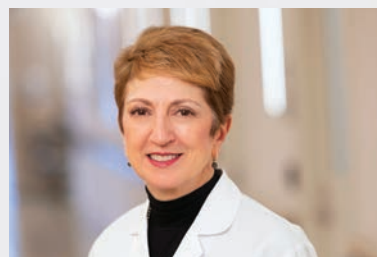
Unfortunately, it's happening more often. Although overall cancer cases are declining, they are on the rise in adolescents and young adults ages 15 to 39. A staggering 90,000 new cases are projected this year alone in the United States. Memorial Sloan Kettering Cancer Center is already at the forefront in this field, treating about 5,500 of these younger patients each year.

This issue of *MSK News* is devoted to our groundbreaking efforts to improve the care of young people with cancer. These patients have not benefited as much from recent advances as those who are younger or older than they are. We must understand why and do better. This is the mission of the new **Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers**. Thanks to the visionary generosity of the Stuart family, this comprehensive clinical and research center, under the leadership of **William Tap** and **Julia Glade Bender**, will transform the experience, care, and outcomes for this often-underserved group.

MSK is uniquely positioned to make a difference because we treat and research cancers in both adults and children. Our program will be one of the first to run digital clinical trials for adolescents and young adults. We will define critical transition points in care — something that's never been done before in a systematic and rigorous way — to track our young patients' experiences over time.

Most importantly, our revolutionary approach will create a plan that goes beyond medical treatment to care for the whole person, offering counseling, nutrition, exercise, and family planning through the use of apps, social media, telemedicine, and more.

We are committed not only to saving more lives but also to helping those lives be full of joy and promise. In this special issue, you will learn how young people can have a future that is not defined by cancer.



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Chief Medical Officer, and  
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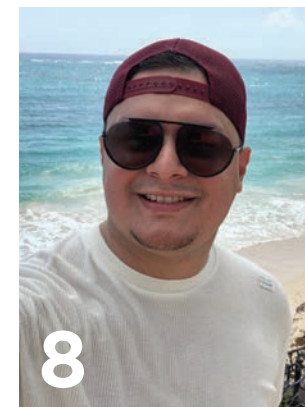


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Learn how MSK is helping young patients navigate their journey and get the best treatment through specialized counseling, digital connections, and more. "The gratitude I feel is so deep. I'm not just alive; I'm living," says Desiree Allen.



## No Longer Left Behind in Clinical Trials

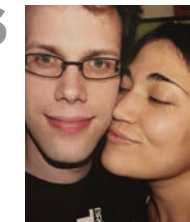
Nearly every advance in cancer care today is possible because of clinical trials. MSK is breaking down the age barrier that has made it hard for young patients such as Irving Romero Torres to participate in and benefit from clinical research.



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The work described in this issue will be expanded and accelerated thanks to the Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers at MSK. For the Stuart family, it's personal.

## BACK COVER Life Beyond Cancer

Meet a few of our brave and determined young patients who are thriving after receiving treatment at MSK.

Our podcast, *Cancer Straight Talk from MSK*, devotes a special episode to adolescents and young adults with cancer.



SCAN HERE TO LISTEN.



# Caught Between Two Worlds

## How MSK Is Connecting to Young People with Cancer

**Before she was diagnosed with cancer in 2020 at age 31, Desiree Allen was living her best life.**

“I was in school part-time and working full-time, and I was — and still am — in a long-term relationship,” says the cardiology nurse, now 32. “As a matter of fact, I was having the time of my life.”

Then she noticed a smooth bump on her knee, but her primary care doctor dismissed it. Cancer is rarely suspected in young people.

“He said, ‘Maybe you’re on your feet too much. Just relax and take aspirin,’” she recalls. “But my gut instinct knew that wasn’t right.”

As a nurse, Desiree knew how to advocate for an MRI, which found a mass. A biopsy revealed Desiree had a cancer of the muscles in her knee known as embryonal rhabdomyosarcoma. Sarcomas are cancers of the muscles and bones.

“The doctors were shocked because it was, like, a one in a million chance,” she says, adding after a pause: “I didn’t want to be this kind of special.”

When a young person is diagnosed with cancer, they can feel lost — too old for pediatrics but decades younger than most cancer patients. In a recent best-selling memoir, *Between Two Kingdoms*, former Memorial Sloan Kettering Cancer Center patient Suleika Jaouad writes about learning from her doctor, at the age of 22, that she had a rare leukemia. “It felt as if he were standing over me with a scalpel, cleaving my life by diagnosis, bifurcating my psyche into separate selves: half of me dancing with a mariachi singer after tequila shots ... making my friends whistle and cheer; half of me crying every night in a sterile hospital room after the visitors had gone home.”

### Helping Young People Navigate Cancer

The unfortunate reality is that recent advances in treatment have not benefited this age group as much as they have others. A key reason: Teens and young adults often don’t have the right kind of support — beyond their families — to get them through the gauntlet of chemotherapy, surgery, and radiation. It’s grueling for anyone — especially for people just learning how to live on their own.

These young people are often facing the usual experiences and challenges their stage of life entails — going off to college, looking for a job, striving for a promotion, going to parties, finding love, and building a family — when cancer upends everything. They often struggle to even imagine a future; they feel stuck, yet they have no choice but to grow up fast.

Supporting these patients so that they not only survive cancer but also live a life beyond it is the reason that MSK created its Adolescent and Young Adult (AYA) program. Researchers from across the institution come together to identify best practices, clinical trial opportunities, and support services for this age group. Now a generous gift will dramatically expand the effort through the **Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers**.

The mission is about more than medical research — it also considers the major milestones young adults experience in their teens, 20s, and 30s.

“It’s such a time of change in anyone’s life, and then to add a medical diagnosis on top of that — it’s even more overwhelming,” says **Rachel Marks, Senior Coordinator of the Stuart Center**. “You are so much more than your diagnosis.”

Working alongside a patient’s primary team, designated nurses and staff are available to meet with patients being treated throughout MSK.

**Social worker Alexandra Russo** asks her patients what’s going on in their lives, and then gets them the support they need. Her team may help with college and job searches, link a patient with a fertility specialist, or just be there to lend an ear. They also teach patients coping skills and offer guidance on talking about their illness with friends and family. Of critical importance is following the patient’s lead.

“It’s about joining with the patient, being really present with them, and starting where they are,” Ms. Russo says.

Understanding that young people need to feel autonomy, **nurse practitioner Emily Sarro** recommends asking parents to step outside the room so that patients can share their feelings in private. “This is key in creating a trusting relationship with patients and making sure their voices and priorities are heard,” Ms. Sarro says.

“You are so much  
more than your  
diagnosis.”

—Rachel Marks,  
Senior Coordinator of the Stuart Center



Suleika Jaouad’s memoir describes her journey through cancer treatment and new life as a survivor.

Suleika Jaouad’s memoir was an instant *New York Times* bestseller when it was released earlier this year. Photo Courtesy: Suleika Jaouad



“It’s about joining with the patient, being really present with them, and starting where they are.”

—Alexandra Russo, Social Worker



Researcher Bridgette Thom uses social media to understand the challenges that adolescents and young adults with cancer face.

This support follows them through their journey — in Desiree’s case this meant being treated by pediatric specialists, because her type of sarcoma is more common in children. She had six months of chemotherapy administered by **pediatric hematologist and oncologist Leonard Wexler**. Then **pediatric surgeon Daniel Prince** removed the tumor in her leg.

“I call him my Prince Charming,” Desiree says with a chuckle. Dr. Prince specializes in orthopedic surgery for children, adolescents, and young adults, making him an ideal specialist for Desiree’s unique circumstances.

Of equal importance as the medical care were the frequent check-ins to discuss career planning, fertility, and other topics important to Desiree. She built strong relationships with her providers, calling nurse practitioner Ms. Sarro her “unofficial official bestie” and social worker Ms. Russo her “professional bestie.”

“They would literally call just to say, ‘How are you?’” Desiree says. “There were no strings attached, no ‘are your meds okay?’ conversations. It was like when your best friend calls. I could be myself.”

#### The Digital Connection

To reach a generation living on its smartphones, the Stuart Center harnesses technology in new ways — teaching,

treating, and supporting patients through the use of apps, social media, telemedicine, and more. Desiree often has virtual appointments.

“Just knowing that my team is a phone call away and seeing them and hearing them from my living room — without masks — adds a layer of physical and emotional well-being,” she says.

MSK also recently connected Desiree with a 31-year-old fellow sarcoma patient, and they’ve developed a friendship over text.

“Sometimes you really need to see that validation, to know that ‘I’m different, but you did it, and maybe I, too, can do this,’” says Desiree.

Teens and young adults also find community online. **MSK’s Lounge App** has become a popular and powerful way to share their experiences, especially when The Lounge’s physical hangout in the main hospital shut down during the COVID-19 pandemic.

Social media and technology are also used for research. **MSK senior research specialist Bridgette Thom** is recruiting a vast range of patients — from teens to

those in their late 30s — via Facebook, Twitter, and other outlets to conduct research. The objective is to identify the social and financial issues they face in order to better help them navigate their care.

“I am struck by how willing they are to share and tell their stories to give back to the AYA cancer community,” says Dr. Thom.

#### “I’m not just alive; I’m living.”

Desiree is back to living her best life. Her last round of chemotherapy was about a year ago, and her most recent scan in April showed no evidence of disease.

She has returned to school, work, and vigorous exercise. She is especially enjoying time with her boyfriend, who stood by her side through the ordeal. Desiree is also pursuing a post-master’s certificate in oncology, with the dream of one day returning to MSK in a professional role.

“I will not rest until I work at MSK!” she says. “They’re probably sick of me saying thank you. The gratitude I feel is so deep. I’m not just alive; I’m living.” •



“I’m not just alive; I’m living.”

—Desiree Allen, MSK Patient

# No Longer Left Behind

Including Adolescents and Young Adults in Cancer Clinical Trials

**When Irving Romero Torres learned that the cancer he'd been battling for three years had come back, he was "scared, really scared."** But he wasn't defeated. "I didn't hesitate to go back on treatment," he says. "I was ready to fight again."

Fortunately, Memorial Sloan Kettering Cancer Center was ready to offer him a clinical trial testing an experimental drug to treat his type of soft-tissue sarcoma — desmoplastic small round cell tumor (DSRCT) — which affects mostly adolescent boys and young men.

"We opened this trial in the pediatric and adult sarcoma services at the same time so that all of the sarcoma doctors at MSK could enroll their patients," says **pediatric oncologist Emily Slotkin**, who is leading the study. "From the beginning, it was designed to be an adolescent and young adult (AYA) trial." This is very unusual, because adult and pediatric patients usually participate in separate trials.

## Saving Lives by Bridging the Age Gap

Nearly every advance in cancer care over the past several decades has happened because of clinical trials. But there's an age barrier that's made it hard for some patients to participate in and benefit from research. Clinical trials for "adult" cancers have required patients to be 18 or older, yet trials for "pediatric" cancers often stop at age 18 or 21. Patients who are neither



Irving Romero Torres recently celebrated his 30th birthday in New York City with his family. Photo Courtesy: Irving Romero Torres



Pediatric oncologist Emily Slotkin is leading the first trial designed specifically for desmoplastic small round cell tumor — a type of sarcoma that affects mostly adolescent boys and young men.

a child nor an older adult can get caught in a gap that can be — quite literally — the difference between life and death.

"Adolescents and young adults with cancer are at risk for worse outcomes, compared with pediatric patients and also with middle-aged and older adult patients," says **hematologic oncologist Niloufer Khan**, who treats AYA patients with lymphoma. "We believe one reason is that this group has historically been underrepresented in clinical trials."

"The current healthcare system doesn't do a great job of meeting the needs of AYA patients," adds **medical oncologist Viswatej Avutu**, who specializes in treating AYA patients with sarcoma. "These patients tend to get lost between adult medical oncology and pediatric oncology."

## By Design: More Trials for Young Adult Patients

Irving was first diagnosed with DSRCT four years ago, after stomach pains sent him to a doctor near his home in Brooklyn. After his diagnosis, he came to MSK, where he received months of demanding chemotherapy and had several extensive operations to remove tumors from his abdomen.

"I had already been through so much," he says. "After being in remission for almost a year, I finally felt like I had my life back."

After his cancer returned in early 2020, he joined Dr. Slotkin's study — the first trial designed specifically for this kind of cancer — which adds an experimental drug called prexasertib to the chemotherapy drug irinotecan. The trial also includes patients with rhabdomyosarcoma, another rare sarcoma that affects children and young adults. The study's co-leader is **medical oncologist William Tap**, who is one of the heads of the new **Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers**.

The Stuart Center is focused not only on developing more trials for adolescents and young adults but also on making it easier for them to learn about and enroll in these trials — regardless of whether their primary doctor cares for children or adults.

"Biologically, the number 18 is not relevant for anything. It's especially irrelevant for cancers, like sarcomas, that exactly cross this bridge," Dr. Slotkin says. "We can't run good trials when we have doctors working in separate departments and patients siloed by age."

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This sarcoma trial is supported by **Cycle for Survival**, MSK's team cycling event that raises money for rare cancers.

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Irving Romero Torres (second from left) with his grandmother, mother, brothers, and cousin at the Brooklyn Botanic Garden in 2019.

Age requirements for enrolling in trials are changing. In November 2018, larotrectinib (Vitrakvi®) became the first targeted therapy to be approved by the US Food and Drug Administration (FDA) at the same time for children and adults who have cancers caused by TRK fusions. “We designed the trial so that from the get-go, patients of all ages were included,” says **medical oncologist Alexander Drilon, Chief of MSK’s Early Drug Development Service.**

When Dr. Drilon later helped design the trials for the drug selpercatinib (Retevmo®), he partnered with the drug company to ask the FDA to include patients as young as 12. That drug was approved in May 2020 for the treatment of certain lung and thyroid cancers; one use applies to adolescents who have a form of hereditary thyroid cancer.

### Making It Easier for Generation Tech

It’s not enough to make trials available to young people. They must be convenient, too. Technology is making it simpler for many AYA patients to enroll in trials. “A lot of AYA patients see healthcare visits as an interruption to their daily lives,” Dr. Avutu says.

He explains that many parts of clinical trials are moving into the virtual space. MSK’s AYA program is even looking at ways that patients can consent to clinical trial participation electronically so that they don’t have to physically be in the room.

“Another way we’ve been able to make trials more accessible is by offering more of them at our regional sites,” Dr. Khan says. “This allows us to capture a larger network of patients, including patients who are not able to travel into the city frequently.”

Although Irving’s trial requires frequent visits to Memorial Hospital for treatment, he still has been able to take advantage of technology. He uses the MyMSK Patient Portal to communicate with his care team and to get test results, and he has been able to have some of his appointments with Dr. Slotkin by telemedicine.

### Irving’s Devotion

In March 2021, Irving’s father, who was living in Ecuador, died after a long battle with diabetes and liver disease. Then his mother developed severe COVID-19. Irving traveled to Ecuador to take care of his mother and one of his two brothers, who also had gotten COVID-19. Because he had been vaccinated in New York, Irving remained healthy. His mother and brother have now recovered.

“Dr. Slotkin helped me through all this, including putting a short pause on my treatment while I was with my family in Ecuador,” Irving says.

Right now treatment is keeping his cancer from growing. As one of the older patients with this kind of cancer, Irving has stepped up as a mentor for the younger patients he meets during his visits. “We’re going through similar stuff, so I’m someone they can talk to,” he says. “I always try to have good energy and a good vibe, and let them know that things are going to be okay.” •



“What is unique about this program is it gives us an opportunity to develop a joint medicine and pediatric oncology fellowship so that we can really begin to train physicians specifically in adolescent and young adult medicine.”

—William Tap  
Chief of the Sarcoma Medical Oncology Service,  
Co-director of the Stuart Center

Philanthropy is essential to advancing research and clinical trials at MSK.  
Make a gift to improve the lives of people with cancer.

**Donate today: [giving.mskcc.org/donate](https://giving.mskcc.org/donate)**

# AGE IS JUST A NUMBER

For Tailoring Cancer Treatment, Biology Matters More than Your Birthday

Memorial Sloan Kettering Cancer Center pediatric oncologist **Julia Glade Bender** recalls very clearly the event that sparked her interest in improving care for adolescents and young adults with cancer. She was treating children with cancer at another New York City medical center when her 24-year-old niece was diagnosed with sarcoma, a type of cancer that starts in the bones or connective tissues.

“My sister, who is also a doctor, came to me, and we decided Emily should come to MSK for treatment.”

The typical approach in a case like Emily’s, in which the cancer is located in the thigh, is to treat the patient first with radiation to shrink the tumor, and then with surgery to remove it.

But Dr. Glade Bender — who had trained at MSK and was about to come back as **Vice Chair for Pediatric Clinical Research at MSK Kids** — had a different idea. Her niece was only 24 years old, and the tumor was low grade.

“I knew that radiation in young people could cause problems later in life, most notably a risk for developing a second cancer,” Dr. Glade Bender says. “For kids with a low-grade tumor, we just take it out if at all possible.”

That’s when she stepped in and asked **Bill Tap, Chief of the Sarcoma Medical**

**Oncology Service at MSK**, whom she knew through national meetings and prior shared patients, to take over her niece’s care. Dr. Tap recommended immediate surgery. Her niece was never exposed to radiation and is doing very well today.

“That was my first entrée into this idea that, even within a single institution, an adolescent or young adult (AYA) patient could end up getting a different treatment recommendation depending on which team of doctors they saw first,” Dr. Glade Bender says.

As a pediatric oncologist, Dr. Glade Bender had the wherewithal to help her niece navigate the process and get her the most personalized care. But others aren’t so lucky.

“Not everybody has an Aunt Julia,” Dr. Glade Bender says.

That’s why the **Lisa and Scott Stuart Center for Adolescent and Young Adult**

**Cancers** is so important and necessary: It will ensure that AYA patients benefit from the combined expertise of physicians and researchers across MSK.

As **Paul Meyers, Chief of the Pediatric Sarcoma Service, Vice Chair of Clinical Affairs, and Robbins Family Chair at MSK**, notes: “We are not a children’s hospital; we are not an adult hospital. We are a full-service cancer hospital that cares for all ages.”

## A New Way of Thinking about Cancer

What happened to Dr. Glade Bender’s niece highlights the need for a new approach to treating cancer — one that is not necessarily based on the patient’s age or even where the tumor started. It’s all about the biology of someone’s cancer cells. The best treatment targets the exact molecular aspects of a tumor.

Doctors now know that cancers originating in different organs can share the same underlying molecular drivers, making them more similar to one another than to tumors arising from the same organ. Lung and thyroid tumors with a type of mutation called a *RET* fusion, for example, will both respond to the targeted drug selpercatinib (Retevmo®), even though these tumors are otherwise very different.

Likewise, children can get tumors that are much more common in adults.

“Not everybody has an Aunt Julia” to help them navigate the process.

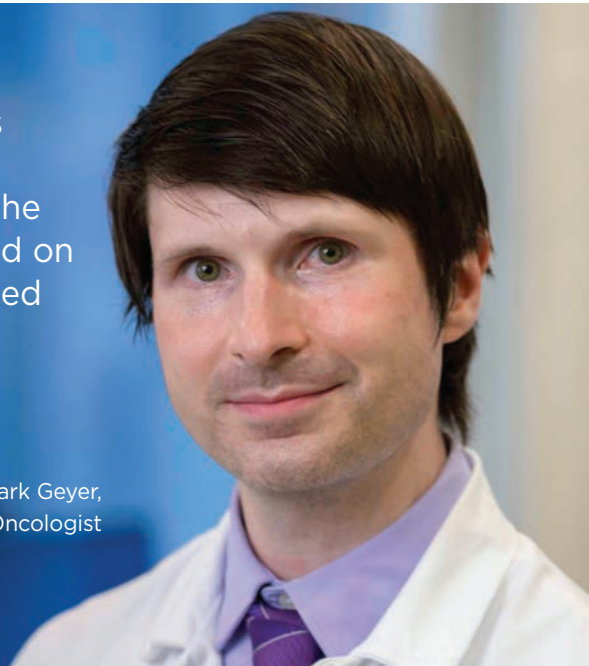
—Julia Glade Bender  
Vice Chair for Pediatric Clinical Research,  
Co-director of the Stuart Center



Julia Glade Bender (right) and her niece Emily.

“We have patients who are currently being treated on the adult service based on protocols developed over decades by the Children’s Oncology Group.”

—Mark Geyer,  
Hematologic Oncologist



For example, colorectal cancer is predominantly a disease of older adults. But increasingly, doctors are seeing more and more young people with this cancer. The greatest increase is in patients ages 20 to 29, but it can be seen in patients sometimes as young as 14.

Although some experts had thought the biology of colorectal cancer in the young is different from its form in older adults and more aggressive as well, an important new study authored by **MSK medical oncologist Andrea Cercek** found that early-onset colorectal cancer is likely not different from average-onset colorectal cancer.

Doctors aren’t yet sure why more young people are developing colorectal cancer. But what’s not in dispute is that pediatric oncologists have far less experience than their counterparts who treat adults with the disease.

“You won’t find a single pediatric oncologist who knows that literature and that biology and those treatment paradigms,” Dr. Glade Bender says.

That’s why doctors at the Stuart Center are partnering with **MSK’s Center for Young Onset Colorectal and Gastrointestinal Cancers** to make sure that young people with colorectal cancer benefit from the expertise of those most likely to treat the disease.

In the case of young people with colorectal cancer, the best treatment may be one developed for adults. But in other kinds of cancer, the opposite may be true.

### Treating Adults More Like Children

**Mark Geyer is a hematologic oncologist** at MSK who primarily treats adults with leukemia. Historically, adults and children with leukemia were treated not only by different teams of doctors but also with different treatment regimens developed specifically for each age group. But that’s beginning to change.

“A number of research groups have found that adolescents who are treated on pediatric-type protocols for acute lymphoblastic leukemia (ALL), for example, have better outcomes than patients in the exact same age group who were treated on adult regimens,” Dr. Geyer says. “On average, they have about 15 percent better long-term survival.”

A large US-based study published in 2008 reported that adolescents ages 16 to 20 with ALL treated on pediatric-type protocols had a seven-year survival rate of 67 percent, compared with 46 percent for those on adult regimens. These findings and others led doctors to study pediatric regimens in the AYA population (up to age 39): Some recent reports have found a three-year survival rate exceeding 70 percent.

There could be several reasons why adolescents and young adults do better on pediatric protocols. Dr. Geyer says it could be that the treatment regimens developed for children are just inherently better. Or it could be that with kids, it’s easier to ensure that patients get to their appointments on time and stick to

dosing schedules. Finally, there could be biological reasons specific to the cancers — which is something MSK researchers are keen to find out.

Regardless of the reason, he says, treating adolescents and young adults with a pediatric protocol suited to their type of ALL has become MSK’s preferred approach for patients up to age 40.

“At MSK, we have patients who are currently being treated in the adult program based on protocols developed over decades by the Children’s Oncology Group,” Dr. Geyer says.

Dr. Geyer and his colleagues also conducted a multicenter clinical trial of a pediatric-inspired protocol designed at MSK for adult patients with ALL and lymphoblastic lymphoma, which incorporates many of the principles shown to be successful in treating children with ALL but adapts them to make the treatment more tolerable for adults — even those up to age 60.

This is the kind of flexibility and tailored treatment that the Stuart Center will help facilitate for every type of cancer, not just leukemia. The ultimate goal is matching patients irrespective of age to treatments that best match the biology of their underlying disease.

### “Jumping Genes” May Explain Why Young People Get Cancer

One of the long-standing questions about cancer in young people is how it can develop in those who haven’t lived long enough to acquire genetic mutations through environmental exposures such as smoking, radiation, or asbestos.

In some instances, the answer may have to do with inherited mutations that predispose children and young people to cancer. Retinoblastoma, a cancer of the eye that predominantly affects young children, is a good case in point: Those affected typically inherit a mutated copy of the *RB* gene that greatly increases the odds of the cancer forming. “MSK’s clinical genetics service, which offers genetic testing and counseling across the whole lifespan, is a crucial part of the comprehensive cancer care that MSK provides,” says **geneticist and pediatric oncologist Michael Walsh**.

But for others, the cause of the cancer remains a mystery — one MSK would like to solve. Thanks to research

conducted through the newly launched **Tow Center for Developmental Oncology at MSK**, led by **pediatric oncologist and cancer biologist Alex Kentsis**, an intriguing explanation has come to light.

It turns out that for a majority of childhood tumors, including medulloblastomas, neuroblastomas, and a variety of sarcomas, a gene called *PGBD5* becomes abnormally activated during childhood. This gene makes an enzyme that snips out DNA segments and moves them to a different location within the genome. This DNA transfer can drastically alter normal gene function and trigger cancer.

So rather than normal cells becoming cancerous as a result of random mutations, *PGBD5* actually produces the mutations that turn cells malignant.

*PGBD5* belongs to a family of enzymes called transposases. The DNA segments these enzymes move are called transposons. Often called “jumping genes,” transposons were originally discovered in the 1940s by cell biologist Barbara McClintock, who studied corn genetics. Jumping genes make up about half of the DNA of a human.

The discovery that jumping genes play a role in cancer has fueled interest in the idea that many, perhaps even most, childhood cancers might be caused by a similar sort of mechanism. And, in fact, a similar jumping gene, caused by a hyperactive protein called *RAG1*, was



Emily (third from left) participates in Cycle for Survival to raise money for rare cancer research.

recently discovered to be a driver of blood cancers, such as leukemia.

“This is exciting because it provides a very satisfying explanation for why young people get cancer. It’s not bad luck per se,” Dr. Kentsis says. “And because DNA transposases, such as *RAG1* and *PGBD5*, control a very distinctive process, that opens up new strategies for therapy that in principle could be not only highly effective but also very safe and precise. That’s what all of us are working so hard to achieve.”

Figuring out what causes *PGBD5*, *RAG1*, and other developmental proteins to be overactive is the next question researchers

affiliated with the Tow Center will try to answer. This kind of scientific collaboration — between doctors who care for patients and laboratory researchers looking at the underlying biology — is what will drive progress toward better treatments.

MSK is about to initiate a clinical trial of a drug designed to target cancers with stressed DNA, such as that caused by *PGBD5*. It will be led by **Michael Ortiz, an MSK investigator** who is co-mentored by Drs. Kentsis and Glade Bender, and made available nationwide through the Children’s Oncology Group to patients with several typical pediatric cancers.

Supported by the Tow Center, **MSK investigator Melissa Lumish** will be pursuing the question of why young people are getting colorectal cancer at increasing frequencies. She’ll be looking specifically at their microbiome to see if there’s something about the microbes in their guts that is putting them at risk.

For her part, Dr. Glade Bender looks forward to a day when laboratory discoveries, such as those from the Kentsis Lab and other laboratories at MSK supported by the Tow Center, provide the tools to tailor treatments.

“The approach is not going to be ‘If you fall into this age group, you get X treatment; if you fall into that age group, you get Y treatment,’” she says. “It’s going to be much more about the biology of your disease and what makes the most sense for you as an individual. Ultimately, that’s what will improve the care for people like my niece and other young people with cancer.” •

“This is exciting because it provides a very satisfying explanation for why young people get cancer. It’s not bad luck per se.”

—Alex Kentsis,  
Pediatric Oncologist and Cancer Biologist,  
Director, Tow Center





A CONVERSATION WITH

# Fumiko Chino



**Fumiko Chino** is a radiation oncologist who cares for people with gynecologic and breast cancers. She also studies the issues of affordability and financial toxicity in cancer care, which she experienced firsthand when her husband was diagnosed with cancer when they were in their 20s. She joined MSK in 2019.

## How Young People Facing Cancer Can Cope with the Cost of Treatment

### How did you become a doctor?

I didn't plan on becoming a physician. I was very happy in my former career as an art director for an entertainment company. But when we were both in our 20s, my husband, Andrew, was diagnosed with an aggressive neuroendocrine cancer and our lives fundamentally changed. After he died from cancer, I realized that I wanted to effect real change — or at least try to. That set me on the path to becoming a physician.

### What did you learn from your husband's cancer?

Our experience highlighted the enormous gaps that some people with cancer fall into. We discovered he was horribly underinsured, meaning his insurance just wasn't enough to pay for his care. We faced excruciating out-of-pocket costs. After he died, enormous debt hung over my head.

I learned about what a lot of families have to deal with — not only this terrible disease but also an additional financial layer that was devastating.

### What did this teach you about the challenges facing adolescent and young adult patients?

As just one example, my husband was job hunting after his diagnosis. The need for good health insurance was so overwhelming that it became really the only consideration that mattered to him in accepting job offers — nothing else.

People in their 20s are trying to establish their careers and often are thinking about starting a family. But cancer and cancer treatment can be so disruptive to education and careers that some young adults facing the disease struggle to become financially independent into their 30s and 40s and even beyond. Fertility concerns can also be both financially and emotionally costly.

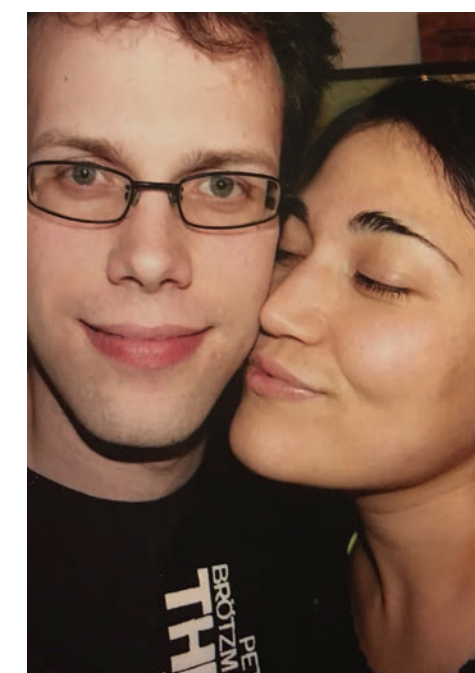


Fumiko Chino with her husband, Andrew Ladd.

In med school I discovered this emerging field called “financial toxicity,” which looks at how the cost of care can create barriers for patients. I realized that this is what I had to do. I literally heard the calling from the lecture room.

The research I'm involved with now looks at the durable financial effects of cancer. The effects can be heartbreaking, such as having to cut corners on treatment or being denied crucial loans for homes and education. These stresses can compromise cancer treatment and outcomes.

In the most extreme cases, it can cause bankruptcy or worse. Research shows that one in 20 Black and Hispanic women diagnosed with early-stage breast cancer becomes homeless owing to the cost of their treatment. That shocked me.





Fumiko Chino says physicians need to let patients know it's okay to bring up cost worries.

### What can be done to help reduce financial toxicity?

First: open communication. My husband and I were terrified that if we told his doctors how hard it was to pay for treatment, we would be tossed in the street. Physicians need to let patients know it's okay to bring up cost worries. For example, if a patient from out of state tells me that missing work will cause them significant financial pain, I can try to find a treatment that's just as effective but requires less frequent visits.

We should also stop nickel-and-diming patients. We recently published

research that shows that relatively small charges, such as parking fees for each visit, can really add up, especially for people on the border of financial instability. I've had patients tell me they just couldn't come into the city for treatment because parking is too expensive.

Thankfully, **MSK's Patient Assistance Fund** can help with expenses such as transportation and parking.

### How is MSK doing on these issues?

In my experience, everyone from C-suite executives down to people in the clinics are focused on creating change. I'm really encouraged.

There is an effort to make care teams more aware of how they can help their patients who are facing financial problems. For instance, in March 2021, a new program was rolled out so that anyone on the care team could refer people to **Patient Financial Services** for help — just like they would for any other service or treatment. The response by doctors and nurses has been really great.

We've also been going to doctors' groups around the hospital to make them more aware of these issues and how to help.

I have also been incredibly impressed with the Patient Financial Services group and its dedication to trying to improve copay assistance for our patients. MSK's Patient Assistance Fund can also help with essential needs, such as groceries and keeping on the electricity, which are so important to good outcomes.

Those are areas in which the generous MSK donor community is so important. Giving people a buffer when they are going through the worst month or maybe the worst year of their life can really help them return to normal life without being crushed financially. •

At MSK, we help alleviate the financial burdens of a cancer diagnosis through our Social Work Patient Fund and Financial Assistance Program.

Make a gift to relieve the strain of uncovered expenses so that people with cancer can focus on what matters most — recovery.

**Donate today: [giving.mskcc.org/donate](https://giving.mskcc.org/donate)**

# But How Will I Have a Family?



First came the news that **Lauren Heuchling** had a rare, life-threatening pediatric blood disorder. Her Memorial Sloan Kettering Cancer Center doctor, **Farid Boulad**, said she needed grueling treatment right away: chemotherapy and radiation, followed by a bone marrow transplant.

Then came another blow and an urgent decision for the 22-year-old: "Once we start radiation, that's going to make you sterile," Lauren recalls Dr. Boulad telling her. "If you're thinking about children in the future, we have to take care of it now."

Helping young people who are concerned about having a family is a top priority for **MSK's Cancer and Fertility Program**.

"We feel lucky to help patients at this point in their disease trajectory understand their options and feel hopeful," says **fertility nurse specialist Rosemary Semler**. "A cancer diagnosis can be so overwhelming, with so many things they can't control. This is one part of it where they can be in the driver's seat and make the decisions."

Cancer survivor Lauren Heuchling holding her daughter, Madison. Photo Courtesy: Lauren Heuchling

Cancer treatments such as chemotherapy and radiation can destroy eggs and can cause some young women and even girls to go into early menopause. For boys and young men, treatments can affect sperm production, requiring years to recover — if ever. Some patients need cancer surgery that removes reproductive organs.

But MSK experts are there to help them come up with a personalized plan that considers their medical and financial needs and helps connect them with the right fertility service provider.

Dr. Boulad recommended Lauren meet with Kutluk Oktay, a fertility specialist at Weill Cornell Medical College (WCMC), across the street from MSK's main campus in Manhattan. One option — freezing eggs for use later — seemed off the table. It would have required delaying chemotherapy, which Dr. Boulad said was unwise. But Dr. Oktay had recently developed an experimental procedure in which ovarian tissue is removed, frozen, and reimplanted after treatment.

"Dr. Boulad is the best of the best, and when I first met with him, he told me he was going to make me better," Lauren says. "My parents and I trusted his judgment on my treatment, so we decided to trust it on the fertility procedure."

One day in July 2006, Lauren had her ovarian tissue removed at WCMC and was literally wheeled back across the street to MSK that same day. By September of the same year, Lauren



In addition to overseeing Lauren's cancer treatment at MSK, Farid Boulad connected her with a top fertility specialist.

finished her chemotherapy, radiation, and bone marrow transplant.

Six years later, having fully recovered from her disease, Lauren had her ovarian tissue reimplanted. In 2016, Lauren gave birth to a daughter, Madison, thanks to an IVF procedure that used eggs that had matured in the reimplanted ovarian tissue. And three years later, she got

pregnant naturally and gave birth to a son, Dylan.

"When I first laid eyes on Madison, I immediately thought to myself: 'How lucky and blessed am I?'" she says. "Every step in my journey to get to this moment — all the hardship, all the struggles and bumps in the road — have all been worth it, and I wouldn't change a single thing."

### Empowering Patients to Plan for the Future

Every year, more than 800 patients are counseled by a team of MSK fertility experts and nurse specialists — including Ms. Semler, **Anne Casson**, and **Lauren Martino**. The majority of patients are young women; young men account for about one-third.

"We try to make sure the physicians and nurses know of our availability to step in at the earliest stage," Ms. Semler says. "Timing is key, and research has shown that patients do better when they know what to expect."

In a 45-minute consultation, the specialists walk patients through the various options. If they have reached puberty, most women can freeze their eggs and men can bank sperm before starting treatment so that it is available if they want to start a family later. But the cancer treatment always takes precedence over concerns about preserving fertility.

The nurse specialists also help patients and their families understand the financial burden. "Unfortunately, that is a big problem for a lot of our patients, because insurance often does not cover

fertility procedures," Ms. Semler says. "We talk to them about discounted rates as well as financial assistance that is available from MSK and other organizations, such as the Livestrong Foundation."

"We provide the information and tell them, 'Whatever choice you make is the right one, because there is probably no more personal decision that you're ever going to make in your life than something like this,'" Ms. Semler says.

### Innovative Surgeries

MSK doctors are also developing new approaches and perfecting older ones to preserve fertility during cancer treatments. Early this year, **gynecologic surgeon Mario Leitao** performed a uterine transposition, the first-known operation of its kind in the United States. The procedure temporarily moved a young woman's uterus up to the abdominal wall so that she could receive radiation to the pelvis as part of her treatment for rectal cancer. After the radiation sessions were over and the tumor was taken out, Dr. Leitao moved the uterus back to its proper place. The patient, in her late 20s, has resumed menstruation and could potentially bear children in the future.

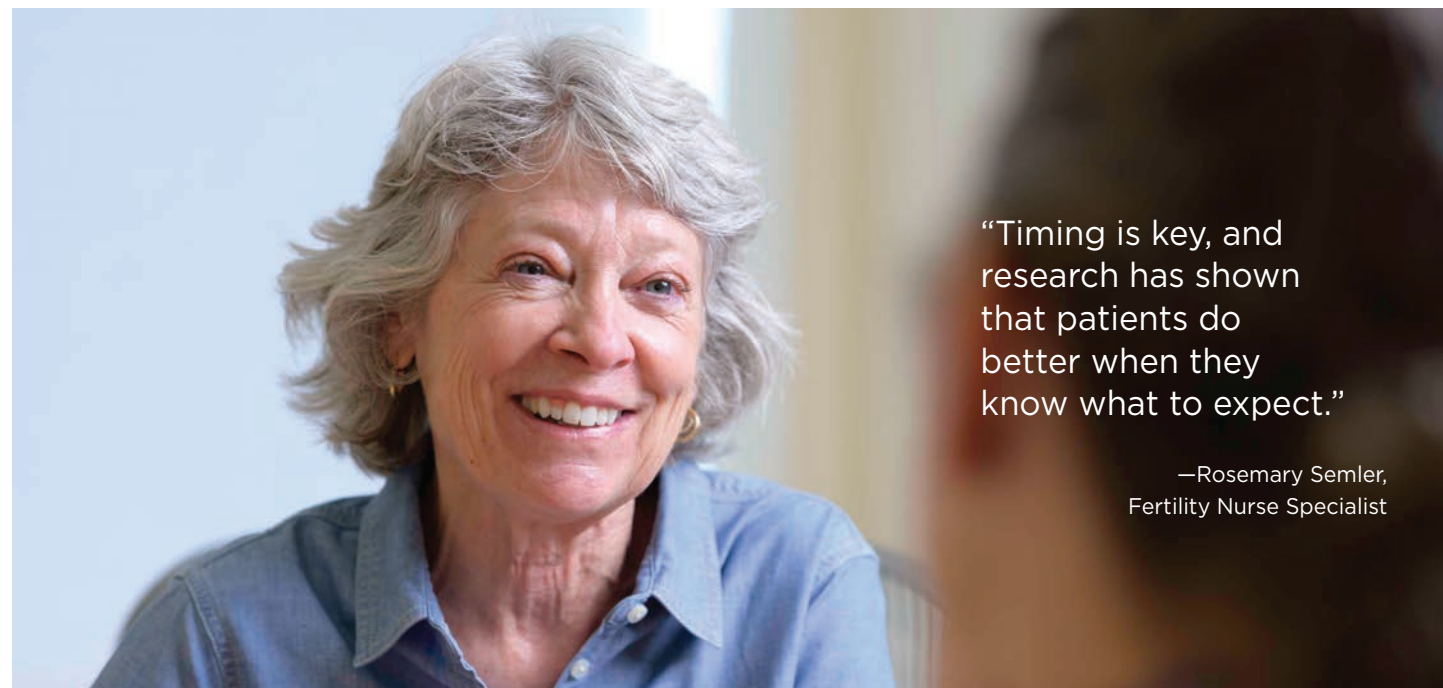
And for two decades, MSK surgeons also have helped women with cervical cancer stay fertile by doing a procedure known as a radical trachelectomy. This operation preserves the uterus if margins of the cervix — the edge or border of the tissue removed in cancer surgery — and the pelvic lymph nodes are found to be free of cancer cells. **Gynecologic surgeon and Avon Chair Nadeem Abu-Rustum** and his colleagues have done more than 200 such operations, and many of the women they've treated later had children.

"The success rate with this approach is very high," Dr. Abu-Rustum says. "MSK is a referral center for young women with cervical cancer — as well as uterine cancer — who want to maintain their fertility."

Regardless of which fertility preservation option a patient may choose, the support given by MSK's team helps them see a ray of hope in a dark time — and a chance to focus on the future.

"It's rewarding to see patients thinking about building the life they dreamed of before they got diagnosed," Ms. Semler says. "It lifts them out of the minutiae of understanding their diagnosis and treatment to think about a life beyond." •

Lauren and her husband, Ray, welcomed a son, Dylan, three years after Madison was born. Photo Courtesy: Lauren Heuchling



"Timing is key, and research has shown that patients do better when they know what to expect."

—Rosemary Semler,  
Fertility Nurse Specialist



# A Gift for Life

**If you ask Scott Stuart, he will tell you that Memorial Sloan Kettering Cancer Center is not in the miracle business.**

“I talk to a lot of people who are being treated at MSK,” he says. “When they go into remission or are cured, they call me up and say, ‘it’s a miracle.’ But my first thought,” he continues, “is that it’s not a miracle. It’s thanks to a lot of hard work, research, and dedication from scientists and doctors and nurses and many others.”

Scott is the Chair of MSK’s Boards of Trustees and Governing Trustees, and he calls his 15 years as an MSK board member “the highlight of my professional life.”

But his perspective is also deeply personal, formed as Scott and his wife, Lisa Stuart, supported their daughter Jessie, who underwent successful but grueling treatment at MSK for non-Hodgkin lymphoma when she was diagnosed at 12 years old.

Acutely aware that the science that saved Jessie’s life was made possible in part by the philanthropy of others, the Stuart family has made a transformational gift to launch the **Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers** at MSK. The goal is to revolutionize cancer treatment for people ages 15 to 39 and to meet their very specific and often unmet needs.

## “A Really Scary Word”

Jessie Stuart, now 29, vividly recalls learning that she had cancer. “We were on the ninth floor at MSK, sitting in the office of my doctor, **Tanya Trippett**, who specializes in pediatric blood cancers. I distinctly remember sitting in a plush chair. My dad was to my left, and Dr. Trippett and my mom were there, too.”

Her father broke the news. “My dad basically said, ‘Okay, this is a really scary word — you have cancer.’” As they did throughout Jessie’s treatment, her parents mixed hope with clear-eyed realism. “He said, ‘It’s going to be a crappy two years, but this is your support team, and we’re going to help you get through this,’” recalls Jessie.

## A Source of Strength

Jessie underwent several rounds of chemotherapy and surgery, sometimes

taking a dozen or more pills each day to deal with the cancer as well as the side effects from the treatment.

Lisa says MSK was a constant source of strength. “I know this sounds a bit crazy, but the ninth floor of MSK, which is the home of MSK Kids, can be a very happy, life-affirming place. There are kids running around, pushing their own IV poles, and a big playroom.” She continues, “People are respectful of each other’s privacy, but there’s a real sense of community.”

Dr. Trippett proved to be their rock. Lisa says, “Our family adores her.” Jessie calls Dr. Trippett “a life-changing person who is not only a brilliant scientist and doctor but was also basically a therapist for my entire family and got us emotionally through the experience.”

## The Good with the Bad

During Jessie’s treatment, Scott and Lisa also took comfort in knowing their family had some good luck to balance out the bad.

Scott explains, “We knew that Jessie’s diagnosis had a high cure rate for people her age. And my brother Rob is an oncologist who started his career at MSK. He thinks very highly of the doctors there, and we think the world of Rob. That helped.”

As Jessie regained her health, Scott and Lisa often thought about people facing cancer who had been dealt a tougher hand than their daughter. Scott still tears up remembering young people he and Lisa met who did not survive, including “this young guy who checked out of the hospital so he could marry his girlfriend — and died two weeks later. It was so heartbreaking.”

Together, they considered how they could help other people facing cancer,

**Philanthropy is essential to advancing the mission of the Lisa and Scott Stuart Center for Adolescent and Young Adult Cancers at Memorial Sloan Kettering Cancer Center.** The Stuarts’ transformative gift will allow MSK doctors and scientists to advance research and care for this unique population for decades to come. Other visionary donors have helped lay the groundwork for this progress. The following donors have made significant gifts that have been instrumental in the center’s launch and early success:

**The Kristen Ann Carr Fund  
Cycle for Survival  
The Friezo Family Foundation  
Kevin Zoltan Merszei Foundation  
Tom and Janet Montag  
Jamie Nicholls and Fran Biondi  
The Olayan Group**

**The Laura Rosenberg Foundation Inc.  
The Sohn Conference Foundation  
Teen Cancer America, founded by Roger Daltrey and Pete Townshend of The Who  
The Tow Foundation  
Nonna’s Garden Foundation  
JHSF/Instituto José Auriemo**

especially people with far fewer resources than those they’ve been afforded by Scott’s successful career in investment and finance.

As usual with the Stuarts, their response was a family affair that included Jessie’s siblings — Daisy, Garratt, and Nate. Scott and his children have pedaled to raise money for rare cancer research as members of **MSK’s Cycle for Survival**. And Jessie ran two New York City marathons to raise funds for MSK as a member of Fred’s Team.

## Paging Dr. Jessie Stuart

Jessie also fulfilled her childhood dream of becoming a doctor, graduating from Harvard Medical School. She is now applying for a fellowship in medical oncology/hematology — nearly 20 years after she was cured of the kind of cancer she will now treat. She says, “I think in all my patient interactions, it adds just an extra bit of empathy and understanding to

know what it’s like to go through such a harrowing experience.”

Lisa believes the Stuart Center will help patients and their families get through the most difficult time of their lives. “The research and new treatment protocols that the center will help produce will be more targeted,” she says. “And the support services for this age group are so promising.”

Scott picks up the thread, saying: “Think about being a teenage girl like Jessie, losing her hair for two years; or a 22-year-old starting his or her career; or a 32-year-old first-time mom. Each one of these age groups has its own challenges. A center that is focused just on this group of patients will do so much good.”

For all the Stuarts, this effort is not extraordinary or miraculous. Says Scott, “This is exactly what all of us at MSK are here trying to do.” •



Scott Stuart with his daughter Jessie at age 13, shortly after she was diagnosed with non-Hodgkin lymphoma. Photo courtesy: Stuart Family

**To meet the Stuart family and learn more about their philanthropy, [SCAN HERE.](#)**



# Life Beyond Cancer

**Ending cancer treatment is an exciting yet tricky transition for adolescents and young adults.** But MSK keeps a close eye on these survivors as their physical, emotional, and social needs change over time. There are three survivorship clinics — each tailored to a specific age group — all guiding patients toward a healthy, happy future.

“We approach each case individually, taking into account where they are in their life,” says **Danielle Novetsky Friedman**, who runs survivorship programs for children and adults treated for pediatric cancer.

Having faced cancer at a young age, these patients learned how to be resilient. Here’s how they describe not only surviving but also thriving after receiving treatment at MSK.

“My goals are the same. I wanted to be a vet before surgery, and I’m still in school to become one.”

**Martina Morris**, diagnosed with a brain tumor at 18, is a student at Cornell University College of Veterinary Medicine.



“It’s so empowering to share your experience with other young survivors — to be there for each other and to pay it forward.”

**Tunav Nanda**, diagnosed with leukemia at 17, is now 25 and a graphic designer.



“The people that have supported me in my treatment will continue to play a huge role in my life.”

**Irene Dimatulac**, diagnosed with sarcoma at age 25, is in school to become a speech pathologist.



“I missed my freshman and sophomore year of high school, but MSK sent teachers and set me up with tutors, which allowed me to stay on track and graduate on time.”

**David Asch**, diagnosed with leukemia at 14, was one of the first people treated with a chemotherapy widely used today. He graduated from the University of Michigan in 2019.



“It’s my desire to continue the work that my doctors have started.”

**Payton Bogert** (pictured with Paul Meyers, Chief of the Pediatric Sarcoma Service) was treated for neuroblastoma as a toddler. Today, she hopes to be a physician at MSK.

