ST. JUDE

inspire

SUMMER 2020

Mighty Mack

After cancer and amputation, this 11-year-old remains unstoppable

Service to St. Jude
volunteer grieves through giving

Far-sighted Plan
patient preserves memories

Cancer Origins
genome project yields clues

Head of the Class
patient lives Ivy League dream


victoria

Motion Pictures

Augmented reality (AR) brings the art of St. Jude patients to life.

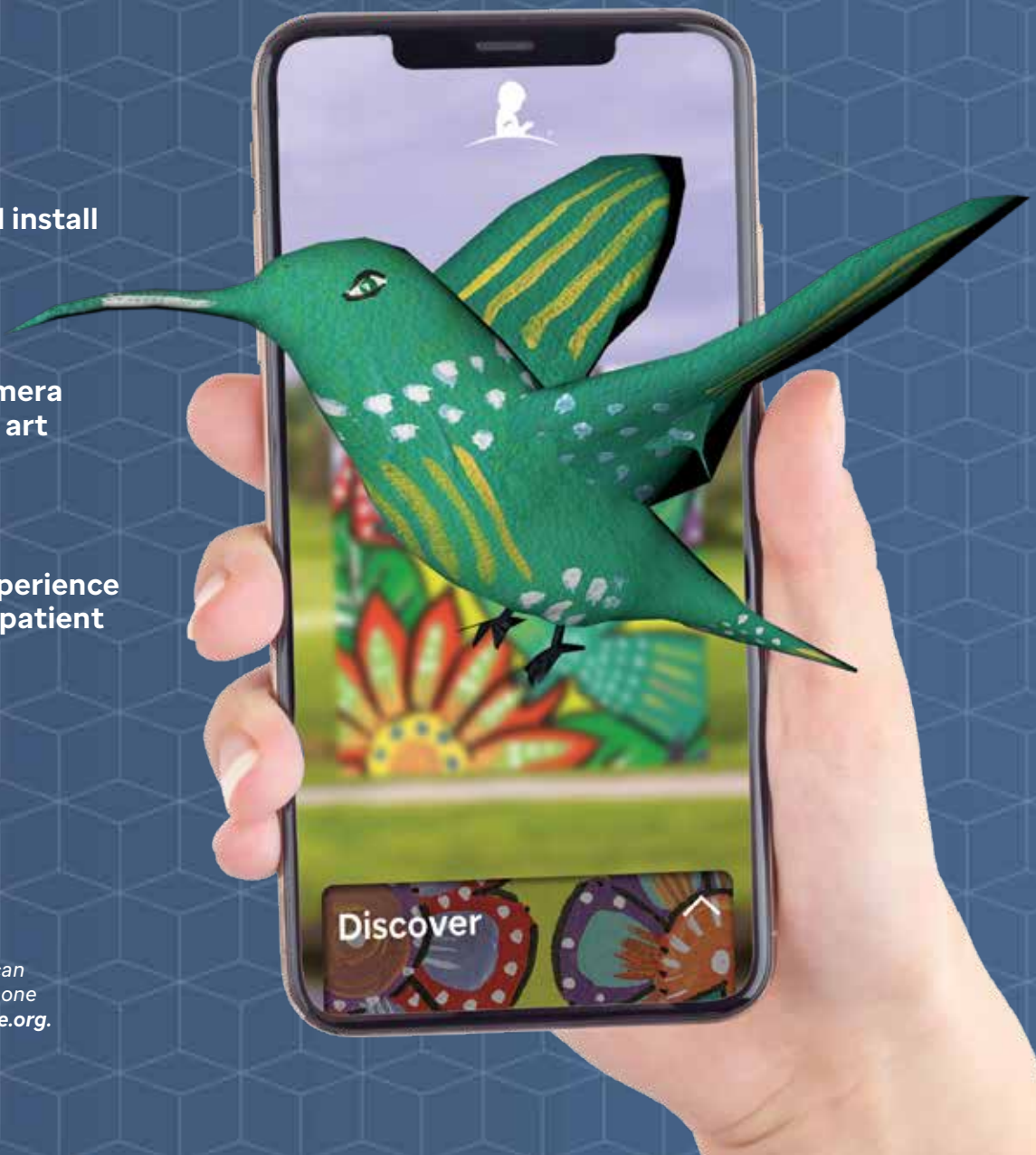
Art therapy is often used to reduce stress or anxiety, explore complex feelings, manage side effects and improve quality of life for patients. Patient art is also used by ALSAC, the fundraising and awareness organization for St. Jude Children's Reasearch Hospital, to raise awareness and support.

The art featured to the left was painted by St. Jude patient Victoria. In 2015, her family learned she had a rare brain tumor called suprasellar atypical meningioma. Today, Victoria has completed treatment and visits St. Jude for regular checkups.

Download and install the app.

Point your camera at the patient art to the left.

Unlock the experience and bring the patient art to life.



To download the St. Jude Experience iPhone app, scan the QR code with your iPhone or go to ***experience.stjude.org.***

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ST. JUDE inspire
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501 St. Jude Place • Memphis, TN 38105
800-211-7164
InspireMagazine@stjude.org

St. Jude Children's Research Hospital®
Finding cures. Saving children.
ALSAC • DANNY THOMAS, FOUNDER

Since opening 58 years ago, St. Jude Children's Research Hospital has led the world in advancing cures and devising therapies to conquer pediatric cancer and other life-threatening diseases.

But it's important to remember not all the vital breakthroughs at St. Jude have been strictly medical or scientific.

Long before St. Jude began operating in 1962, back when it was still a quixotic dream of founder Danny Thomas, it was envisioned as a beacon of equality, inclusion and social justice. Unlike other hospitals in the South and elsewhere in our nation, St. Jude patients of all races would share rooms and receive treatment from healthcare professionals of all races – and everyone would dine in a common cafeteria.

This vision was outlined in local newspapers in 1952 when Thomas announced St. Jude would be built in Memphis. The research hospital will be "non-racial," as one article put it. "And that goes for the medical staff as well as the patients."

Consider how bold that promise must have seemed during a time of strict, pervasive racial segregation across the South and, honestly, much of America. The U.S. Supreme Court ruling overturning the "separate but equal" doctrine for schools was still two years away, and a seminal event of the civil rights movement – the Montgomery bus boycott – wouldn't begin for another three years. Most Americans had not yet heard Dr. Martin Luther King Jr.'s name, much less his courageous voice.

Audacious as it may have been, this commitment to equality was enshrined in the preamble to the 1957 constitution of ALSAC, the fundraising and awareness organization Thomas founded first to support St. Jude. In it, ALSAC pledged "to love and care for our neighbor, regardless of color and creed." That manifested itself in the construction of St. Jude to find a cure for "leukemia and related blood disorders in children, absolutely free."

It could be said racial inclusion was built into the foundation of St. Jude. The original hospital structure was designed by renowned African-American architect Paul R. Williams of Los Angeles. And when the

Audacious as it may have been, this commitment to equality was enshrined in the preamble to the 1957 constitution of ALSAC, the fundraising and awareness organization Thomas founded first to support St. Jude.

blueprints were drawn, a Memphis architect who was advising Williams' firm on local codes and customs noticed what he thought was an oversight: The plans didn't include separate bathroom facilities for whites and blacks. This, he later learned, was no oversight.

So when St. Jude opened its doors on Feb. 4, 1962, it became the first fully integrated children's hospital in the South. At a time when other medical facilities maintained separate areas for African Americans, if they admitted them at all, St. Jude accepted Black patients.

At a time when African-American physicians typically weren't allowed to treat white patients, St. Jude hired Black doctors like John Wesley Smith and Rudolph Jackson, and Black technical staff members like Melvin Charles Smith to work side-by-side with white colleagues in helping kids of all races.

St. Jude took financial considerations out of healthcare to ensure equal access and quality specialty healthcare to all, regardless of race or ability to pay.

We're proud this commitment to healthcare equality also drove changes that extended far beyond its campus. After initially planning to build an on-site lodging facility for patient families, it opted to send them to nearby hotels.

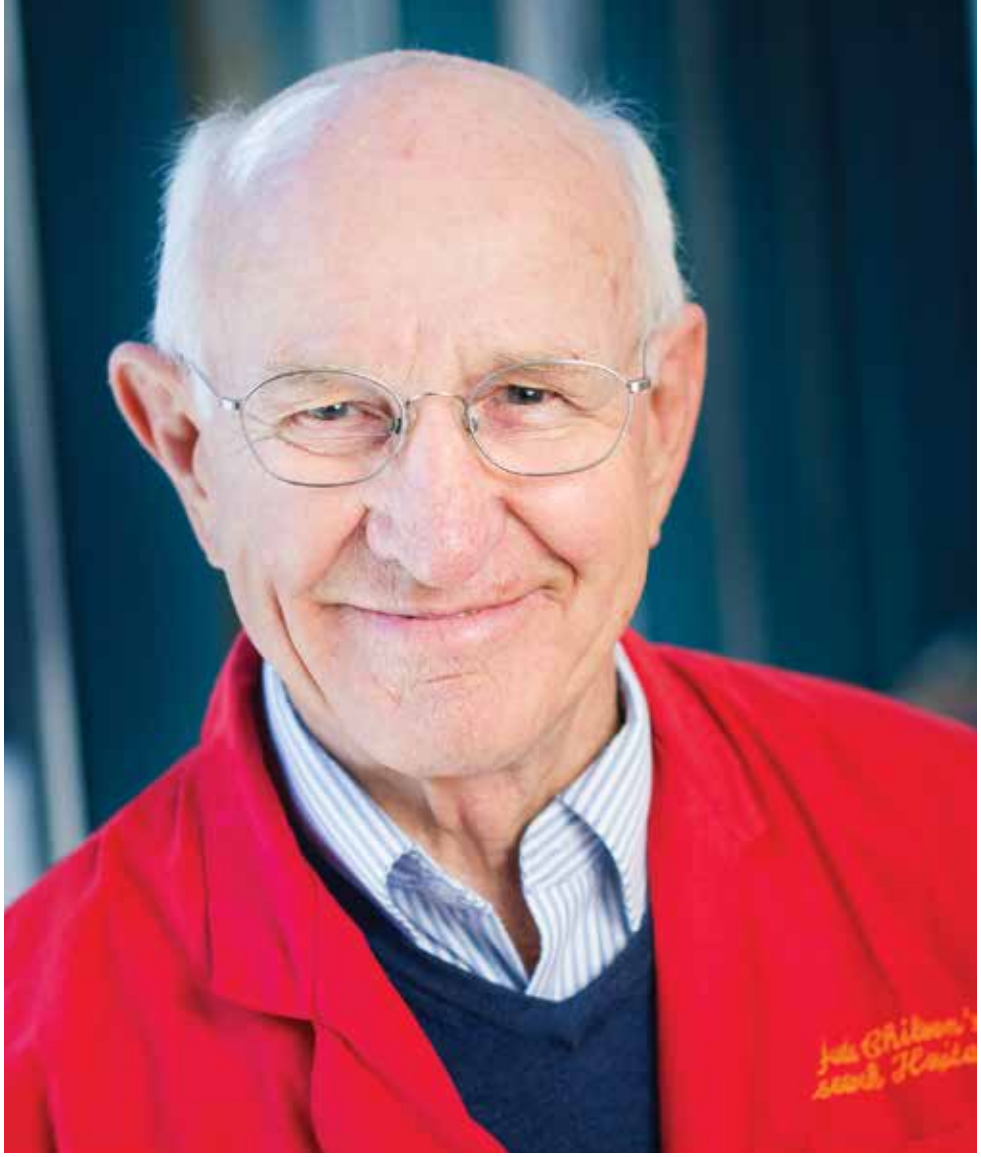
When officials at a prominent hotel nearby balked at registering African-American patient families, Thomas and Dr. Donald Pinkel, the first medical director, warned if the establishment didn't accept Black patients, it would get no business from St. Jude. Hotel operators offered to allow Black families to stay, provided they ate meals in their rooms instead of the dining room. Again, Thomas and Pinkel held firm and the hotel relented.

In the aftermath of Dr. King's 1968 assassination in Memphis, efforts of St. Jude to promote racial progress and healthcare equality expanded further. Dr. Jackson, who headed a program to treat kids with sickle cell disease, noticed many of his patients from low-income households suffered from anemia, parasitic infections and growth impairment. In response, St. Jude enrolled thousands of infants and mothers in a program that provided nutritional assistance, medicine and even diapers. The program served as a prototype for WIC, the federal initiative serving women, infants and children.

And, I could go on. Day after day, year after year, we continue to drive healthcare equality worldwide. St. Jude Children's Research Hospital has always been a unifying force around the fundamental belief that all people, especially sick children, should be treated equally, with dignity and respect. It was our founder's belief then. And now, more than ever, it's our clarion call.

It's humbling to know you've accepted as your own this special mission Danny set out on decades ago. Thank you for your incredible loyalty and generosity.

Richard C. Shadyac Jr.
President and Chief Executive Officer, ALSAC
@RickShadyac



ST. JUDE LEGEND DR. ROBERT WEBSTER REFLECTS ON COVID-19 AND HIS GROUNDBREAKING INFLUENZA RESEARCH

HAVING STUDIED VIRUSES FOR A HALF-CENTURY, HE'S OPTIMISTIC ABOUT EFFORTS TO CONTROL COVID-19, WHILE EMPHASIZING THE CONTINUING NEED TO PROTECT CHILDHOOD CANCER PATIENTS FROM INFECTIOUS DISEASES.

BY THOMAS CHARLIER · ALSAC

Through all the pioneering research he's conducted on influenza and other viruses over the past half-century, Dr. Robert G. Webster has been dogged by a single, persistent question that he can't answer just by looking through a microscope:

Why does St. Jude Children's Research Hospital, an institution best known for fighting childhood cancer, work so hard studying infectious diseases?

The New Zealand-born Webster, now member emeritus of the St. Jude faculty, heard the question shortly after joining the staff in 1968 when he met with an official of the National Institutes of Health. He had a quick and pointed response.

"I said, 'Sir, what kills our children at St. Jude?' And he thought cancer. I said, 'No, sir…It's the infectious diseases — like influenza, like measles, like whooping cough, — that kill our children.'"

Infectious diseases are especially dangerous to children undergoing treatment with chemotherapy and other measures that ravage their immune systems. More than that, Webster said, flu and other illnesses can interfere with the treatment necessary to overcome cancer.

That explains Webster's decades-long focus on influenza. He and his colleagues established that influenza viruses emerge from the aquatic birds that migrate all over the world. In live-animal markets such as those proliferating across China, a "switch" can occur, Webster said, that transmits the viruses from wild to domestic birds, then to humans.

Still considered an authority on viruses at age 88, Webster offers observations about the COVID-19 pandemic though he is not directly involved in researching that disease. He expresses confidence in efforts to develop a vaccine and to find effective therapies for those who are infected with COVID-19.

"We will be on top of this virus by the end of this year, I am optimistic."

RUNNING, RESILIENCE AND A 'ROBOT LEG'

ONE BOY'S JOURNEY BACK FROM CANCER

STORY BY GRACE KORZEKWA EVANS
PHOTOGRAPHY BY MIKE BROWN | ALSAC

MACK IS A BOY IN MOTION.

HE RUNS AND JUMPS AND TUMBLES...

... AS MUCH AS ANY 11-YEAR-OLD. Mack is also a cancer survivor and amputee, though that's an afterthought in his day-to-day. He employs his "robot leg," as his brother and sisters call it, to play in a community basketball league, lead the line to lunch at school and explore the neighborhood around his home in a small town in East Tennessee.

"It's like a side skip, side step kind of thing," Mack's mom, Amanda, says of his gait. "He falls all the time. He has crafted it. It's beautiful. It's like those slow motion movies, that's how he falls."

This is a story about a boy falling, and getting back up again.

A TYPICAL MONDAY NIGHT

Mack is working through his reading comprehension homework. He's gotten a handful of the answers wrong already, but he giggles about it, undisturbed. "What does the phrase 'run like the wind' mean?" he asks aloud, then answers himself, "B. Run fast." Fittingly, he gets that one right.

Mack and his mom are cramming in a little homework before they head to Mack's last basketball game of the season. His challenge with reading comprehension is a lasting effect from chemotherapy. He also has a heart murmur that's being monitored. And in place of his right leg, a titanium prosthetic. The plastic connector where it fits on is adorned with Scooby-Doo characters. In the past, it's been Teenage Mutant Ninja Turtles and The Avengers.

Mom helps with homework, basketball keeps the heart strong. And Mack himself is the master of his prosthetic.

Mack runs everywhere. "He doesn't walk anywhere anymore," Amanda says. "If we don't break the prosthetics, we outgrow them. The prosthetic place has a warranty on them now."

But at age 6, Mack made a decision that would determine if he'd ever run again.

INTERLUDE: CHILDHOOD CANCER

Mack hoped to play basketball during the fall season of 2014. But what began as leg pain developed into a knot. And then what was thought to be a bone infection was diagnosed as Ewing sarcoma, bone cancer. Mack had already spent a month in the hospital.

"We always heard St. Jude Children's Research Hospital is the best place for children's cancer, so we didn't really question the referral when we got it," Amanda says. Mack was in multi-organ failure by the time he arrived via air ambulance at St. Jude on Christmas Eve. He hadn't moved in two weeks.

"His system was shutting down," Amanda recalls. "He was yellow from jaundice, his kidneys had stopped. St. Jude started that night trying to make him better. That just shows how much they care about the kids there."

After arriving at St. Jude, Mack mustered the strength to ask that his Christmas gifts be sent to his three younger siblings: Jacob, Sarah and Emily.

THE HARDEST DECISION

St. Jude identified that Mack was having a severely adverse reaction to medications such as antibiotics. After his care team stopped the antibiotics, Mack's body began to recover quickly. He then endured 14 rounds of chemotherapy and eight months of uncertainty about whether he'd be able to keep his leg.

St. Jude has a team of experts who perform limb-sparing procedures in children with bone tumors such as Ewing

"PARENTING A CHILD WITH AN AMPUTATION WHO'S HAD CANCER, THERE'S NO RULE BOOK FOR THAT ... I SAY LET HIM LIVE. LET HIM DO KID THINGS. — AMANDA

sarcoma, but in some cases amputation is necessary to ensure the tumor is completely removed. Mack's parents were hopeful their choice would provide his best chance at survival and a more active life.

Even days before his surgery, the team was undecided.

St. Jude's approach to patient family-centered care underlines the importance of open communication

Ryan uses his height to make the family basketball goal portable, prepping the parking lot of a church for a family game.

between family and care team, empowering Mack and his parents to weigh in on such a life-altering decision.

"We talked to Mack about it, even though he was only 6," says Amanda. "We really left it up to him and went over both surgeries and, in the end, he accepted it before we did. He said, 'Mom, it's sick, just chop it off. After this leg is gone I can run again.' He, his dad and I knew this was the best for him, but deep down I was so sad for him."

THE BEST OUTCOME

Mack's not ashamed of the robot leg – he plays with it and throws it behind his head when he's fidgeting. He can get around without it, too. The family recites a litany of inconvenient places where Mack has discarded his prosthetic for the time being, hopping away. His grandfather once tripped over it and broke a toe.

Above left: There were lots of serious faces at Mack's last basketball game of the season. Above right: Homework has to be done before basketball in Mack's house. Amanda helps him with his reading assignment, accompanied by the family cat.

Mack is curt when asked about his leg: "They cut it off because of cancer." Even now, he refuses this as his main story line. It is part of him, but it is not him.

"The first thing I wanted to do was play basketball when I got out of surgery," Mack says now. Less than 24 hours post-amputation, he was ready to take his first steps.

The moment is captured on video: Hooked up to every kind of monitor imaginable and still an inpatient at St. Jude, Mack walks, in disbelief at his accomplishment. "I'm doing it?" he says in a small voice as his care team and parents, surrounding him, hoot their encouragement and admiration.

CREATING HIS OWN SHOT

Basketball remains a grounding force. A kid thing. A family thing. Three out of four kids play in leagues, and everyone practices together. They don't watch much TV or play video games.

"Parenting a child with an amputation who's had cancer, there's no rule book for that," Amanda says. "Yeah, we probably should keep him in a bubble and away from people. But who knows how long anyone is going to be on this earth. I say let him live. Let him do kid things."

That's the paradox of Mack. He's different, even beyond the robot leg. Even before COVID-19, Mack wore a mask to school every day because even a sinus infection will have him in the hospital. But he's also like most kids – reluctant to do his homework or eat his vegetables – and wants to be one of the pack, treated the same. He puts in the work to do the things he loves, and continues to be a walking, mostly running, contradiction.

"You can't baby him forever, because the world is not going to be nice to him as an adult," Amanda says. "He's going to have to do things for himself. So after his amputation, he was 6 years old. We taught him how to do everything for his prosthetic leg that an adult would do with an amputation. If he learns it now, it's going to get better as he gets older."

On this Monday night after a long day of school and homework, challenges in their own right, Mack plays three quarters in his community league game. Running in that prosthetic must be grueling, but Mack doesn't cut his game short. Frustration turns his face red when he misses a free throw. Exertion keeps him sweaty. He runs the full length of the court, back and forth, over and over. Dad pounds the bleachers. His sisters are both doing their version of cheerleading. Mom just laughs and yells encouragements.

Mack keeps his eyes on the ball and his hands up, waving. He's open.

“I had the pleasure of painting...

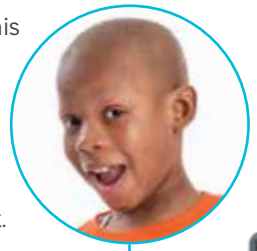
Photos by Cliff William Photography

... Cole. *– Robert Vargas*

At this year's LA Art Show, Los Angeles-based painter, friend of St. Jude and artist of the world Robert Vargas created a new masterpiece. The subject? St. Jude patient Cole. *To watch Vargas in action, scan the QR code or go to* ***stjude.org/vargas***

ST. JUDE HALL OF HEROES

In the battle against cancer, St. Jude patients fight back with courage like the heroes they are. Now, thanks to virtual reality, we can celebrate the bravery of these kids at the scale it deserves.



Despite his young age, Quincy took ownership of his treatment immediately. The doctors asked him questions directly, and he answered. When things got really hard, his spirit never wavered. If Quincy could choose a superpower, he says he'd like to be armed with cancer-destroying "Chemo Bombs," so he could help other children who are sick.

Annika has an incredible peace about her. You'd never guess she's gone through chemotherapy, spinal taps and biopsies. No matter how sick Annika felt, she was always more concerned about the other children around her and how they felt. She set a goal to be home by her birthday, and she made it with three weeks to spare.

Every day, the staff at St. Jude Children's Research Hospital witness extraordinary bravery from kids battling cancer and other life-threatening diseases. But these inspiring kids have never been celebrated with statues … until now.

The **St. Jude Hall of Heroes** is a virtual reality (VR) world of floating islands where 12 brave patients are depicted as towering 60-feet-tall superhero sculptures.

Each statue represents a story, a battle, a team and, at the center, a young patient.

Through the Oculus family of VR headsets, visitors can explore the islands and wander freely through the statues, float up for a closer look, and hear the personal stories behind each one, as told by the children themselves and their families. Discover how playing the guitar helped Caleb take his mind off the side effects of chemo, or why Matthew is called the "Mayor of St. Jude," and more.

View each statue and hear from the patients and their families at ***stjude.org/hallofheroes***

Jazzy and her mother refer to cancer as their "adventure." Through eight months of chemo, Jazzy's laughter and fearlessness have inspired the people around her. No matter how hard the days have been, her smile never seems far away. Jazzy recently finished her in-patient treatment and could finally get back to her favorite activity: swimming.

When he was 5, Caleb left most of his family in the Bahamas to be treated at St. Jude. He sought solace in the guitar strings and piano keys in his housing facility's music room, where the music took his mind off cancer. Now, many years into remission, he's working toward a degree in health studies. He says his relationships with St. Jude nurses motivated him.

Volunteering for St. Jude put purpose back in a grieving widower's life. His grandson's own childhood cancer fight gave that purpose a name.

CHARITY BORN OF TRAGEDY

BY TIFFANY SMITH-FLEISCHMAN · ALSAC

It was 1987 and John Nagle's wife, Virginia, known as Ginger to everyone, had died. He was standing in his backyard in Long Beach, California, with his mother-in-law when she said, "There is no pain greater than the pain of losing a child."

John's eyes were trained over her shoulder at his own kids: two boys, two girls. When their mom died, they were 7, 9, 17 and 19.

"Oh my God," he thought. "What would I do if I lost one of these kids?"

John was working a job requiring travel, but as a newly single father, leaving his kids each week wasn't tenable. He needed a new job.

That new job was in Washington state, at Boeing. Not long after the family moved, John was walking through a mall where volunteers for St. Jude Children's Research Hospital were asking for a $10-a-month donation to become a St. Jude Partner in Hope.

With his mother-in-law's words still on his mind, John thought, "it would be a perfect tribute."

It wasn't an easy time financially, but John signed up. He didn't know it then, but it was the beginning of a relationship with St. Jude that would last decades and become deeply personal. Soon after signing up as a Partner in Hope, he began volunteering for the KMPS-FM radiothon, where the first call he took resonated deeply.

"It was a gentleman, his voice was rather cracked – for most of them the reason they are calling is that cancer has affected their family. I'm listening to his story and he's telling me that his wife had passed away a year before and he had just been diagnosed himself."

He lived a full life and accepted his fate, the caller told John, adding, "But these children, we've got to do everything we can to help them."

He pledged $1,000 per month to St. Jude.

That was in 1989 and John would become a fixture of every KMPS radiothon until the station was sold in 2017.

Over the years John's sense of obligation and service to St. Jude has grown. "Doing this work with St. Jude, never did I see it coming back to me – this was me giving – other than the feeling that I know I'm doing something good."

It became personal, however, with a visit in 2000 from his daughter and her family. John was at work and everyone else was tubing down the river. John's grandson Nick, 14 at the time, was bored and off by himself, throwing rocks into the river.

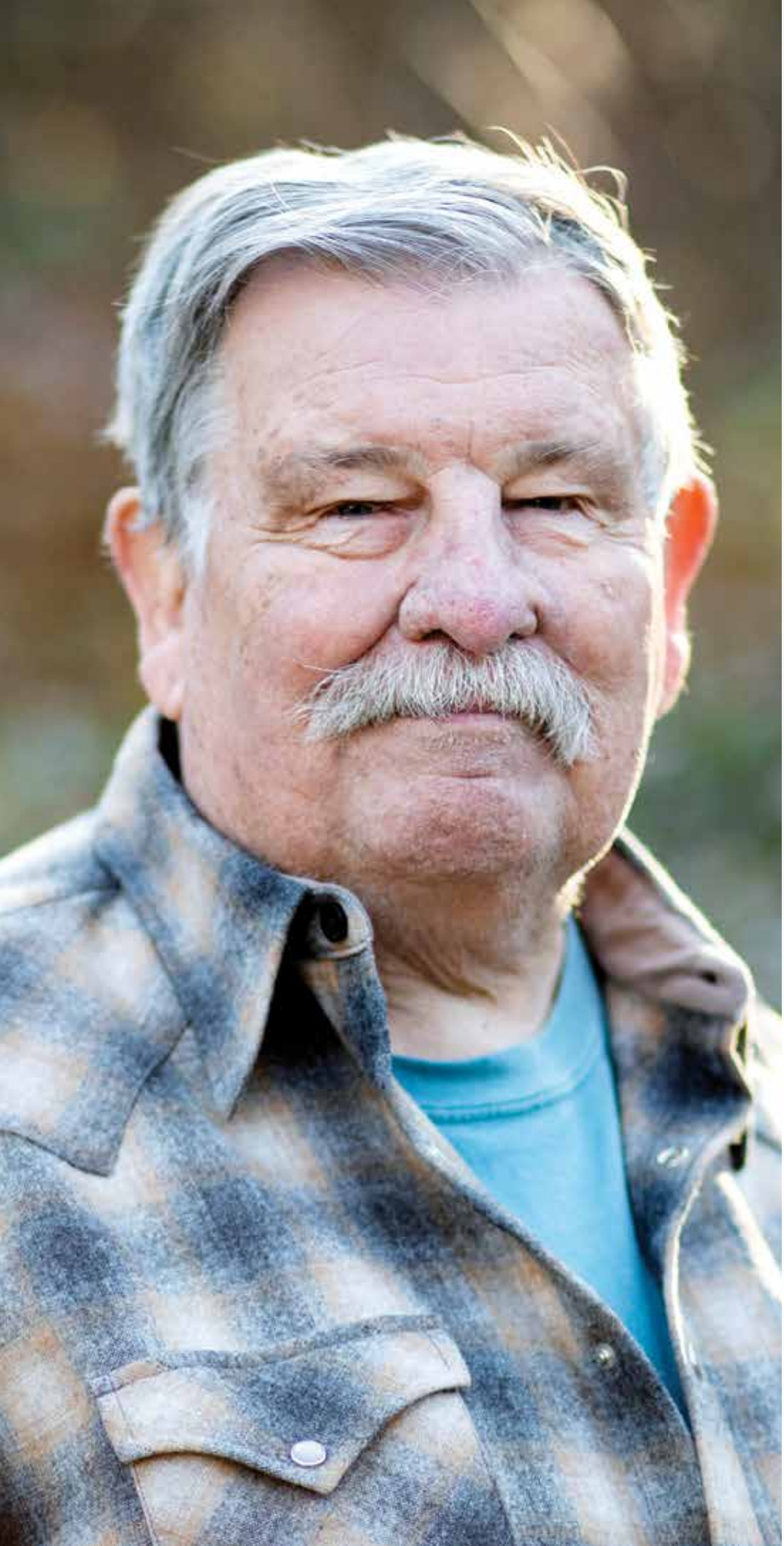
"He threw one and his arm just snapped in half," John said.

The family rushed to the hospital where tests were ordered. They were back home before the doctor called asking them to return to his office. "He said, 'Your son has cancer … bone cancer,'" John said. "So I know what that feeling is like when a parent gets that news."

John needed information and reassurance. He called St. Jude. "I just wanted to know what we were dealing with."

He received a packet from St. Jude with details to help his family make sense of the coming year. And though Nick was being treated in Seattle, some 2,200 miles away from Memphis, Tennessee, two of the protocols used to treat him were developed at St. Jude.

Nick responded to the treatments, but he was weak. He didn't like the food at the hospital, so his grandfather made his special lasagna. Not only did



“DOING THIS WORK WITH ST. JUDE, NEVER DID I SEE IT COMING BACK TO ME... OTHER THAN THE FEELING THAT I KNOW I’M DOING SOMETHING GOOD.

Nick eat it, he ate everything John brought with him. “It got to be quite the joke with the staff, ‘What’s Nick got to eat for dinner tonight?’” John said. And it was just what Nick needed.

“The treatment was complete, and he did very well,” John said. “He was 14 then, and now he’s 33.”

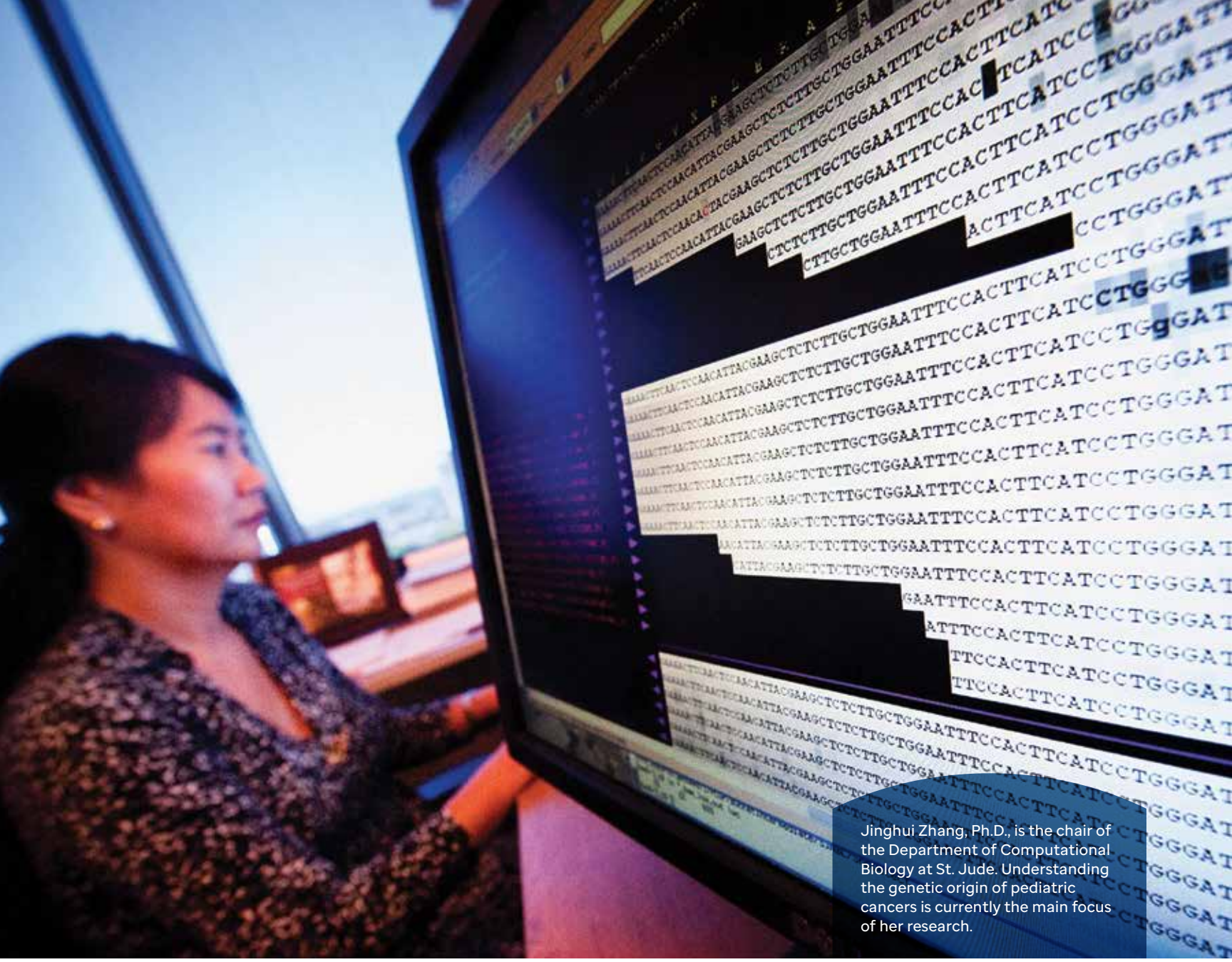
John’s volunteer shifts at the radio station were different after that. Before, he was a committed volunteer, paying a lasting tribute to his late wife. After Nick’s illness, treatment and recovery, he had his own story to tell. Those volunteer shifts gave him “an opportunity throughout the day to talk about Nick.”

And John could speak to the very real, very tangible, very effective protocols developed at St. Jude, because they helped save his grandson.

John continues to volunteer today, whether it’s the St. Jude Rock ‘n’ Roll Seattle Marathon, a golf tournament, or a gala or songwriters’ showcase. “Any event, I am there from the beginning to the end.”

He shows up year after year, decade after decade, because he knows that by helping St. Jude, he is helping make a difference in the lives of children everywhere.

He knows it, because he’s seen it.



Jinghui Zhang, Ph.D., is the chair of the Department of Computational Biology at St. Jude. Understanding the genetic origin of pediatric cancers is currently the main focus of her research.

WAVES OF DISCOVERY

SCIENTIFIC ADVANCES DURING THE FIRST 10 YEARS OF THE ST. JUDE-WASHINGTON UNIVERSITY PEDIATRIC CANCER GENOME PROJECT RAISE EXPECTATIONS OF WHAT MAY LIE AHEAD

BY THOMAS CHARLIER · ALSAC

For all of its ambitious goals and breathtaking challenges, for all the intricate science it brought to bear on decoding 3 billion base pairs of DNA, the Pediatric Cancer Genome Project launched by St. Jude Children's Research Hospital and Washington University 10 years ago took aim at some very basic questions.

Such as:

How does a white blood cell get hijacked into becoming a leukemia cell?

Or:

What makes a healthy brain cell morph into a burgeoning brain tumor?

"We knew the answer was in the DNA," said Dr. William E. Evans, who was St. Jude's president and CEO from 2004 until 2014. "Cancer is a disease of DNA."

The groundbreaking initiative birthed in 2010 has grown into the most ambitious effort in the world to discover the origins of childhood cancer and seek new cures. Researchers have analyzed the genome sequences of normal and tumor tissue of some 800 cancer patients, and conducted further genetic testing on an additional 1,200 patients.

A decade later, having wrought changes in the way pediatric cancer is researched, diagnosed and treated, the project continues to deliver results. It's given rise to nearly three dozen scientific papers in high-impact journals, with new findings still being published. What's more, data generated by the genetic sequencing has been freely shared with researchers around the world through the St. Jude Cloud, an online collaborative platform.

"The Pediatric Cancer Genome Project has had a profound impact on our understanding of the genetic lesions that drive the formation of pediatric cancer and how resistance to treatment develops," said St. Jude President and CEO James R. Downing, M.D., who is the project's architect and was the hospital's scientific director in 2010. "In turn, this information has had a direct impact on the way we diagnose, risk-stratify and treat pediatric cancer patients."

Or, as St. Jude Oncology Chair, Ching-Hon Pui, M.D., put it: "PCGP revolutionized

Number of St. Jude cancer patients whose genome sequences have been analyzed by researchers

Cancer is a disease of the DNA

Number of childhood cancer patients who have potentially inherited mutations in known cancer-predisposition genes

> *"We decided, let's just roll up our sleeves and do it.*
>
> – St. Jude President and CEO James R. Downing, M.D.

how we study cancer and find cures for previously incurable patients."

It began with St. Jude and Washington University in St. Louis announcing a three-year, $65 million initial phase of the project, funded in part by a $20 million gift from lead sponsor and longtime St. Jude supporter Kay Jewelers. As enthused as they were about the initiative, researchers understood that success was not guaranteed.

"There was no road map for us to follow, there was no safe way to go," Downing said. "We decided, let's just roll up our sleeves and do it."

The project proved so fruitful that St. Jude committed another $30 million to extend it in 2014.

The sequencing work, all completed on time and under budget, yielded important insights into the genetic origins of brain tumors, leukemia, solid tumors and cancer of the peripheral nervous system.

One of the most fundamental breakthroughs made by researchers was establishing that childhood cancers differ profoundly from adult cancers – and should be treated as such.

"The driver genes we discovered in pediatric cancer (are) different from adult cancer patients," said Jinghui Zhang, Ph.D., computational biology chair at St. Jude. "Kids cannot be treated as a small-sized adult."

One of the most fundamental breakthroughs made by researchers was establishing that childhood cancers differ profoundly from adult cancers – and should be treated as such.

Jon Connelly is associate director of the Center for Advanced Genome Engineering at St. Jude.

In another major discovery, researchers learned that about one in 10 childhood cancer patients has potentially inherited mutations in known cancer-predisposition genes. Armed with that knowledge, St. Jude has been able to arrange for monitoring and follow-up checks involving family members of patients identified as genetically susceptible to cancer.

The genome project also has produced tantalizing clues about the causes of – and possible therapies for – some of the most difficult and deadly childhood cancers. For instance, through analyses of the genome of tissue from patients with an incurable, fatal brain tumor known as diffuse intrinsic pontine glioma, researchers identified a specific mutation that drives 80 percent of the cases.

"We can now use that information to start that journey to develop new therapy for these children that are dying of that disease," Downing said in a speech last year.

Yet the discoveries from the genome project are hardly over. In fact, because the initiative opened so many new avenues and means of exploration, the most startling and important breakthroughs may be yet to come.

"I think there will be discovery after discovery, waves of discovery, that come forward as we learn more about how to interpret the data that was generated," said Suzanne Baker, Ph.D., director of the St. Jude Brain Tumor Research Division.

"So this will last for a very long time."

St. Jude Patient Art Buttons: 4-pack

Become a fan of St. Jude with these buttons featuring St. Jude patient artwork. Each button is 1.75" diameter.

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St. Jude Light-Up Retractable Pen and Stylus

Light up your note-taking with this retractable pen and stylus. Logo lights up to show your support for St. Jude.

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gift guide

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Support St. Jude by purchasing this T-Shirt, hat and silicone bracelet combo.

9159BLU **$26**

Insulated Stainless Steel Tumbler in Silver

Enjoy 16 hours of condensation-free cold drinks, and keep your coffee hot for 8 hours with this 12 oz. tumbler. Comes with a clear, push-on lid.

2085SLV00 **$18**

stjude.org/giftshopinspire

an ivy league student in a class of her OWN

BY DAVID WILLIAMS · ALSAC

To understand her mom's reaction when Courtney declared she wanted to go a thousand miles away for college – *"this nonsense,"* as Audrey now calls it, with good humor – you have to go back to the beginning.

Actually, before the beginning.

Six months into her pregnancy, a test showed Audrey's baby would be born with sickle cell disease. There was a family history, so Audrey wanted the test. She wanted to know so she could prepare, so she could give her baby every chance to thrive with a disease that can cause chronic, sometimes debilitating pain.

And Courtney has thrived, thanks to St. Jude Children's Research Hospital. "I tell people I thank God, and I thank St. Jude second-most, for, really, all aspects of her life," Audrey said.

Because St. Jude wasn't just a healing place for Courtney. It's where she learned to read, in that difficult summer between first and second grades, as she struggled with the cognitive side effects of her disease. It's where her personality "bloomed" – her mom's word – as the chance to participate in St. Jude fundraising events drew out this once-timid girl who went from "being afraid of everything and everybody," to an impromptu singing performance on stage in a ballroom full of people.

Or, as Courtney said, with a laugh, "And then one day somebody at ALSAC (the fundraising and awareness organization for St. Jude) handed me a microphone, and apparently they couldn't get it away ever since."

Sickle cell disease did not define her. She wasn't about to let it confine her: As a high school senior in Memphis she was accepted at Cornell University. Think of it – an Ivy League education for a girl whose mother once worried "the child would never read."

Now mom was worried about other things. About things of great consequence to the parent of a sickle cell

patient, like geography. Cornell is in Ithaca, New York, a thousand miles from Memphis and the support system with which Courtney grew up. A thousand miles from mom, and St. Jude.

And there was the weather. Winters can be harsh in Ithaca, and cold weather can trigger pain episodes in sickle cell patients. It was so cold the first time Courtney visited campus that she had to borrow a heavy coat from the girl with whom she was staying – and that was in October.

"I said, 'Don't you think that should be a concern, that you need a big ol' coat in October, and you have sickle cell disease?'" Audrey said.

But nothing would dissuade Courtney. And in trying to win over mom, she had some key allies – her caretakers at St. Jude.

Their reaction?

Oh, my God, Courtney's going to Cornell! Oh, we're so proud of you! We're going to find you a doctor up there, don't you worry. We're going to take care of you, you'll be fine.

PAIN AND BRAVERY

Sickle cell disease is an inherited blood disorder in which red blood cells, which should be round, instead become sickle-shaped, and have difficulty passing through small blood vessels. It can cause intense pain, like "someone hitting your joint with a hammer over and over again," as Courtney heard it described once by another sickle cell patient.

Between the medical definition and the more visceral analogy lies the reality for some 100,000 people in the U.S. with sickle cell disease, most of them African Americans.

St. Jude has been researching sickle cell disease since the hospital's founding in 1962. Today, the hospital operates a groundbreaking clinic to help 18-year-old patients make the transition from St. Jude to adult-care facilities.

> *"My mom had been preparing me my entire life... whether I was going an hour away or 14 hours away.*
>
> – Courtney

Courtney, 19, says she has "good weeks and bad weeks," but calls herself "incredibly blessed in my journey with sickle cell," compared with those whose pain is more frequent and severe.

As for the Ithaca winter, nobody lied about that. "To have that first winter, to walk around in negative 2 degrees weather," she said, "it was definitely a shock to my body."

But for about seven months – until March, when the pandemic sent students everywhere home – Courtney persevered. She prospered. She lived her dream.

ONE PROUD MOM

Mothers know best, even when they don't. Or put another way, Audrey may have been overly protective in wanting Courtney to stay closer to home. But think of the daughter she raised – a girl who hasn't just learned to cope with sickle cell disease, but rise above it.

"My mom had been preparing me my entire life," Courtney said, "whether I was going an hour away or 14 hours away."

Mom doesn't take credit, of course. She thanks God and St. Jude, and marvels at Courtney's maturity in her freshman year so far from home, amid the ice and ivy of Cornell.

"We don't have her grades from this semester, but last semester she made all A's," Audrey said. "Being a million miles away from us, little Southern belle girl at an Ivy League school, upstate New York, freezing cold, didn't know anybody in the world.

"I'm still like, how'd that happen?"

HELPING PATIENTS WITH SICKLE CELL DISEASE TAKE CHARGE OF THEIR HEALTH

By Jane Hankins, M.D.

Associate member of the Department of Hematology at St. Jude Children's Research Hospital

More and more, people have access to personal technology (e.g., smartphones, tablets) and are using it as a tool to help meet their health care needs. Turning to technological solutions, including the use of mobile health (mHealth) and electronic health (eHealth) approaches, is becoming more common in health care including the care of patients with sickle cell disease. However, there is no smartphone app to help patients with sickle cell disaease take medicine as directed.

Sickle cell disease is a common inherited blood disorder affecting approximately 100,000 Americans, mainly of African descent. Red blood cells in people with this disease take on a sickle, or crescent shape, rather than a normal round shape. This disease is associated with lower quality of life, increased need for health care and early death. It is a debilitating illness with both acute and chronic complications. These complications can include pain, heart problems, cognitive dysfunction and worsening organ damage.

Hydroxyurea (hydroxycarbamide) is a medication used to help manage the effects of sickle cell disease. This treatment has been available for more than 30 years, and reduces disease complications, health care use and costs. Current treatment guidelines recommend hydroxyurea for adults with sickle cell disease-related symptoms and all children with sickle cell disease. But there are barriers that can make it difficult for patients to take this medication consistently over long periods of time.

In 2016, the National Heart, Lung, and Blood Institute provided support to St. Jude and collaborators to develop a mobile health app to improve the use of hydroxyurea by sickle cell patients. Our team, spearheaded by Nicole Alberts, Ph.D.; Sherif Badaway, M.D.; and Jerlym Porter, Ph.D., M.P.H., recently published an update on our work in this area. To do this, we worked with patients living with sickle cell disease to determine the barriers to taking hydroxyurea, learn about patients' needs and preferences for receiving support via mHealth, and begin developing the InCharge Health app.

IDENTIFYING AND OVERCOMING BARRIERS

For an mHealth intervention to be effective, patients must be involved in the design and development from the outset. The same is true when designing an app that helps support people with sickle cell disease. So we took a phased approach to getting feedback from patients living with sickle cell disease, including hosting a digital workshop, giving surveys and conducting interviews and focus groups.

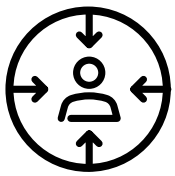
We identified factors that get in the way of regularly taking hydroxyurea that included forgetfulness, fear of side effects, insurance or price, stigma and fatigue. Additionally, more than half of the study's participants reported low health literacy, suggesting a need for clear and easy-to-understand educational materials about sickle cell disease and its treatments.

Patients identified seven key features of a potential app that they would find helpful, including:

Medication reminders and a tracking feature

Disease education

Communication



Personalization

Motivation

Support during pain episodes

Social support

Sickle cell disease is a common inherited blood disorder affecting approximately 100,000 Americans, mainly of African descent. Red blood cells in people with this disease take on a sickle, or crescent shape, rather than a normal round shape.

This feedback informed the design of the InCharge Health app. Our prototype app is a customized product for the sickle cell disease population, created with substantial input from users. The goal of the app is to improve the quality of life and health outcomes for patients with sickle cell disease.

A clinical trial is underway so adolescents and adults with sickle cell disease can test the app, and we can evaluate if it helps patients take hydroxyurea as directed. mHealth interventions for other diseases have shown considerable potential to help improve quality of life and health outcomes. By developing InCharge Health, we hope to leverage mHealth to better support patients with sickle cell disease, and ultimately help them experience the benefits of hydroxyurea treatment, including a longer, healthier life.

This article originally published on the St. Jude Progress blog.

TP53: ONE IMPORTANT GENE IN RARE CANCERS — AN UPDATE

By Emilia Modolo Pinto, Ph.D.

Associate scientist in the Pathology Department at St. Jude Children's Research Hospital

Cell division, the process of making new body cells, is a lifelong process. If you live to an average age, your body cells will divide about 10,000 trillion times. That's one, followed by 16 zeros. In any one of these divisions, just one mistake could be the beginnings of a tumor.

THE *TP53* GENE: ONE OF THE MOST IMPORTANT GENES IN CANCER RESEARCH

I study the molecular biology of pediatric adrenocortical tumors, a rare disease. And because of the strong association with a genetic defect in the *TP53* gene, I'm also interested in this gene.

The *TP53* gene is responsible for monitoring cell division in your body. If a cell's DNA is damaged or improperly copied, *TP53* stops the cell from dividing. *TP53* can correct the damage, prevent replication or send an apoptotic message, forcing the cell to die. In effect, the *TP53* gene is the guardian of your genome.

We're learning more about cancers and other conditions associated with *TP53* mutations, including adrenocortical tumors (ACTs) and Li-Fraumeni syndrome. Our ACT research has also led to more information about Beckwith-Wiedemann syndrome.

"If a child has an adrenocortical tumor, many times, it's because they have an inherited *TP53* mutation," says Gerard Zambetti, Ph.D., associate director of training and education for the St. Jude Comprehensive Cancer Center. "But there are other ways of getting to that same tumor type."

But what about ACTs that are not showing germline mutations in the *TP53* gene? This question left our team and the clinical team with a problem to solve. Our work published in the *Journal of Clinical Oncology* showed how some ACT cases can also occur through a germline, or inherited, defect in chromosome 11p, and some others because of an unidentified molecular event.

ACT AND THE BRAZILIAN STORY

Years ago, Raul Ribeiro, M.D., worked at St. Jude as a fellow. He then returned home to practice in Brazil and noticed a high incidence of ACT in children. He returned to St. Jude and began to organize the International Pediatric Adrenocortical Tumor Registry (IPACTR), collecting clinical and demographic data from pediatric patients with ACTs around the world.

Pediatric ACT is rare in the U.S., occurring in about 1 in 3 million children. In Brazil, pediatric ACT occurs 15 times

more often. Dr. Ribeiro and his team showed that ACTs in Brazilian patients were all associated with the same inherited *TP53* mutation, even though the children were from different families.

I determined that this single mutation, *TP53-R337H*, could be traced back several generations, and is the same for all Brazilian patients. Because the registry developed at St. Jude traced this mutation in patients from Portugal and Spain, it led us to the hypothesis that this mutation originated in Iberic Peninsula and spread to Brazil.

We learned that all of these families have the same founder mutation. Some families with the mutation have cancers of all kinds, like Li-Fraumeni syndrome, where catastrophic mutations in *TP53* result in a nearly 100 percent chance of developing cancer, sometimes multiple cancers, and usually at a young age. But other Brazilian families have little or no instances of cancer. This suggests other environmental or genetic interactions with the mutations may be involved.

Through the International Pediatric Adrenocortical Tumor Registry, physicians around the world began sending medical and demographic information about their ACT patients. They also sent blood and tumor samples to give us more data for our research.

MORE SCREENING AND EDUCATION NEEDED

Because ACT can show up for quite different reasons, it's important for patients and their families to find out the driver of that tumor.

Through whole-genome sequencing and other projects, we are learning more about the genetic events that lead to benign and aggressive cases.

A child with a *TP53* mutation is at a higher risk for cancer. If a child is tested and found to have a mutation in this gene, then the child's siblings and family members can also be checked for the mutation. That information is critical in terms of future screening and surveillance.

Through whole-genome sequencing and other projects, we are learning more about the genetic events that lead to benign and aggressive cases. We recently published in *Science Advances* the results of a whole-genome sequencing study focused on individuals of Brazilian ancestry who have the *TP53-R337H* founder mutation. We found that in some people, a second variant in the tumor suppressor gene *XAF1* occurs. Together these inherited variations in *TP53* and *XAF1* can greatly increase a person's risk of developing cancer.

Our research and clinical team remain committed to investigating unknown instigators of this disease and furthering treatment options. Indeed, our molecular analysis of adrenocortical tumors in the lab can inform clinical decisions regarding the effectiveness of specific treatments for patients.

SUPPORT AND REGISTRY SUCCESS

We encourage patients to enroll in our registry. It not only leads to discoveries, but it offers resources and support.

We still have a lot of work to do. Fortunately, we can now better understand the genetic events that trigger this rare disease and select treatment options because of those findings.

This article originally published on the St. Jude Progress blog. To read more from doctors and researchers, visit **stjude.org/progress**.

in his mind's eye

By Thomas Charlier · ALSAC

Once the surgery was over and the anesthesia had worn off, once it had come time to remove the eye patch, Max's parents knew all too well that their little boy would never see again. They just hoped he'd remember. His mom, Yanin, and dad, Shane, hoped that even in blindness Max would remember the sight of candles glowing on his birthday cake, Halloween pumpkins slathered in paint, lights twinkling on Christmas trees. They hoped that in his mind's eye he would still see the blazing red sheen of a fire truck, the dizzying panoramas of an amusement park and the lush greenery of nature.

Artwork by St. Jude patient Valentina

They hoped, in short, that the rich visual banquet they served up for Max during those whirlwind weeks before the surgery would feed memories that would continue to flicker for the rest of his life.

That's all you can do for a boy who'd had one eye removed as a baby and was now losing the second: Make sure he sees as much as possible before he sees nothing at all.

And it helped. Ever since the surgery, Max has adjusted well, his parents said, even if he's still trying to make sense of it all. He occasionally blurts out a question that sounds like the product of a 6-year-old's phantasmagoric imagination.

Who took my eye?

Then there's the related question:

Will I see again?

To both queries, his parents respond with gentle candor. Doctors at St. Jude Children's Research Hospital removed his right eye, they explain, because, just like the left one, it was sick and could have made the rest of him sick.

And, no, they tell Max, no, you'll never see again.

But this story is not a tragedy at all. It's a tale, instead, that traces intersecting paths of compassion and mercy that connected a cancer-afflicted boy in China with the Illinois couple who adopted him from an orphanage. Their paths took them to St. Jude, where he and the family received lifesaving treatment and comforting support in equal measure. Max was just 4 months old when he was abandoned at the gates of the orphanage in Changsha, capital of China's Hunan province. No one knows exactly why the boy's birth parents left him

Flower artwork by St. Jude patient Diana

there, but Yanin, having read the file, suspects it was because they were alarmed by an ominous white coating on his left eye.

"I think the parents already knew there was something there. I don't think they knew it was cancer, but they knew there was something there," Yanin said. She went on to explain that medical care can be ruinously expensive for Chinese families, with doctors often demanding payment in advance. Parents are left with the choice of letting a child die or giving him or her up.

Max eventually was diagnosed with retinoblastoma, a cancer of the eye. When he was a year old, doctors enucleated the eye to prevent the cancer's spread. Enucleation means the eye is removed but the eye muscles and orbital contents are left intact.

The boy was still living in the orphanage when doctors found cancer in the remaining right eye, as well. Max underwent chemotherapy that drove the cancer into remission, even though the conditions were less than optimal.

"Only by the grace of God we were able to navigate those waters and come out the other side. We owe a lot of that to St. Jude. They met us just where we were at and really helped us get through this.

Meantime, on the other side of the globe, Shane and Yanin, who already had two biological children, decided they wanted to expand their family though adoption.

"We've always had it on our hearts," said Shane, a pastor. "God's blessed us with a big enough home where we could have more kids. There's a lot of kids who need a home, so God has taken us on that journey of adoption."

Part of the journey involved skimming through a book containing photos of children in need of adoption. The photo of Max caught the couple's attention, and the fact that he has the same birthday as Yanin solidified him as their choice. After they had begun the process of adopting Max, however, the couple received conflicting information about whether the cancer in the boy's remaining eye had returned. They chose to continue the adoption process anyway.

"We knew if he was not treated he was going to die there," Yanin said.

In March 2018, the couple traveled to China and came home with their new son, then 4 years old. But a few months later, doctors found four active tumors in the boy's right eye. The family quickly headed for St. Jude. Shortly after treatment began, doctors discovered still more tumors. By mid-September, they told Shane and Yanin that Max's only remaining eye should be enucleated, as well. If not, the cancer might spread to his brain. The couple agreed.

"We had to think of the life of Max before the eye of Max," Shane said.

Surgery was scheduled for three weeks later, meaning the couple had a mere 21 days to prepare for their son's permanent blindness. Thus began a race against time.

"It triggered us," Shane said. "We came home and we tried to give Max all the experiences possible, visually, just to create memories."

And that they did. Shane and Yanin arranged family trips to places like an amusement park in Missouri. Max loved the rides – the higher and faster, the better. No boring carousels for him. "He doesn't get scared," his mom said.

The amusement park was part of a development that included a Christmas store, which allowed the family to squeeze in a visit so Max could see lighted trees for the first time.

Christmas tree by St. Jude patient Macey, package by Emmalee, sibling to a St. Jude patient; pumpkins by Madyson, sibling to St. Jude patient Kayleigh

Shane and Yanin also wanted the boy to experience a little of Halloween. Even though it was weeks away, they found pumpkins for him to paint.

They celebrated Max's birthday early so he could see a birthday cake – an experience he never had in the orphanage.

They took him to parks and arranged for him to see fire trucks. A friend of Shane's who was a police officer got permission to bring a squad car to their home.

"We just tried to do as much as we could," Yanin said. "Basically try to, in less than a month, cram everything you can imagine."

As time grew ever shorter, the couple had to race to fulfill a special dream of Max's. "He was obsessed with monster trucks," Yanin said, referring to vehicles that are 11 feet tall and weigh more than 9,000 pounds.

The most challenging task for the couple, however, might have been explaining to Max that he would never see again after the surgery. Still, more than a year after the eye was enucleated, Shane and Yanin marvel at how well Max has adjusted, given all he's been through.

"We came home and we tried to give Max all the experiences possible, visually, just to create memories." – Shane

"He knew no English when he got here – all he had was Chinese. He just got to the country, had been adopted by a family he barely knows, then we've got to take his eyesight. All this within a year," Shane said.

Max doesn't even complain about his blindness, Yanin said. She and Shane think they know one reason why: By the time his right eye was enucleated, his vision had deteriorated as the tumors proliferated.

"It was kind of like a blessing that he started losing his sight little by little because he was kind of getting used to not seeing that well with the only eye," Yanin said.

When Max asks whether he'll see again, and why not, his parents emphasize the senses he still has. They tell him he has hands to feel with, a nose for smelling, a tongue for tasting and ears for hearing.

Languages seem to come easily to Max. Within six or seven months of moving to the U.S., he was speaking English "like anyone else," Yanin said.

Max takes jiu-jitsu classes, loves to ride on the back of a tandem bike and can't get enough of jumping on a trampoline. He's smart and sociable, the center of attention wherever he goes.

"Nothing holds him back," his dad said.

Max wears prosthetic eyes, which he can take out himself. He needs a little help putting them back in.

As Shane and Yanin see it, their son's progress has served to vindicate their own decisions to adopt and to agree to the enucleation surgery.

Especially rewarding for Shane and Yanin are those moments when Max lets them know he remembers the sights they presented him just before the surgery. Sometimes they ask him about a specific memory, and he says yes, he recalls the sights, just as they had hoped.

Last fall, a year after the surgery, the family visited Walt Disney World, where Max enjoyed rides once again. As he felt the wind in his face and experienced the gyrations of dips and turns – no doubt reminding him of the Missouri amusement park – he could barely contain his joy.

It was further proof that even in Max's sightless world, the future appears as bright as the happy memories that still shine.

Zebra artwork by St. Jude patient Coraliz; monster artwork truck by St. Jude patient Dionisio

Donor-advised fund gifts can help secure the future for patients and families

St. Jude patient **Brieanna** rhabdomyosarcoma pictured with her mom

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Hope on the other side

"Mason was still in the hospital, having just been diagnosed with liver cancer. All of this had been going on around us and we hadn't even realized it.

Within days we were in an ambulance to Baton Rouge, and then a plane to St. Jude Children's Research Hospital in Memphis as medical evacuees. Hurricane Katrina bore down on the Gulf Coast and overwhelmed the levees, changing the direction of so many lives."

Mason was a preemie with liver cancer. D'Anna was a young mother at the beginning of college. Approaching the 15th anniversary of Hurricane Katrina, she opens up about their life since, and the parallels she sees between the devastating hurricane and COVID-19 pandemic.

stjude.org/mason

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