

ST. JUDE inspire



FALL 2021

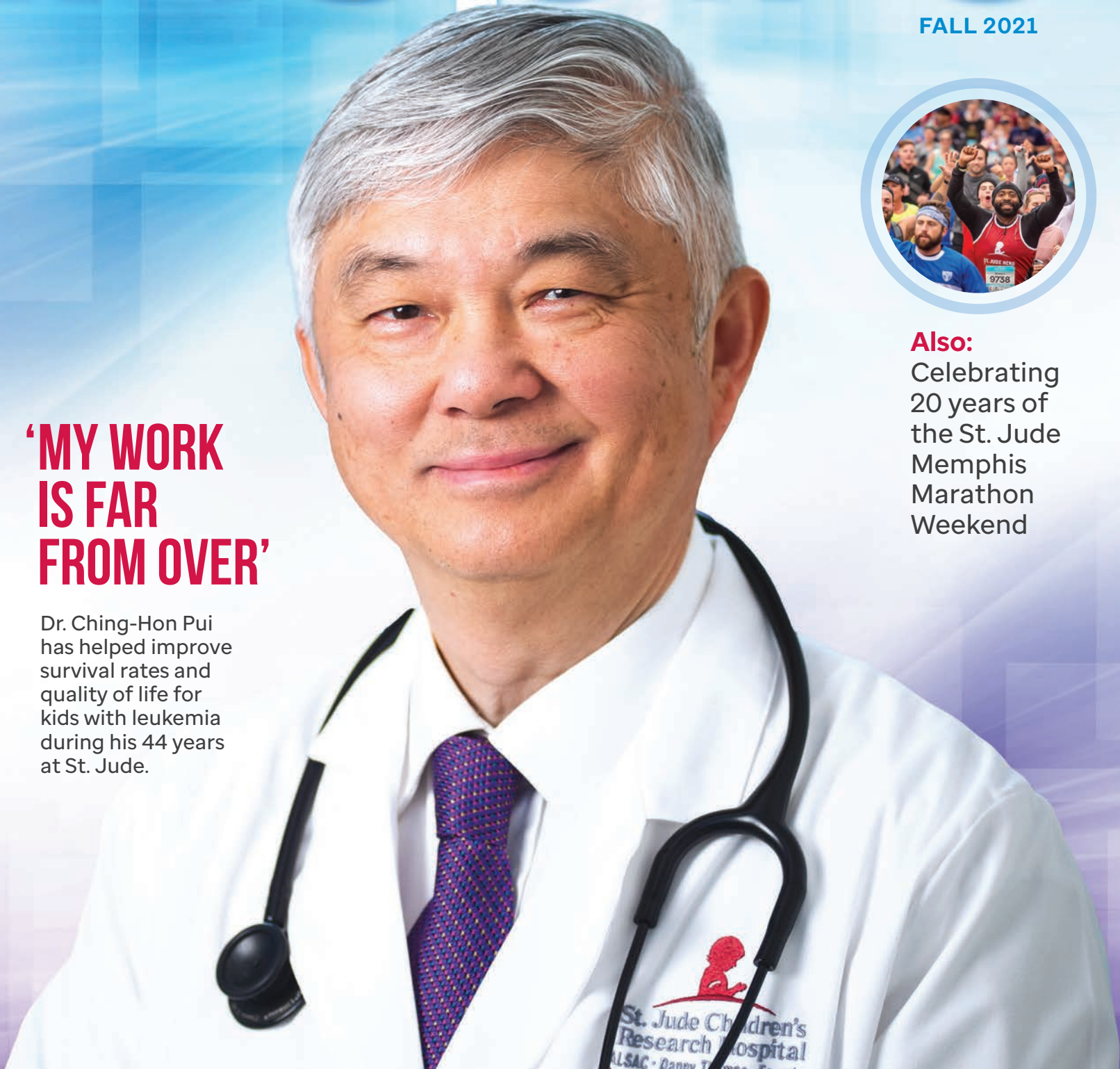


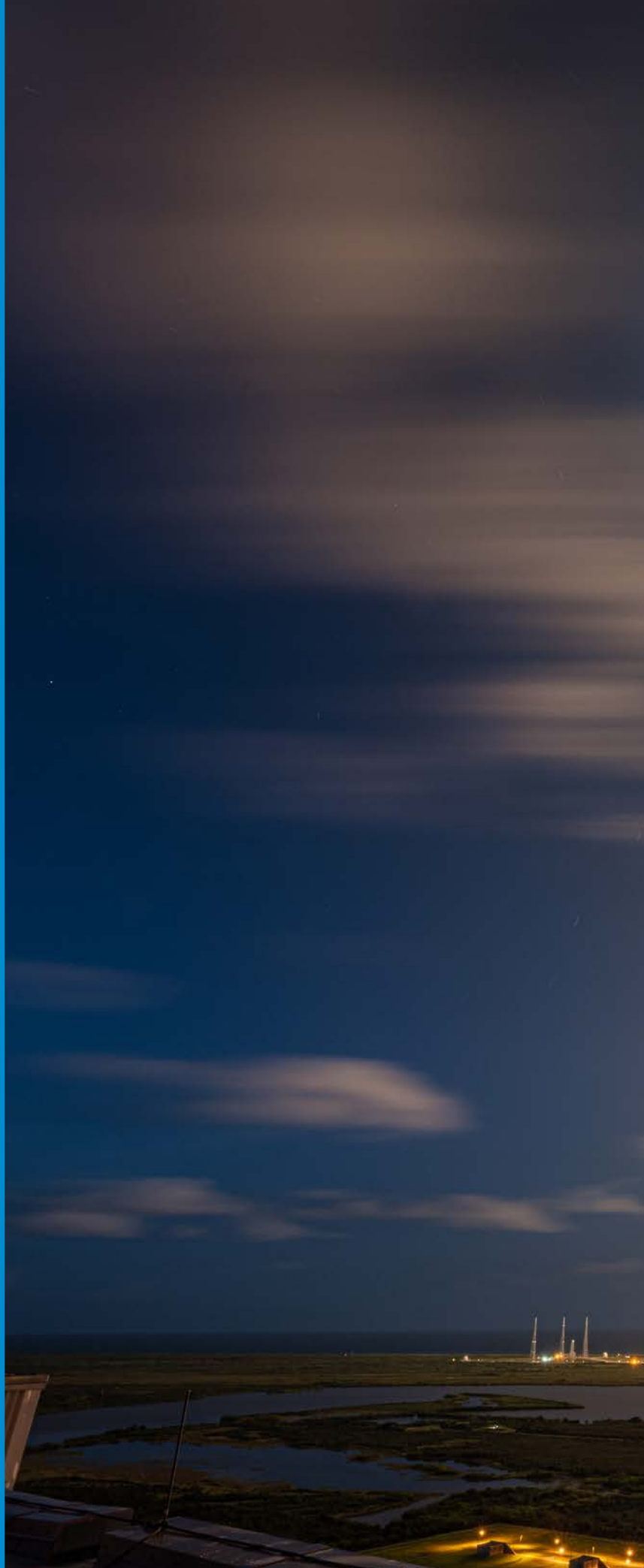
Also:

Celebrating
20 years of
the St. Jude
Memphis
Marathon
Weekend

'MY WORK IS FAR FROM OVER'

Dr. Ching-Hon Pui
has helped improve
survival rates and
quality of life for
kids with leukemia
during his 44 years
at St. Jude.







In flight

The Falcon 9 rocket streaks across the Florida night sky in this long exposure photograph as the SpaceX Crew Dragon launches into space carrying the Inspiration4 crew, including St. Jude pediatric cancer survivor and current St. Jude physician assistant Hayley Arceneaux (left). The three-day space flight was the first all-civilian mission to orbit Earth.



As Inspiration4 launched St. Jude pediatric cancer survivor Hayley Arceneaux and her fellow civilian astronauts into orbit, and into history, I thought of our founder's words:

"They said it was impossible."

Danny Thomas spoke those words about St. Jude Children's Research Hospital. His dream of a hospital where children of all races, creeds and economic stations could be treated. His vision of a research institution to cure diseases considered incurable.

The impossible made possible.
The possible made real.

Or, to put a face on it, bright and beaming – Hayley, St. Jude patient turned St. Jude physician assistant turned space explorer in a mission to benefit the kids of St. Jude.

"They'll be able to see a cancer survivor in space," said Hayley before the flight, "someone just like them."

She took her love of St. Jude to space, and literally beamed it back. Hayley and crew interacted live with patients *from space*, answering questions about everything from their view of Earth to whether there are cows on the moon.

Floating upside down and wearing St. Jude gear, Hayley told patients, "If I can do this, you can do this."

After three days of orbiting Earth and then splashing down safely

back home, Hayley focused not on personal glory but the greater good. She thanked everyone who supported Inspiration4 and the accompanying mission of raising \$200 million for St. Jude. Hayley said she was filled with "awe and gratitude."

That it was possible – that it *happened* – was testament to humanity's restless spirit and relentless drive. It was testament to Danny's audacious dream, and science's ceaseless push to discover.

When Hayley was diagnosed with osteosarcoma as a 10-year-old, she had limb-sparing surgery instead of amputation. She received a titanium prosthesis that could be lengthened remotely, as she grew.

Today, the 10-year-old girl who remembers saying, "I don't want to die," is 29 and has flown circles around the Earth. She's shown us that, sometimes, even the impossible is possible.

Richard C. Shadyac Jr.

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Research Hospital**
Finding cures. Saving children.
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You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate



ST. JUDE MEMPHIS MARATHON WEEKEND

Moments

2002: The debut St. Jude Memphis Marathon Weekend drew 2,900 runners and raised \$213,500 – an outstanding beginning for an event that would show staggering growth in the years to come.





2005: The 5K is added and participation (7,286) and funds raised (\$546,450) in the event had both increased more than 2½ times in just four years.

2007: Marathon participation climbed past 10,000 and revenue more than doubled from 2006 to \$1.3 million.



2008: Races were capped at 3,000 runners for the marathon, 8,000 for the half marathon and 3,000 in the 5K – and the event sold out, a first in its history. With 14,000 participants flowing through the streets of Memphis, another record was set: \$1.6 million raised.



CELEBRATING 20 YEARS OF RUNNING FOR THE KIDS

This year, we commemorate 20 years of running to benefit the kids of St. Jude. For this milestone anniversary, we salute the longtime support of our heroes who have participated in every single St. Jude Memphis Marathon Weekend since the beginning.

We also acknowledge the St. Jude Memphis Marathon isn't just a day of races. It's a day of devotion to a cause like no other – to achieve the day St. Jude founder Danny Thomas dreamed of, when no child dies in the dawn of life.

2009: This year marked the introduction of what might be called the event's signature feature – the run through campus. It's become the most emotionally stirring moment of the day for runners, streaming through the grounds of St. Jude as patients and families, caregivers and supporters line the sidewalks to cheer, wave signs of support and clang cowbells.



2011: The 10th edition of the St. Jude Memphis Marathon Weekend raised \$4 million, a \$1.2 million jump from the previous year. Spoiler alert: The next year, 2012, fundraising would reach \$6 million.





THESE RUNNERS HAVE PARTICIPATED EVERY YEAR OF THE ST. JUDE MEMPHIS MARATHON

By Betsy Taylor - ALSAC

On a December night in 2002, Miriam Dillard downed some burritos and margaritas with a friend at a Tex-Mex restaurant in Memphis. The next morning on a lark and without training, the 21-year-old biology major at Rhodes College ran her first half marathon.

You might have heard of it.

The St. Jude Memphis Marathon, back then, was just a small, regional race.

Before it became a nationally acclaimed destination event that draws 26,000 racers worldwide. Before it became the largest single-day fundraiser for St. Jude Children's Research Hospital.

And one year before Miriam Dillard – now Miriam Dillard Stroud – became a researcher at St. Jude and embarked on the rest of her life.

“Seeing it go from a tiny number of people to a huge number of people, I think it just gets more and more special,” said Miriam, who runs every year.

2013: An ice storm in Memphis forced the cancellation of the races, but the spirit of the event, and the cause it serves, were kept alive by a few intrepid runners. Consider the five marathoners from Kentucky who made the trip, ice and all. The race was canceled four hours after they arrived, but they decided to run on their own anyway.

2014: Unable to run following knee surgery, former St. Jude patient and three-time cancer survivor Hillary Husband, was pushed in a wheelchair by a friend, St. Jude Hero and fitness professional Jay Cardiello. The year before, Hillary completed the 26.2-mile journey, one mile at a time, in the halls of St. Jude while recovering from a bone marrow transplant.

MIRIAM

DILLARD STROUD



'WE WERE DOING IT'

Of the 2,846 runners that debut year, fewer than 20 have participated all 20 years. These are the stories of five who started running for St. Jude in 2002 at the first St. Jude Memphis Marathon Weekend – and never stopped.

They've run every single race for the past 20 years, except in 2013 when an ice storm cancelled it. (And some of them ran on their own even then.)

It's more than what they do. It's who they are.

Miriam, who as a Platinum St. Jude Hero for Team Rhodes, commits to raising at least \$5,000 for St. Jude each year, has kept all her St. Jude medals, "and I don't really hold onto race medals."

She remembers that first race in 2002 and how she strapped a portable CD player to her chest so she could listen to her mix CD as she ran. All the runners wore cotton. And no one had digital cameras yet.

Her cotton shirt from 2002 "has holes in it, and I've had to have it sewn up multiple times because I'm like, 'I'm not letting go of that.'"

"I like to think we were all running before people figured out the juggernaut of what running is now. We were all doing it wrong, but it's fine," said Miriam. "We were doing it."

And they'll keep doing it.

RAJ

BETAPUDI



'PUSHING THE LIMITS'

As a young boy in Akavidu, India, Raj Betapudi would often run with his dad around the high school track. He moved to the U.S. in the 1990s, and when he heard about the fledgling St. Jude marathon event from a colleague, he felt compelled to try, little realizing that through the process of training, he was weaving his past with his present.

Building up for the half marathon meant overcoming what Raj calls "a mental block" of self-doubt.

His breakthrough came on a treadmill at work when he ran farther than he ever had.

He thought of that little boy in India running with his dad. Back then, he'd had no worries, only dreams.

Raj accomplished his first St. Jude half marathon in 2002, and has accomplished many more since. He's proud to have been part of the St. Jude marathon since the very beginning.

He sees a beautiful pattern in the warp and weft of his running life.

"My dad had three kids. A girl, boy, and a girl, and I have the same sequence of kids, and they do running. I guess this is the joy of passing (traditions) on.

"I think it's just a great joy to be outside and enjoy the nature, and also challenging your body to do more than what you thought you were capable of doing and pushing the limits."

2016: Many St. Jude Heroes raise money for the cause without having been touched by childhood cancer. That was Peter, who said about running the 2016 St. Jude Memphis Half Marathon, "I was raising money for a hospital I didn't even fully understand. But I always said, if it was my kid, I would want somebody to be doing this for them." Less than two years later, his daughter, Olivia, was diagnosed with leukemia and began treatment at St. Jude.

2017: The half marathon featured a surprise marriage proposal between a Kansas couple. He ran ahead of her, allowing him time to finish the race and change into a tux, so as to pop the question in style, just after she crossed the finish line. And yes, she accepted.



KERI NUNLEY



'LORD, I WAS SO SLOW'

Keri Nunley wanted to do the St. Jude race for her dad.

"A friend of mine was going to do it, and she said, 'Hey, do it with me.' And I was like, 'Oh Lordy, I can't run, girl.' I was like, 'I'll walk.' So I really trained. I trained and trained and trained."

It started as a way for her to wrest meaning from an incomprehensible loss.

Her father had died in April 2001 from colon cancer. After his death, she learned he'd been a devoted giver to St. Jude for years, and he'd directed his memorial funds there. She felt the impressions of his handwriting on the checkbook ledger as though they were inscriptions on her heart: Page after page said St. Jude.

"We just never knew he donated like he did, and this is just my way to keep his donation going."

Alone as the sole member of Team Hertwig that first year — "Lord, I was so slow. I was out there all by myself." She walked 13.1 miles, her feet aching but her spirits high. It took 3 hours and 40 minutes, but she did it.

Keri walked alone that year but it was the only time she'd ever have to. After that, her family joined her, flying in from as far away as Pennsylvania, Texas, Florida and California to gather in Memphis for a family reunion of sorts, in running shoes.

Today Team Hertwig boasts 35 members and raises about \$30,000 each year.

"It's been 20 years since he's been gone, and this will be our 20 years for St. Jude," she said. "I think he would be super proud of what we're doing and that we're all still getting together."

RICH VANMETER



'IT'S TOUCHED EVERY PART OF MY LIFE'

Rich VanMeter's muscles were aching, tired from the exertion of his 2007 St. Jude marathon, but when the St. Jude Hero looked over and saw his girlfriend Nicole Tice and her son William right where they said they would be along the route, talk about a runner's high.

They'd been dating several months and she wasn't a morning person, but they came out anyway, holding a sign William had scrawled in his little kid handwriting that said, "Go Rich!"

The thought occurred to him: He'd never been happier.

In 2002, Rich had been running with a group of guys where he worked at the Navy base in Millington, Tennessee, who wanted to be in peak shape. One of them brought up the idea of running in the new St. Jude marathon event.

How could he have known it would set him on a path to the rest of his life?

Rich's running in the St. Jude marathon led to volunteering at St. Jude, which led to meeting the pretty brunette and fellow volunteer Nicole.

"If I hadn't started running the marathon that first year, then I wouldn't have gotten into the volunteering for it. ... You know it all trickles down. I met Nicole, got engaged, got married, got a son, Adam — two sons, counting William, too. It's touched every part of my life."

Rich proposed to Nicole in the lobby of Tri Delta Place in 2009 on the St. Jude campus, the place they'd met as volunteers.

2019: Some 26,500 participants from all 50 states and 17 foreign countries descended on Memphis for race day, among them 7,200 St. Jude Heroes who raised a record \$12.3 million for the cause.

2020: The marathon went virtual, along with most everything else in the pandemic-stricken world. But something good came of it — people from around the world, who wouldn't have made it to Memphis for a traditional in-person event, participated in their own hometowns and countries.

DONNIE BALDOCK



'I'M CRYING AGAIN'

What do you say about the energetic jokester Donnie Baldock, who, when the pandemic caused the St. Jude Memphis Marathon to go virtual last year, made sure a 14-year-old St. Jude leukemia survivor was able to achieve his dream of running his first half marathon? Donnie secured the permit for the young man to run with a police escort through his hometown and joined him to set the pace.

Who when St. Jude needed platelets, not only rolled up his sleeve, but brought 18 healthy, fit runner friends to do the same?

Who finished his half marathon, only to run to volunteer at the full marathon finish line?

Who runs as part of the St. Jude Breakaway Running for a Cause team that trains anywhere from 150-300 runners per year to participate in the marathon weekend for St. Jude? The team has raised well over \$1 million.

During his life, Donnie has been a lifeguard, a PR guy, a graphic designer, a youth praise team leader, a garage band performer, a running trainer and a first responder. He's a jack of all trades, but his true talent lies in how well he cares for other people. "I'll work over at the St. Jude Heroes table and play guitar and stuff like that to welcome people, and you meet people from all over the world" – but especially the kids of St. Jude.

His wife is a 25-year cancer survivor. He's kept his bib from the very first race. When he runs, he pins a photo of a St. Jude patient to his shirt. When he talks about St. Jude, he chokes up.

"I'm crying again. It's just the families out there. The thank you signs, and I don't know, just knowing families that have been St. Jude patients and stuff is awesome. I don't know. It's awesome, during the race."



Visit stjude.org/marathon to learn more or to support a St. Jude Hero.

Rebecca Krynski Cox, a professional opera singer, made her debut as a St. Jude Hero, running a half marathon through the breathtakingly beautiful countryside of Switzerland amid views of the Alps and Lake Lucerne. She made stops along the way for yodeling and to pet some friendly goats, all the while raising money for the kids of St. Jude.

"I was blown away by the positive response," said Cox, originally from Charlotte, North Carolina. "Within the first 24 hours of posting that I was running, I had nearly doubled my fundraising goal. Everyone that donated did so very enthusiastically, and expressed to me how much they love St. Jude."

DR. CHING-HON

Pui

This St. Jude doctor
helped change the odds
for childhood leukemia
patients worldwide

By Tom Charlier - ALSAC

*Dr. Ching-Hon Pui, MD
poses for a photo with
St. Jude patient Santiago
following a clinical
appointment in 2019.*





uring those first frantic hours following her family's arrival at St. Jude Children's Research Hospital, Nancy wasn't looking for any surprises, but got one, anyway. A good kind of surprise, actually. It came when a diminutive man with graying hair and a white lab coat walked into her little boy's room and introduced himself.

Nancy excitedly phoned her husband, Patrick.

"You've got to get over here," she said. "It's *him*."

Like countless other parents of kids with leukemia, Nancy and Patrick knew enough about Ching-Hon Pui, MD, chair of the St. Jude Department of Oncology, to regard him as something of a rock star in the field. Pui, after all, was a major reason they wanted 4-year-old Brian treated at St. Jude. It is Pui's imprint that's found on treatment protocols used the world over, and it was his name that kept popping up as they scanned the Internet for the leading experts in pediatric leukemia research and treatment. The first article they found went so far as to call him "the best of the best."

But as comforted as they were to have Brian treated in the same hospital where Pui worked, Nancy and Patrick weren't sure they would ever meet him. Friends and relatives who worked in government research and who knew of Pui told the couple he likely would be too busy traveling the world giving lectures and training health care providers.

Pui is internationally renowned for his work to improve survival rates and the quality of life for kids with acute lymphoblastic leukemia, the most common form of childhood cancer. He's coupled those efforts with a personal campaign to extend that advanced care to families around the world, including those in low- and middle-income countries.

Along the way, he's authored more than 1,000 articles and accumulated prestigious awards from institutions everywhere from Washington, D.C., to Shanghai, China. Since 2004, Pui has been recognized by the Web of Science Group as one of the most highly cited researchers of the decade, and just last year, he received the American Cancer Society Medal of Honor.

But for all his achievements, Pui is perhaps best known among St. Jude families for his comforting, playful rapport with patients — for knowing how to do magic tricks as well as medical procedures.



Dr. Pui speaks during an Interventional Radiology Workshop in September 2017.

Now 70, and entering his 45th year at St. Jude, Pui shows no interest in retiring or even cutting back on his 14-hour days. "My work is far from over," he said, "because we are still losing children to leukemia."

The long journey from Hong Kong

It was a movie, of all things, that helped propel Pui on his life-saving path. The film he saw as a middle-school student in his native Hong Kong wasn't about monsters or aliens, but another type of horror. It featured a young boy who survived an atomic bomb blast only to succumb to leukemia resulting from radiation exposure.

"Watching this child and his loving parents suffer helplessly had an enormous impact on me, and I trace my decision to become a pediatric oncologist to that movie," Pui said in a commencement address at the University of the South in Sewanee, Tennessee, in 2017, after receiving an honorary degree there.

Given all the medical and scientific feats he would later accomplish, it may come as a surprise that Pui, by his own admission, wasn't an especially good student as a child. He grew up with two brothers and three sisters. His parents, who both worked, relied on older siblings to help the younger ones, including him, with their schoolwork.

"My oldest brother would rather take me to play with him in the streets than complete the assigned homework. Of course, I was more than happy to comply," he said during the Sewanee speech.

What eventually transformed Pui into a dedicated student wasn't a scolding or ultimatum, but an encouraging, if not entirely accurate, compliment. While he was waiting

to catch the bus home one day, a teacher in the Anglican school he attended walked up and praised him for being a good English student.

“Well, that wasn’t exactly true. But the compliment stuck and became a motivating force in my academic life. I started doing my homework and began to pay more attention at school because I didn’t want to disappoint her.”

After blossoming academically, Pui got further encouragement from a high school biology teacher, who recommended he study medicine in Taiwan. He was accepted at the prestigious National Taiwan University.

After earning his MD in 1976, Pui was accepted into a pediatrics program in the U.S., serving as a resident in a St. Louis hospital. He spent a year there before moving on to St. Jude.

The field of pediatric oncology was about to be transformed forever.

A perfect fit at St. Jude

If you ask Pui, all these years later, what it was about St. Jude that impelled him to stay, he’ll speak of the many unique qualities of the place: How the generous support of donors gives doctors and scientists the latitude to conduct wide-ranging research and provide the highest-quality care without ever sending families a bill.

He’ll also talk of the groundbreaking history on which he could build. Under the guidance of pioneers such as Donald Pinkel, MD, the research hospital’s first director, and later directors such as Joseph Simone, MD, St. Jude piloted studies showing ALL was curable.

And then there’s the interdisciplinary collaboration among researchers, clinicians and physicians to develop, test and refine new cures – again, funded with the generous contributions of millions of St. Jude donors.

“It has a world-class team of clinicians and scientists working together to find better ways to cure children with leukemia,” he said.

“Since my life-long passion is to take care of children with leukemia, St. Jude is obviously the best place for me to stay.”

Still, when Pui arrived in 1977, fewer than half of the children with ALL were surviving long-term. All too often, patients who had gone into remission would relapse and die.

“Since my life-long passion is to take care of children with leukemia, St. Jude is obviously the best place for me to stay.”



St. Jude patient Matthew gives Dr. Pui a small gift in March 2018.

To Pui and his colleagues, the deaths were a cause of heartbreak, but also a source of motivation to develop new and better treatments.

Showing a passion and work ethic that often astonished his colleagues, Pui became the driving force and intellectual leader in ALL research and treatment, said William E. Evans, PharmD, who served as director and CEO of St. Jude from 2004 to 2014 and is now an emeritus faculty member.

“Dr. Pui took the baton, if you will, from Dr. Joseph Simone, who worked with Dr. Pinkel in the earliest days and was part of the team that achieved a 50 percent cure for children with ALL,” Evans said.

“From that day forward, his goal has been to cure every child and to reduce the toxicity of treatment to ensure a good quality of life.”

Pui helped lead the way as St. Jude boosted ALL survival rates past 70 percent in the 1980s and to 90 percent and above in the early 2000s.

With ALL survival rates now reaching 95 percent for St. Jude patients, Pui is looking to raise them further still. Drug dosages and other therapies are carefully calibrated based on patients' individual metabolism rates and the genomic characteristics of their cancer cells.

This kind of precision medicine, which safeguards against the under-treatment or over-treatment of patients, is one of the keys to raising survival rates without increasing toxicity, Pui said.

"Realizing children with leukemia are quite different in many respects, we introduced several innovative treatment approaches with the help of many scientists. We studied the biologic characteristics of the leukemia cells and the normal host cells so we can use the right drugs at the right dose."

Over the years, Pui has expressed optimism that ALL might be completely cured in his lifetime. He acknowledges that achieving a 100 percent survival rate will be difficult, given the research showing that some children are born with genetic predisposition for cancer.

"But we will certainly increase our efforts, not only to cure the leukemia but also to prevent the development of second cancers. Losing a single child from cancer in the dawn of life is unacceptable."

Reducing treatment side effects

Pui is interested in more than just saving lives, however. He wants to make them better.

In what is widely considered one of his signature achievements, he designed and led a clinical trial, called Total 15, to test his bold notion that cranial radiation could be eliminated from the ALL treatment protocol in all patients without any decrease in survival rates.

From its earliest years, St. Jude had pioneered the use of radiation in conjunction with chemotherapy to develop the first-ever cures for children with ALL. But while it killed leukemia cells in the central nervous system and helped prevent relapse, radiation caused often-devastating long-term effects, including IQ loss, endocrine disruption, even fatal brain cancer. Pui has called it "a terrible thing to do to a young brain."

Based on findings from the trial, St. Jude was able to announce in 2009 that with specialized and targeted chemotherapy, survival rates of 90 percent or more could be sustained without cranial radiation.

With those findings, the way in which doctors worldwide would approach treatment for children with ALL dramatically shifted.

Helping children globally

Not satisfied with saving lives and improving treatment at St. Jude and across the U.S., Pui has spent decades working to make the highest level of care available to children around the world, in low- and middle-income countries no matter where a child lives. He's been collaborating with chairs of leukemia committees of 14 major national study groups around the world for more than two decades.

"All patients with leukemia around the world are important to me," he said.

Nowhere has his influence been more profound than in China, where childhood cancer patients long had been left to die at home because of the high cost or lack of access to care. Pui's collaboration with hospitals in Beijing and Shanghai helped convince the Chinese government in 2010 to extend health coverage to childhood leukemia patients.

Pui, in the words of former health minister Zhu Chen, is "the doctor who introduced the most advanced leukemia treatment protocols to China."

At the same time, Pui's work in China has produced reciprocal benefits in the U.S. and elsewhere. Because childhood leukemia is relatively rare, researchers often have trouble enrolling a sufficient number of participants for clinical trials – a problem China's immense population helps alleviate. Just last year, Pui and other researchers were able to report findings from a study involving 20 Chinese hospitals that led to a change in therapy for the more life-threatening form of ALL called Philadelphia chromosome-positive ALL.

Long days of treating patients, doing research

After nearly a half-century of contributions, Pui still pursues his work with the same passion and vigor. He typically arrives at the hospital in the predawn darkness, at 6 a.m. – although he starts work from home around 5 a.m. – and doesn't get home until 7 p.m.

“His work has not only helped children with leukemia survive, but also thrive once treatment ends.”

— Dr. James R. Downing,
St. Jude president and CEO



Dr. Pui makes a friend in Maelin-Kate, who is not his patient, in 2019, but the two have a special bond.

He sees 10 to 12 patients daily and, when not making his rounds, devotes time to research.

“I try to find treatments that can improve both the cure rates and quality of life of children with leukemia, including those who live in resource-limited countries,” Pui said.

Evans sees no let-up in his colleague’s efforts.

“Dr. Pui is either at the hospital working, or he is thinking about his work when away from the hospital. One of my worries was that he would burn out from working too much. But he has proven me wrong about that, as he has more energy and drive today than he did the first day I met him in 1977,” he said.

As serious as he is about his work, Pui reveals a playful, humorous side when interacting with patients. He cracks jokes, does magic tricks and hands out small toys.

“The way he is with the kids is something special,” said Patrick, father of former ALL patient Brian. “He becomes a different person.”

As Pui sees it, the rapport he develops with the children is a vital part of their treatment and overall St. Jude experience.

“I want to maintain a good relationship with patients so they will not be afraid to come to the hospital for treatment. In fact, most of my patients are looking forward to coming to St. Jude to have a good time. Many of them have a lasting and wonderful memory of their time spent at St. Jude.”

In the same way so many patients and families are thankful for Pui, St. Jude itself “owes a debt of gratitude” to him for his many contributions over the past four-plus decades, said James R. Downing, MD, president and CEO of the research hospital.

“His work has not only helped children with leukemia survive, but also thrive once treatment ends. He has shared this work with the world, helping raise survival rates and quality of life for countless children far beyond our Memphis campus.

“Dr. Pui is a tenacious researcher and a compassionate physician,” Downing said. “He is also a dedicated educator and mentor, helping shape the careers of many investigators in pediatric oncology.”

Like Pinkel and other pioneers at St. Jude, “Dr. Pui is among the visionaries who created a trajectory of discovery and innovation that persists to this day,” Downing said.

Those laudatory comments from Pui’s boss reflect on a career that’s both full and exemplary.

But that’s not to say it’s anywhere near an end. Pui expresses no interest in retiring, saying he’ll work “as long as my mental and physical conditions allow me.”

Whenever his career does draw to a close, Pui’s impact will remain indelible for patients and their families.

“There should be a movie made about the life of Dr. Pui,” Patrick said.

Unlike the film Pui saw so many years ago in Hong Kong, it would be an uplifting production, to say the least.

Research by Dr. Pui and others at St. Jude is possible because of generous supporters like you. stjude.org/donate



(l-r) Khristia Bridges, Christopher Bridges, Kaitlyn Bridges, Khirsten Bridges



ST. JUDE MAKING PROGRESS TO SUBDUE SICKLE CELL DISEASE

New advances have increased the life expectancy for patients born with the blood disorder, and researchers now are driving toward a cure.

By Tom Charlier - ALSAC

Seventeen-year-old Khirsten never knows just when the pain will come, but she can predict with graphic precision the knife-like jabs it will bring.

"It feels," she said, "like I'm getting stabbed a whole bunch of times back-to-back."

If teenagers are famously prone to drama, there's no hint of it in Khirsten's voice. Her tone is steady and matter-of-fact while describing the piercing, debilitating pain produced by sickle cell disease, an inherited blood disorder she shares with one of her two sisters and an estimated 100,000 other Americans.

Pain, however, is just part of the burden weighing on sickle cell patients. They also can suffer fevers, infections, fatigue, strokes and organ damage. Typically, they die 20-30 years earlier than people who don't have the disease.

As dangerous and relentless as sickle cell disease is, however, Khirsten and her 12-year-old sister Kaitlyn have

benefited from therapies at St. Jude Children's Research Hospital that help manage and minimize the pain crises while reducing organ damage.

The girls also are enrolled in a groundbreaking St. Jude study aimed at gaining insights into the progression of sickle cell disease, with the side benefit of giving patients important health screenings.

Although it is perhaps best-known for treating and developing cures for childhood cancer, St. Jude has been a pioneer in battling sickle cell disease ever since the hospital's founding in 1962. Its first research grant, in fact, funded a study of the disorder. And in 1983, St. Jude achieved the first cure of a sickle cell patient through a bone marrow transplant that also cured the same child's leukemia.

Over the past quarter-century, advances developed by St. Jude researchers and funded by the research hospital's donors have factored significantly in increasing the average lifespan of sickle-cell patients by 98% — from

the mid-20s to around 50. Now, St. Jude scientists are studying new therapies they say offer hope for a cure of the disease.

"St. Jude has been part of almost every single innovation that's come out for sickle cell disease," said Yvonne Carroll, RN, JD, director of patient services in the St. Jude Department of Hematology.

BATTLING THE ODDS

For parents Christopher and Nichole, the bad news came during what should have been the most joyous of times. Just two weeks after the birth of Khirsten, their second daughter, they received a letter from St. Jude alerting them to the results of routine newborn screening: Their baby had sickle cell disease.

Sickle cell disease refers to a group of blood disorders that impair the flow of oxygen-carrying red blood cells throughout the body. People with the disease usually have a type of hemoglobin that forms hard fibers in the red cells, transforming those cells from oval into banana, or

sickle, shapes that can get wedged into sticky clumps in blood vessels, cutting off the oxygen supply to tissues, muscles and organs.

“Every part of the body is affected – the heart, the kidneys, the spleen, the brain, the muscles, the eyes – it’s a progressive disorder,” Carroll said during a video discussion with donors last year. “It affects every part of their body, and it affects them their entire lives. And that’s why it’s so catastrophic.”

The disease is more prominent in those of African, Latin and South American descent; however, people of any race or nationality can have sickle cell disease, which is most common among descendants of people from Africa and other areas where malaria is pervasive. About 1 in every 365 African-Americans is born with it.

Khirsten’s parents were shocked to learn she had the disease, though Nichole had known she carried the sickle cell trait. What neither parent knew was Christopher carried the so-called hemoglobin C trait, meaning his red cells also contained abnormal hemoglobin. Together, the two parents’ traits added up to a 1-in-4 chance any pregnancy would produce a child with sickle cell disease.

As it turned out, the odds were even greater for Christopher and Nichole. Although their eldest daughter, Khirstia, was born without the disease, Khirsten was diagnosed with it. Then, while Nichole was in the hospital with complications from Kaitlyn’s birth, she got a heartbreaking phone call about the results of newborn screening for her third child.

“To hear that news all over

again,” Nichole said, “it was very devastating.”

THE FRUITS OF RECENT DISCOVERIES

With their early diagnoses, both girls began treatment as infants, starting with penicillin. St. Jude had been part of a pivotal early study showing that administering penicillin to children with sickle cell disease before they reached the age of two months reduces mortality by 84%.

That startling discovery led to sickle cell becoming one of the initial diseases for which newborns are screened, Carroll said, and it prompted the National Institutes of Health to declare it would be “unethical,” henceforth, to fail to give penicillin to babies born with the blood disorder.

By the time they reached the ages of 6 or 7, Khirsten and Kaitlyn began taking daily doses of hydroxyurea, a chemotherapy drug that has been used to treat sickle cell patients for some 20 years. Hydroxyurea boosts the level of fetal hemoglobin in red cells, allowing them to stay round and flexible so they can navigate tiny blood vessels more easily.

With better blood flow, there are fewer pain crises and infections. The drug also appears to prevent damage to the lungs, spleen, kidneys and brain.

As the girls grew, their parents encouraged them to participate in activities and pursue as normal of a childhood as possible. Still, the disease occasionally asserted itself. “It started out they didn’t have many crises,” Christopher said. “But as they got older they started having a lot more.”

Cold weather is a reliable trigger of pain. As blood rushes to the skin surface to keep the body warm, blockages often form. During a rare snowstorm in Memphis last winter, Christopher and Nichole allowed the girls to go outside, but for no more than 45 minutes.

Similarly, strenuous exercise can induce pain crises, as Khirsten discovered after joining the school track team. “Track has put Khirsten in the hospital for long periods of time,” Nichole said, “and she realized that may not be something she needs to do.”

Both girls are energetic, and their parents anguish at the restrictions they face.

“They both love to be out in the world,” Christopher said.

“That’s one of the hardest things that I think Nichole and I have to deal with. We see the life in them, we see the personalities, the things they want to do.”

DEALING WITH PAIN CRISES

Despite all the steps taken to prevent them, the crises still occur. And when the pain comes, it strikes “really deep,” Khirsten said.

“It’s not something you can just rub and be OK,” she said.

“Normally, it puts me out. I can’t walk, I can’t move. Basically, I can’t take care of myself. I’m stuck in the bed all day, or my dad’s having to help me walk to the restroom, stuff like that.”

Or, even worse, a stay of a week or so at St. Jude may be required. Doctors

there make assessments and often use a saline drip to hydrate the body. The girls also get pain medication, although they don't respond the same to certain drugs.

"Even though they both have the same disease, we've realized that the disease has affected Khirsten differently than the way it affects Kaitlyn," Nichole said.

As St. Jude had demonstrated nearly 40 years ago, a bone marrow transplant can cure sickle cell disease, but its use is limited. There are challenges finding a matched donor, and the procedure is associated with numerous complications.

With Khirsten's older sister a close match for her, the family considered the option, but "the chances (for a cure) are not high enough for us to say, 'OK, we're going to put her through that,'" Christopher said.

The family, however, is seeing benefits from a new therapy administered as part of a study.

Khirsten is getting monthly infusions of a drug known as crizanlizumab, which, as a paper published in the *New England Journal of Medicine* in 2017 reported, significantly reduces pain crises for sickle cell patients. Since the infusions began, she's been hospitalized only once, with most of the pain crises manageable with medicine. Kaitlyn is too young for the infusions.

PROSPECTS FOR FURTHER ADVANCES

When she arrived at St. Jude in 1999, Carroll saw sickle cell patients faring much worse than today. More often than not, they died before reaching

age 30. She saw 3-year-olds who had suffered strokes and had symptoms just like those seen in adult victims, including walking difficulties and drooping facial features.

"Not only that, you'd see the guilt from the parents and just the devastation from the parents from thinking they had done something wrong, that they didn't see the signs or the symptoms," she said.

In addition to its work on the penicillin study, St. Jude participated in early research that tested the use of a type of ultrasound of the brain to predict if a sickle cell patient is at risk of a stroke. It has turned into a preventative measure "that has dramatically decreased the number of strokes in children with sickle cell disease," Carroll said.

"And St. Jude just continues with these types of innovations."

One of the most promising avenues of research now underway is gene therapy, which essentially involves replacing the defective gene causing the disease with a corrected copy.

"I think that gene therapy is going to revolutionize the treatment of sickle cell disease," Carroll said.

In the meantime, St. Jude is conducting a number of initiatives to help sickle cell patients live longer and thrive.

The Sickle Cell Clinical Research and Intervention Program, in which Khirsten and Kaitlyn are participating, monitors how the disease progresses and provides health screenings. It also helps patients make the transition from the care they receive at St. Jude to adult care, which they'll have to manage on their own. In the past,



Khirsten Bridges speaks at a St. Jude fundraising in October 2017.

about half of sickle cell patients failed to make that connection.

"What we were finding, anecdotally, was that they were not surviving long after they left our care," Carroll said.

And because sickle cell patients often experience cognitive setbacks that affect their schooling, St. Jude offers tutorial support and programs that help with reading.

For Christopher and Nichole, the initiatives and the research advances are sources of optimism for their daughters' futures.

In fact, Christopher, who worked in a hospital unit in the Army Reserves, took a job as lab technician at St. Jude in part to contribute to the effort to subdue his daughters' disease.

"I'm very hopeful that they will live normal lives and far exceed us," he said.





A TWITCH STREAMER MOVED CROSS COUNTRY TO BE CLOSER TO ST. JUDE

*Trevor Gomes
livestreams himself
singing and playing
piano to raise
thousands for the
lifesaving mission of
St. Jude and has even
trained as a tour guide*

By Ruma Kumar - ALSAC

This is a love story. Only not the kind you think. This is the story of a pianist named Trevor Gomes, a lifelong Californian, who visited Memphis three years ago for a fundraiser at St. Jude Children's Research Hospital. He says he was so "smitten" with the work and the mission he saw unfolding on this rose-hued campus, he uprooted himself from everything familiar – his home, family and friends, and moved cross country to Memphis. All to be close to St. Jude.

No, this is not your typical love story. This is not a meet-cute. This

is about a man who fell in love with a cause.

"When I saw what was happening at St. Jude, I felt like a fist in my chest, pulling me to stay here, to be here," Trevor said.

Like the best love stories, Trevor Gomes stumbled into love, when he wasn't looking.

When he first heard about St. Jude, it was part of a fundraising opportunity in a virtual game show where Trevor was competing against 13 other up-and-coming streamers on Twitch, the Amazon-owned platform where various gamers, artists and personalities

livestream their interests and talents to an online audience.

The winner would get \$60,000 to allow them to turn their streaming hobby into a full-time job. Trevor was the only musician in a field heavy with video gamers. He was desperate to win.

Trevor is the millennial version of a pianist in a hotel bar lobby, virtual and fantastically versatile. His viewers bring him a variety of online sheet music, ask him to play and tip him for his performance. He can perform a range from sweeping classical pieces to ebullient Sesame Street-meets-Disney style tunes. Fans of his

stream were (and continue to be) drawn to how nimble and playful he is with music and song. Like the time when his tortoiseshell cat Maja hopped on the keyboard mid-stream pawing out a few notes and he built on the melody and played a heady Rachmaninoff-esque piece, calling it “Rach-meow-ninoff.”

“WHEN I SAW WHAT WAS HAPPENING AT ST. JUDE, I FELT LIKE A FIST IN MY CHEST, PULLING ME TO STAY HERE, TO BE HERE.”

– Trevor Gomes

He’d begun to build a loyal following and longed to stream regularly, and rely less on the inconsistent gigs he received from the movie studios and entertainment parks in and around Los Angeles. He’d spent years toiling in the background of orchestras on movie scores and in auditions for performers vying for singing gigs in parks or cruises. Trevor said he was worn out with the “gotta make it attitude,” in show business.

On the flight to Memphis, he thought, using his stream to raise as much as possible for St. Jude, could be his way out of the grinding life in L.A.

He spent two days at St. Jude. As a part of the St. Jude PLAY LIVE seminar in April 2018, he took a tour of the campus, played video games with patients, learned of the scope of research, treatment and cures

being pioneered here, and in the end, he says quite simply: “I was smitten. I was just crazy about it.”

It’s funny what you remember about first impressions. St. Jude didn’t smell like a hospital, he said. “There wasn’t that mix of cleaning chemicals and plastic and sadness,” he said.

Instead, he remembers natural light streaming in through large windows, interactive videos and sensory walls that sparkled when you moved, and people who smiled and remembered your name, even though you were new and this was your first time in the building.

He remembers playing video games with patients who were competitive and sassy though they were receiving treatment for catastrophic diseases. This was a place that reminded them they were defined by far more than a diagnosis.

All of this moved him. By his third and last day in Memphis, he’d forgotten about winning a contest and began considering moving here. He scoped out local real estate and was pleased to discover it was significantly more affordable than in Long Beach, California, where he struggled to keep up with rent on the small house he shared with two other guys.

The flight home was difficult and unexpectedly emotional for him.

“I was crying the whole flight home and I’m not typically a super emotive person,” he said. “I think it was just that I wanted to be there still. St. Jude became in my mind, this little hub of goodness that I hadn’t seen or found anywhere else and I thought selfishly if I can be close to that hub of goodness, it’ll make me be good.”

He was approaching 30 and it struck him that this was the first time in a long time when he felt a sense of purpose in his life. The last time he’d felt such a strong pull was to music when he was 10 years old.

As a child, music spoke to him. He listened to it all the time, and when he listened, he also tried to play it on his piano. He heard a soundtrack to everything he did. By the time he was in fifth grade, he improvised and composed and put melodies together in such polished and resonant ways, his father once asked him about the new composer he was playing.

“It’s mine,” he had told his father. “I wrote that music.”

From that point on, he knew music would stay in his life, always. He felt the same certainty now, nearly two decades later, about St. Jude. He knew he’d have to be close to it and be involved in the mission in some way.

Not wanting to be too impulsive, he spent another year in California, shoring up his savings for the 1,800-mile move. Along the way, he continued to raise money for St. Jude: \$11,000 in 2018, the year he first visited the campus in Memphis, and \$25,000 more the following year in May.

He tried to explain to friends and family the magnetic tug he felt to the city on the banks of the Mississippi River. People understood moving for work, of course.

“But who moves to be close to a place that you want to fundraise for? I know it didn’t make sense. But I had to do it,” Trevor said. “It came down to this: Which decision would I regret looking back at this time? Would I regret moving to Memphis? Or would

I regret staying in California? And it was clear that I'd regret it if I didn't move, if I didn't at least try to make it in Memphis."

By August 2019, 15 months after his first visit to St. Jude, he was ready. He loaded his piano into one of those large storage pods and shipped it to Memphis. The rest of his life, he crammed into his Honda Civic, along with his father (key for moral support and to help with the drive and unpacking) and of course Maja the cat. They drove 27 hours over two days to get here.

Trevor had rented a home on the northeastern edge of town, an ode to 1970s chic with vaulted wood-beamed ceilings, an imposing stone fireplace and a large brass chandelier that made the spacious living room oddly reminiscent of an old English tavern. It was quirky. Perfect for him. When they arrived over Labor Day weekend, Memphis boasted its hottest temperatures of the year and Trevor realized he'd unfortunately forgotten to connect the utilities to his new home.

In his excitement for a fresh start, he also neglected to realize there was neither stove nor washer and dryer in his new home. Walking through a deserted Walmart at midnight, looking for a camping stove and lamps for his new home, Trevor worried this was an omen. Had he been too rash?

No air conditioning and lights at the hottest time of year in a city where he didn't know a soul, aside from a couple of folks at ALSAC, the fundraising and awareness organization for St. Jude. This was not the promising start he'd envisioned.



But slowly and steadily the pieces of his dream to start fresh and have purpose fell into place.

It was a fellow streamer and Memphian who emerged as a hero and friend in his early days. He'd read Trevor had moved to Memphis and offered to help him move his furniture into the home. His computer and keyboard and piano set up just so, Trevor began happily streaming from his living room, and his clout and viewership rose. He was happy and settled and it came across on his stream. Scorching Labor Day weather gave way to a mild fall, and he loved Memphis in autumn, crisp and flush with auburn-colored maples and oaks.

He reached out to St. Jude to explore volunteer opportunities and wondered whether he could be a pianist in Kay Café, providing

patients, families, researchers and physicians with a unique, upbeat musical score to their daily lives. But the process to become a performer there proved complicated, so he pivoted and instead worked the registration tables at events like the St. Jude Country Cares Seminar. He also trained to be a hospital tour guide. Over two months, he completed the training and had successfully led a mock tour, but then the COVID-19 pandemic hit and shut down all that.

Still, he found safe ways to fulfill his promise to help St. Jude and used his musical stream on Twitch to raise money for the research hospital's lifesaving mission. Last spring during the St. Jude PLAY LIVE prize season, he set a goal of \$36,000. He raised \$115,000.

He is gradually growing his fundraising prowess, still driven by what he saw and experienced on that very first trip to St. Jude. He remembers a wall at St. Jude, illustrating the "ABCs of Cancer," assigning patients' drawings and emotions about cancer treatment to each letter of the alphabet. The letter Y particularly struck a chord for him. "Y is for Yucky," one poster read.

"It's just such a simple emotion and experience captured with that one word 'yucky,' right?" said Trevor, who has raised more than \$35,000 this month for St. Jude and will be continuing through the end of May.

"It feels so wrong for any kid to have to go through that, you know, and it's like a simple equation for me. I'm here; I want to help St. Jude take away the yucky from these kids' lives."



CALEB'S 'SPECTACULAR' PODCAST OF HOPE

Longtime St. Jude patient hopes to inspire others, especially those with special needs, to persevere and achieve goals.

By Tom Charlier - ALSAC

Caleb will never run a marathon or join the military, but it's hard to imagine anyone more at ease cracking wise with an accomplished distance runner or an Army recruiter. His face stretches into a mischievous grin, and his voice bubbles with enthusiasm and mirth.

"You're taller than me. I don't judge you there at all," the 4-foot Caleb tells 6-foot-9-inch-tall Staff Sgt. Jonathan Walker, an Army recruiter.

At 20 years old, Caleb has been treated by St. Jude Children's Research Hospital nearly all of his life for Hurler syndrome, the most severe form of a rare and incurable genetic disease known as MPS1. His body lacks an enzyme needed to break down and dispose of certain sugar molecules, which consequently accumulate and cause progressive damage, attacking the heart and other organs. Few people born with it survive past age 10.

Caleb has done more than just survive, though. He's bounced back – from all the transplants, surgeries and procedures needed to slow the progression of the disease, from heart and kidney problems and loss of mobility – to embrace laughter, music and the joy of everyday living.

Last year he graduated from high school and attended a pandemic-restricted virtual prom. He plans to get a job soon.

"He's always happy, always smiling, and he can have a good time no matter what the circumstances are," Richard C. Shadyac Jr., president and CEO of ALSAC, the fundraising and awareness organization for St. Jude, said in a recent video chat.

And now, Caleb has found a new way, as his mom Kelly says, to "spread his joy." It's through a podcast.

Called "The Spectacular Trio," it features Caleb, who lives in Mississippi, and another young man in Colorado with Hurler named Nolan, with the third seat rotated among friends. Their goal is to inspire others, especially those with special needs, and to give them courage so they don't give up on their dreams in the face of difficulty.

"I want to show and tell people that they don't have to be special needs or non-special needs to reach their dreams or talent," Caleb told Shadyac.

And, besides, as he told sidekick Nolan on one episode: "I thought that I was more capable of doing something than just sitting on the couch all day."

Guests on the podcast have included Walker, the recruiter; marathon-runner Justin Gillette; radio host Zach Sang; Thomas Russell, author of a book on bullying; and Jeff "Swampy" Marsh, co-creator of the animated musical series 'Phineas and Ferb,' as well as local clergy members and friends. Tune in to any given episode, and you're likely to hear ad-libs about everything from restaurants and art to super heroes and theme parks.

During his appearance, Walker asked Caleb and Nolan what inspired them to launch the podcast. The two spoke of their shared disease, how others put them down because of it. How they believed no one should have to endure put-downs. How everyone should be assured of their worth.

"Dude, that's awesome," Walker responded.

"We've both been through a lot," Nolan continued, "and we kind of realized that we shouldn't, um...."

And this is where Caleb broke in to finish his sentence.

"Be ashamed of who we are."

Awesome, indeed.



St. Jude patient Caleb celebrates his birthday during the 2018 St. Jude Memphis Marathon Weekend Pasta Party.





THREE YEARS ON, Lizzy's light REMAINS AN INSPIRATION

Her story is one of love, loss and legacy.

By Kelly COX- ALSAC

That December day in 2017 approached 68 degrees, but Lizzy Wampler, thin and bald from chemotherapy, needed a fuzzy blanket around her shoulders to be out in the street.

And she insisted on being in the street. It was the St. Jude Memphis Marathon Weekend, and Lizzy, previously an athletic child, couldn't walk without crutches, much less

run. But she wanted to go out and encourage those who could.

"Now, you got a marathon here," recalled her dad. "I'm not talking a trickle of people."

There were more than 25,000 participants that year, in fact. "And Lizzy wanted to wheel herself out in her chair and give everybody a high five. We can't remember if she knew the news yet or not."

It was everyone's hope that Lizzy was nearing the end of treatment for bone cancer. But recent scans had shown the cancer was back. For her parents, John and Jennifer, what Lizzy knew or didn't know at that moment wouldn't matter later on. What would matter was Lizzy beaming at the runners, aglow in the golden winter light, finding the strength within herself to lift others up.

Growing Pains That Weren't

A little over a year prior, in Missouri, Lizzy had been saying her leg hurt. "She would tell me she actually felt her bone growing," said Jennifer. But their oldest had complained so frequently of growing pains at Lizzy's age that they went for an x-ray, and it was nothing. Lizzy was sprouting up with the same consequences.

Still, when Lizzy screamed in pain one day while playing, they decided to err on the side of caution again. The pediatrician felt around her knee and found it swollen. "Humongous, because the tumor was in it," in Lizzy's recollection.

When the biopsy results were shared, Lizzy was crying, Jennifer was crying, and John was grasping at information like someone going over a waterfall clutching at twigs. He asked the doctor to spell it. O-s-t-e-o-s-a-r-c-o-m-a.

Days later, on Thanksgiving, John heard from St. Jude Children's Research Hospital regarding referral. They were ready to bring Lizzy to Memphis.

What She Went Through

Halfway into her treatment protocol at St. Jude, Lizzy had been through a limb-sparing surgery

that replaced part of her femur with a prosthesis. She had endured nerve pain that she likened to being "sliced with a sword every second," and she was on chemotherapies that left her sick and weak.

But her scans were good – no cancer in the right leg, no spots in the lungs, which are a common site of metastasis in osteosarcoma. And her outlook was, characteristically, positive. A bounce-back type of person, she was forthright about the hardships, but she never threw a pity party.

There was another type of party ahead. A No More Chemo party, a tradition that celebrates the successful conclusion of treatment, and Lizzy was going to be ready. With the day finally around the corner, the Wamplers were cutting up confetti, collecting balloons, coloring, baking cookies and writing thank-you notes.

Lizzy was mentally compiling a list of foods she planned to eat when no longer plagued by nausea: pizza, wings, chocolate, sushi, cake, hamburgers...

"Honestly it wasn't even on my radar that she would relapse," said Jennifer.

But before her much-anticipated last dose of chemo would come that news: Lizzy's cancer was back in her right femur and had appeared in the left side of her pelvis.

St. Jude countered with a new treatment plan. Several weeks later, the Wamplers were able to take a family vacation, and Lizzy returned to St. Jude with a little album of pictures to show her care team.

What her team had to share in return was crushing. In spite of all



efforts, the cancer was growing. Time was short.

Childhood cancer is horrifying enough in the abstract. But when you see it close up, you realize how merciless it really is. How physically appalling, how existentially unfair.

Lizzy had wanted so badly to go back to school, and had pushed herself in physical therapy to get off crutches before then.

"She worked so hard to learn how to walk again, over and over after surgery. She worked so hard just to bend her leg," said Jennifer, "and I think of the hours she spent trying to get better, and she just passed away."

The first three months of 2018 were the last of Lizzy's life on earth, and they were often excruciating to experience and to witness.

On March 15, 2018, John posted: *Lizzy has bravely and courageously ran and finished her race here on earth. She was in the*

arms of her mother at 3:30 a.m. when God called her home.

The day of her burial, it rained, but a ray of sun emerged to light up her headstone, *Elizabeth Joy Wampler*: that irrepressible Lizzy glow again. They snapped a photo.

Lizzy's Legacy

Lizzy liked to fly kites. Her favorite color was mint blue. She had her mom's quiet thoughtfulness, and loved writing and reading, devouring a series of books about a mouse detective just about faster than they could stock the next installment.

In her absence lay the wracking monotony of grief. A wasteland, a bewildering loss of direction, of purpose. The focus had been on helping Lizzy for so long. Now desperate anguish filled their days, but it was unsustainable; it was incompatible with living. And it was no kind of tribute.

John and Jennifer wanted to honor Lizzy. They wanted Lizzy's legacy to live on in helping others. A family friend advised them to use the momentum of other people's support and the catalyst of their grief, and do it now.

They formed the Lizzy's Walk of Faith Foundation, with the dual focus of engaging and supporting the childhood cancer community in their local area and financially contributing to St. Jude. The foundation's first event was a 5K in their hometown. To date, they have donated about \$80,000 to St. Jude.

"We may never be able to give back what Lizzy's care cost — I don't even know what it cost. She had so much chemo, so many surgeries, so many MRIs," Jennifer said. "Unfortunately,

the kind of cancer she had was resistant to treatment. But we knew nothing was withheld from her. Even the last time we met with her doctor, he was always open. Had we said we *want to try more*, they would have done it. But we all wanted what was best for Lizzy. They never gave up."

From before her diagnosis, she was in pain. The day in December she went out to encourage the runners, she was in pain. Ultimately even treatments intended to be palliative caused her pain. Still, said Jennifer, "with every ounce of her body she was trying to give out help."

She even wanted her body after she left it to help by furthering the search for a cure. Per her wishes, her tumor went to St. Jude, and parts have now travelled the world, being studied on several different continents to further the research.

"We just believe that nothing is ever wasted on earth: Your sorrow, your pain, your suffering, it's not wasted. There's a purpose for that pain. We feel that's what we're doing in giving back," said Jennifer. "We know it makes Lizzy's heart happy."

Grief and Gratitude

In December 2018, just nine months after Lizzy's death, and again in December 2019, Jennifer ran the half marathon during the St. Jude Memphis Marathon Weekend. The course took her through the hospital campus, and right past the spot where Lizzy had been giving out high-fives that memorable day.

Jennifer would have given anything to see her, to touch her. But she certainly felt her.

"It was very helpful and healing for me as a mom, to be there and

get to run through the campus," she said. "Lizzy was a joy, from the moment she was born. There was a gentleness about her, a compassion about her. I didn't get to have her as long as I would have liked, but I had to focus on what a beautiful experience I was given to have 10 years with her."

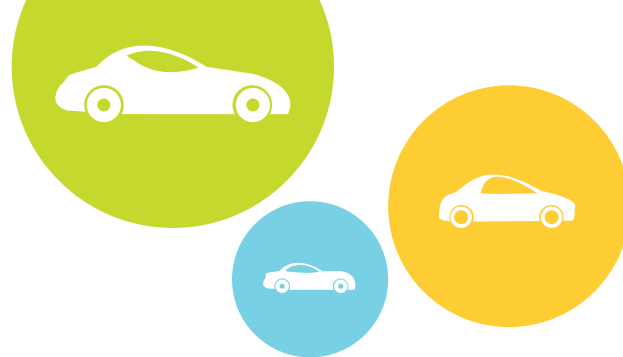
As a family, the comfort they take is often hard won. Last year on March 15, John, Jennifer, Lizzy's brother Daniel and her sister Hannah gathered at her grave to mark the anniversary of her passing. The day was cold and wet and miserable, and news of the pandemic didn't help anyone to feel lighter.

"Yesterday is not how I would want anyone to spend a day in their life," wrote Jennifer. "We are all hurting and broken. We wanted to grieve together and do something special in honor of Lizzy, but in reality we all kind of grieve on our own. In the bleakness of the day, I wanted her to know her sweetness is so missed in this life. Her gentleness and love is so needed."

The day before, Jennifer had looked through hundreds of photos and videos of Lizzy, and this brought some lightness to her heart. There were images of Lizzy's suffering, but there were also images of her kindness, like reaching out to another patient with a hug even when she was feeling rotten herself.

"And that just opens my heart a bit more to love," wrote Jennifer. "If you are going through an uncertain season of isolation and discomfort or pain, I pray a ray of love would touch your heart. Even while it's hard, even while it hurts, reaching out to another person hurting or doing an act of kindness is really the way to go."

GIDEON'S GIFTS



St. Jude mom DeeAnna Janku shares about her son's love of cars and the lessons it taught her.

I remember the Sunday morning a sweet friend handed us a car track made of cloth. It was easy to roll up and had pockets for exactly 17 Hot Wheels.

They were the favorite toy of my 3-year-old, Gideon, and we were getting ready to get on a plane to head to Memphis. Only three days earlier, we had learned the spot on his cheek I had just wanted gone for family pictures was actually melanoma.

I had only a couple of days to figure out what to do for my four other children while I was gone and get packed for what we were told would be at least two weeks at St. Jude Children's Research Hospital. Memphis was so far from home in Vancouver, Washington, and I'd never visited.

I had to look up St. Jude on the Internet just to learn where it was located. When the travel agent called to make our flight arrangements, I learned St. Jude covered travel, housing and even food on top of the world-class treatment my son would receive.

As we sat on the plane, Gideon happily played with his cars, complete with "zoom" sounds. He seemed oblivious to the reality that to me seemed so big. Every time his head turned and I saw the spot on his cheek we now knew was cancer, I was reminded of why we were here.

I was terrified. There had not been any time yet to process emotions. When we landed and walked underneath the large St. Jude Children's Research Hospital sign at the airport – it hit me: My kid was sick enough that we needed to be here. I felt so out of control.

An hour later, we sat at registration, and the woman sensed the fear in my voice. She reached across the desk and took my hand. She said, "It's going to be okay; you're at St. Jude."

She was right.

But Gideon already knew. He walked over to a child sitting in a little red wagon and without saying a word, gifted him one of his precious cars. An act that would be repeated many times over the next couple of days.

Soon, he had given away all of

them. When we went home, he refilled his track before we headed back just four days later. Again, he gave them all away before his surgery to remove the tumor.

The surgery took a large portion of his cheek, and Gideon didn't want anyone to look at him. He'd often walk around with his hand over his cheek so he "wouldn't be seen." The only time he'd let down his guard is when he happily searched his bag for the right car to give to another child.

A year later, he asked for more cars as a party gift. He wanted to give one to everyone he met. Our community came together and gifted him more than 5,500 cars.

On his next trip to St. Jude, Gideon packed his suitcase with nothing but cars, still new in their package, and passed them out whenever he saw another child. He would choose a car "just for them" and hand it over, mostly without a single word.

St. Jude gave him his true wish though – a plastic surgeon to fix his scar. And now you can hardly even tell. When you see him, you see his smile, not his scar.



People have given him another 1,500 cars, and over the years, he's managed to distribute all of them, most of them one at a time, personally gifted by Gideon. As his mom, I shared this story with a number of radio station partners at St. Jude. One of them found me the next day to tell me that they had found their "St. Jude moment." While watching a video of a child's "No Mo' Chemo" party,

they saw the child grasping a small toy car. We will never know, but from his perspective, it was definitely one of Gideon's gifts.

I will never forget the lesson my son taught me. While I felt like I had no control, he simply gave what he had. Of course, he was just 3, but he always forgot his own hurt and just gave, one car at a time, until he had no more to give.

I asked Gideon recently what he remembers about the cars, and he said, "I just wanted them (other patients) to know that I saw they were sick and the car might make them smile."

Today, Gideon is a healthy fifth grader, and it's been more than five years since he's had any sign of cancer. He's been gifted more cars and still can be found passing them out on his yearly visits to St. Jude.

GIFT GUIDE

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4" Glass Ornament
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Imani

Give thanks for the healthy kids in your life, and give to those who are not.

At just five weeks old, Imani's health was declining due to childhood cancer. When she came to St. Jude, Imani started chemotherapy and slowly began to thrive. After several months of care, Imani is back home, growing bigger and stronger every day. Thanks to donors like you, Imani's family will never receive a bill from St. Jude for treatment, travel, housing or food—because all they should worry about is helping her live. Today, Imani's parents are filled with thanks for the milestones they've celebrated: Imani's first New Year's, her first Ramadan, her first birthday and more.

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Space crew

The Inspiration4 crew members (clockwise from left: Jared Isaacman, Chris Sembroski, Sian Proctor and Hayley Arceneaux) completed a three-day orbital flight in September before splashing down in the Atlantic Ocean. The Inspiration4 mission, so-named to inspire support for St. Jude, aims to raise \$200 million to continue the hospital's lifesaving work. Read more and watch videos about the mission to space. stjude.org/inspiration4



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