

ST. JUDE inspire

SUMMER 2022



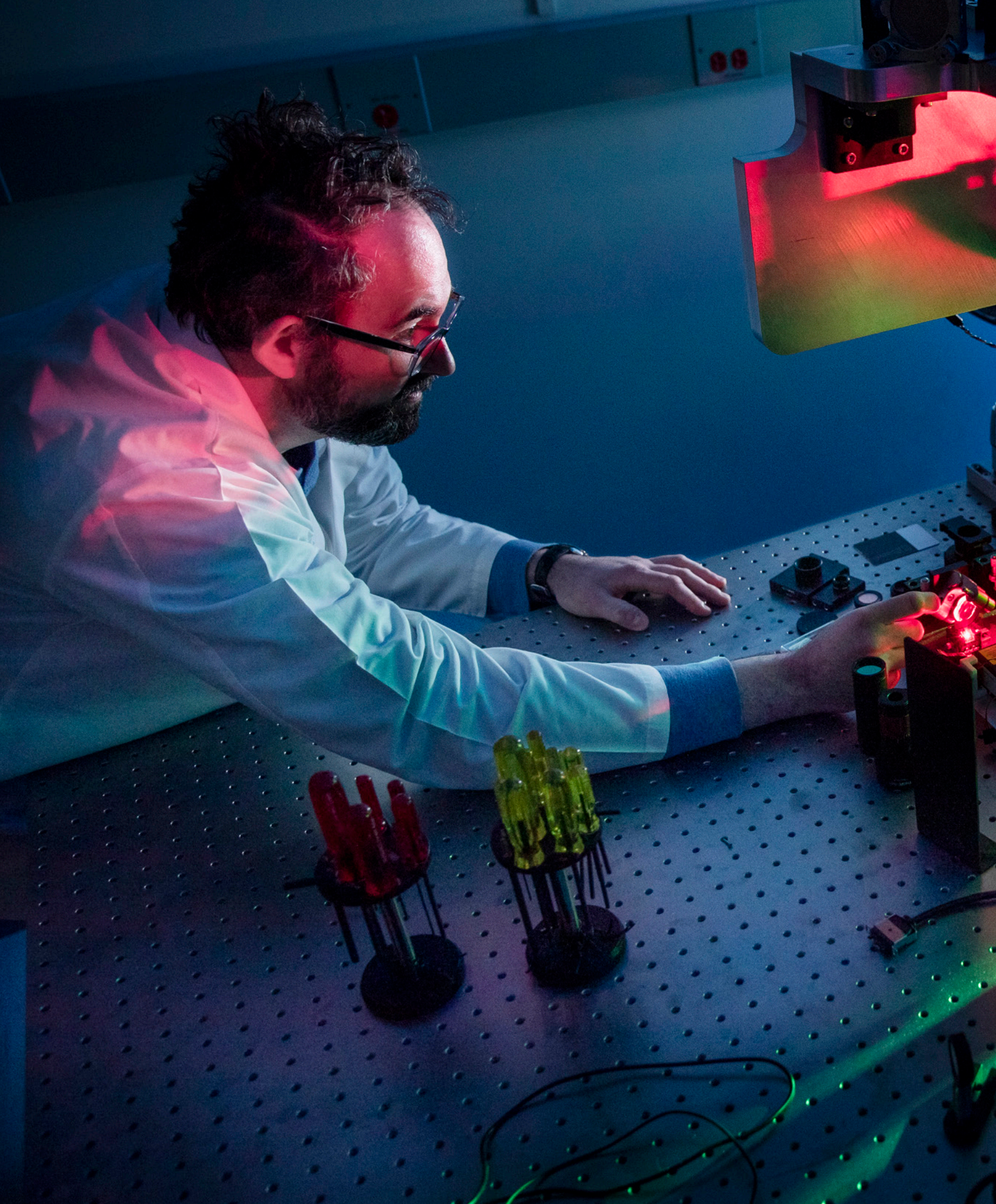
INSIDE:
Global Mission
SAFER Ukraine

Juan's incredible legacy

Genetic information fuels research, helps save
lives of kids today and patients of tomorrow.

SPECIAL REPORT

St. Jude brain tumor program
means better outcomes for kids.





Outer space to inner space

Daniel Stabley, PhD, is seen here working on the MOSAIC microscope. This custom-built system utilizes adaptive optics (a technique borrowed from astronomers) to correct image distortion in real time, thereby allowing biologists a better look into the inner workings of cells and tissue.

There are only a handful of these instruments in the world, and thanks to our donors, St. Jude will be among the first to apply these advances toward a better understanding of catastrophic childhood diseases.



Their faces tell much of the story. Maybe not the harrowing part, the beginning when explosions lit up the sky and the decision to leave their home country was made.

But the hopeful part. That's what we see in the faces of cancer patients brought to St. Jude Children's Research Hospital from Ukraine, via Poland, beginning in late March.

They're safe now, these eight children and their 21 family members, yet the war follows them. One mom, Natalia, doesn't sleep well. She left her husband and two teenage daughters behind. When she arrived at St. Jude, the phone app warning of an imminent air raid still dinged, connecting her with home and fear. "My soul is hurting," she said. "My heart is breaking for my children back at home."

It's a difficult story to hear, but a necessary one, especially as she ends by saying, "I am here with one purpose, to cure my son."

In her voice is the worry and fear of every parent faced with a child's cancer diagnosis. In her resolve is hope and the promise of a second chance at life.

In this time of global need, we're reassured that the St. Jude mission

to care for the most vulnerable – children of all races, religions and economic status – can and does unify us.

We hear it in the voices of moms and see it on the faces of kids who so recently gazed upon the devastation of war – reminders that, regardless of the circumstance and no matter how dire the situation, children should be allowed happiness and health and safety.

We're humbled by the support of donors and volunteers around the world who believe, just as our founder did, that no child – anywhere – should die in the dawn of life.

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ST. JUDE inspire

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**St. Jude Children's
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

When **war** broke out, **St. Jude** and its partners were ready to *help*

Coordinated by St. Jude Global and ALSAC Global, the SAFER Ukraine humanitarian effort shepherded pediatric cancer patients and families to safety and continued treatment.



By **Richard Alley** - ALSAC

On February 24, when Russia began its invasion of Ukraine, some families found themselves fighting a war on two fronts – bombs and bullets splitting the air and a sudden stop to lifesaving cancer treatment for their children.

Within hours, the call came in: *Could St. Jude help?*

What happened next was an extraordinary effort on the parts of healthcare institutions and foundations from around the world. Over the ensuing months, St. Jude Children's Research Hospital has helped ensure the continued care of more than 1,000 children.

A month after the start of the invasion, eight such patients and 21 family members arrived at St. Jude Children's Research Hospital in Memphis.



Tabletochki

Doctors had moved patients to damp hospital basements without the ability to power necessary medical equipment. Huddled beneath exposed pipes and peeling paint, they slept side by side in makeshift beds on the floors.

“One of your kids may die because of cancer,” said Olga Kudinenko, founder of Tabletochki Foundation in Ukraine. “And other parts of your family may die because of the war. So, I cannot imagine how hard (it is) for those families in hospitals to be separated right now – to fight for their lives on two fronts.”

Because of years of networking and build-up, St. Jude, the only World Health Organization Collaborating Centre for Childhood Cancer, was in a unique position when that initial call came. A command center was quickly set up and the unified effort to evacuate and place children with cancer in oncology clinics throughout Europe and North America became known as SAFER Ukraine.

It all began with Tabletochki. But Olga was out of the country, on vacation with her family. And her colleague, Svitlana Pugach, had left home with only a backpack, passport and a pair of t-shirts

when the bombing started. She spent more than a week sleeping on a basement floor, going days without seeing daylight.

And yet, this foundation, which supplies medicine not available through public resources to 21 oncology units throughout Ukraine, treating 500 children with cancer each month, began the herculean effort of moving families toward the border with Poland. Olga, with little more than a cell phone and contacts list, began coordinating the delivery of extension cords, batteries, lights and food to hospitals.

These provisions might get them through a day or two, but she knew real safety could only be found outside of Ukraine.

Herosi

The long-established partnerships that make up St. Jude Global – 193 institutions in 64 countries – worked toward one end: Poland. And safety.

The linchpin in the SAFER Ukraine effort, a 5,000-mile chain that wrapped its way from Kyiv, Ukraine, throughout Europe and North America, was a vacant 190-room hotel in Poland, newly named the Unicorn Marian Wilemski Clinic. It was operated by the two employees of St. Jude Global partner Herosi Foundation.

The English translation of Herosi is telling – Heroes.

Malgorzata Dutkiewicz and Karolina Bauer worked around the clock armed, much like Olga in Ukraine, with only cell phones and an urgent sense of purpose to coordinate the safe passage of hundreds of critically ill children from the border of Poland to their makeshift clinic-command center-transportation hub in Bocheniec.

“The more patients arrived, the less space and place we had in our Polish clinics,” Malgorzata said. “So, thanks to (the) Global Alliance and St. Jude Global, and the connections and the openness and the willingness of other European clinics we were able to very quickly find support in western Europe.”

Jared Isaacman, founder of St. Jude partner Shift4Payments and commander of the Inspiration4 and Polaris Dawn space missions benefiting St. Jude, personally donated and delivered SpaceX Starlink communications equipment and medical supplies to the Unicorn Center to better aid the effort.

After triage, Ukrainian families were sent to waiting oncology centers with capacity for new patients in Moldova, Germany, Italy, Spain, United Kingdom, the Netherlands, Canada and the U.S.

St. Jude Children's Research Hospital

For most of the patients and families arriving at St. Jude, the 5,000-mile intercontinental trip was their first time on a plane, said Yuri Yanishevski, an IT Director with ALSAC, the fundraising and awareness organization for St. Jude. “Their faces lit up as they heard me speak in the language of their homeland,” he said.

The patients ranged in age from 9 months to 9 years old. They and their 10 family members and caregivers, once registered and checked by medical staff at St. Jude, were settled in at Tri Delta Place patient family housing facility on campus.

Though safe, the horrors of war were never far behind. One Ukrainian mother, Natalia, kept tabs on a phone app that warned of imminent air raid warnings back home where she'd left her husband and two daughters. “My soul is hurting,” she said. “My heart is breaking for my children back at home. Now I am here with one purpose, to cure my son.”

By the end of the week, she and the others were visited by First Lady Jill Biden, who also toured labs and spoke to an audience of St. Jude and ALSAC staff and former patients. “You offer healing and hope, care and community, a place of refuge for those facing the worst,” she said.

One week after the first arrival, a second group of four patients – ages 6 to 17 years old – and 11 family members followed the links of chain from uncertainty to arrive in Memphis on a plane chartered by St. Jude.

“The biggest thing is the trust they are placing in us to literally pass their patients over into this system and then trust that they would be well taken care of, as if they were our patients,” said Asya Agulnik, MD, MPH, Director of the Global Critical Care Program for St. Jude Global. “I think that's a big thing. It's a big step to say, ‘We can no longer take care of these patients locally,’ and to ask for help, especially in a time of crisis like this.”



Scan the QR code to learn more about our global efforts.






Meeting **four young** **Ukrainian** **cancer patients** has renewed my *soul*

By **Yuri Yanishevski** - ALSAC

I was a refugee
from Ukraine 31 years
ago. My welcome to the
young evacuees from my
homeland at St. Jude:
You're safe now.



Yuri Yanishevski, an IT Director at ALSAC, the fundraising and awareness organization for St. Jude Children's Research Hospital, was at the airport to meet the first Ukrainian children with cancer arriving at St. Jude. Acting as translator, Yuri, in their native language, assured them they were safe. This is his account.



In nervously climbed the steps to the small plane that had just landed at Memphis International Airport, bringing the Ukrainian families to St. Jude.

Until this moment, children like the four aboard had been only stories I imagined from the scenes abroad. My wife, Lana, who's a pediatrician, and I have been volunteering with St. Jude Global as translators.

We had worried and wondered, and now I would meet four young patients, ranging in age from 9 months to 9 years old, accompanied by their moms, mostly, and siblings.

They wore their journeys on their faces.

Each of the patients had run out of medicine and holed up in damp basements of hospitals in Ukraine, bombs dropping around them, before making panicked, treacherous trips to safety in Poland.

On Monday before dawn, they left Unicorn Marian Wilemski Clinic, a Polish triage center where St. Jude and Fundacja Herosi work with partners in Poland, Ukraine and across Europe to ensure the safe passage of every child. The families boarded a U.S. government-operated medical transport aircraft at 5 a.m. and flew 5,000 miles before finally touching down in Memphis. For most, this was the first time they'd flown on an airplane.

Lana and I made a similar journey 31 years ago when we left Kyiv, then part of the former Soviet Union, emigrating to the U.S. I remembered what it felt like to be in a strange new place so far from all the things we knew.

Now I was among a dozen people from St. Jude and ALSAC to meet the families.

Some parents cradled sleeping children. I stayed close to Erica Sirrine, Director

of Social Work at St. Jude, and repeated her greeting in Ukrainian:

I want to officially welcome you to the United States!...We want to ensure you and your children feel safe and have everything you need."

Their faces lit up as they heard me speak in the language of their homeland. I had been silently practicing my Ukrainian, which had grown rusty over decades. I asked if they understood Russian and they nodded that they could. I promised they were safe.

We gathered their luggage and helped them off the plane. I stayed by the stairs, worried someone might fall because they were so exhausted, and one mother held her child in her arms. The time difference meant it was close to 1 a.m. for them.

On the shuttle bus to St. Jude, I handed out water bottles and told them in Ukrainian, "Guys, you were on the flight and you get dehydrated on the flight, so please drink water." The children reached for Oreo cookies.

The drive to St. Jude was just 15 minutes. I reassured them, telling them they had only to worry about their children. Everything else would be taken care of.

At St. Jude, more people helped register the patients before they were checked by medical staff. One little boy, almost 2 years old, cried in his mother's arms. I went from family to family, my arms filled with their toys, stuffed animals and pillows in the hopes of offering comfort with familiar items.

They all seemed under a cloud of utter exhaustion.

By 9:30 p.m., we took the families to Tri Delta Place, a patient family housing facility on the St. Jude campus, helping with luggage and keys and showing them the white noise machines that would mask the strange sounds of a new city.

The children seemed wide awake now and rushed to play with the toys and art supplies on shelves in their rooms.

One girl, about 4, roughhoused with her brother, about 7, who giggled and called out, "Help me! Help me!"

I laughed, marveling at the resiliency of children.

It was close to 10 p.m. when I got to my car and that's when my emotions began to hit me. Before, I had been operating on adrenaline, not feeling anything.

I called my wife who already was making plans to bring the families borscht, a popular soup in Ukraine. She'd wait up for me to hear more.

From the early days of the war, we watched helplessly as the Russians invaded our homeland, horrified by the destruction and the brutal attacks on civilians. It helped to volunteer. To feel useful. To make a contribution.

But helping these families at St. Jude does even more.

It's saving our souls.

When I am helpless, I feel darkness filling me on the inside, and frustration and depression.

When I can help, there is light that is coming inside, and the darkness goes away.



St. Jude mother, worried her **son** would be **forgotten**, realizes he left a **Legacy**

Amelia Salas lost one son to cancer. She's counting on what St. Jude researchers and doctors are learning from genetic testing to save another. By **Karina Bland** - ALSAC

It's been four years since Juan Salas died and his mother, Amelia, worries he's been forgotten.

Juan was 9 when he was diagnosed with a rare brain tumor. Amelia said an oncologist at a children's hospital in Arizona told her Juan had just months to live, even with available treatment.

With treatment at St. Jude Children's Research Hospital,

Juan lived for another six years, each day a chance to create more memories. Amelia is grateful for that.

Juan was 15 when he died on June 8, 2018.

When a child dies, many people are unsure what to say, so they say nothing at all. But Amelia wants to talk about her son. There's not a day she doesn't think about him, that she doesn't wish he still was here.

It's not true what people say, that it gets easier with time. She and her younger son, Javier, who's 14, talk about Juan, wondering aloud if he'd like a movie they're watching or what he'd think of the latest family news.

"We have to keep talking about him," Amelia said. "It's how we keep him from being forgotten."



*Juan and
Amelia*

Only pictures, a chest filled with his belongings, an urn holding his ashes and their memories mark that Juan was here. Amelia had imagined planting a tree in Juan's memory, maybe a park bench marked with his name where she and Javier could sit and read. For a lot of reasons, those things didn't happen.

"I want something that will have his name so he'll have a legacy," Amelia said.

'There's something in his head'

Juan had been sick that weekend in July 2012, throwing up and running a fever. By Monday, he was well enough to go to school.

That night at home, Juan's left arm went numb. Something was wrong.

Amelia couldn't afford health insurance, so they'd been to the emergency room before. Sometimes, they'd wait hours to be seen. This time, Juan was rushed to an examination room.

The doctor asked Juan to smile. Amelia watched as only the right side of his face turned up.

It could be a stroke, the doctor said. Amelia stayed with Juan as he was taken for an MRI. "You can't go back there," someone told her. She could watch the monitors.

"There's something in his head," Amelia whispered to her sister Elizabeth on her cellphone.

In the images on the monitor, Amelia could see a hazy circle next to her son's brain.



The next morning, surgery to remove the tumor relieved the pressure causing weakness on Juan's left side. He woke up and smiled at his mom, both sides of his mouth turning up.

Amelia wouldn't give up.

Finding hope at St. Jude

The oncologist referred Juan to St. Jude. Amelia had seen the ads on TV featuring children with cancer. Children who got better.

Within days, Amelia and Juan were on their way to Memphis.

At St. Jude, the staff told Amelia they wouldn't give up either.

While in Memphis, Amelia felt a lump in her breast. She didn't give it much thought – she was only 26 – and her concern was for Juan. He had a second surgery and received 33 rounds of radiation over two months.

Juan finished treatment in late November and they flew back to Arizona. They'd return to St. Jude for checkups every three months for a year and then every six months.

Juan had kept up in school with help from teachers at St. Jude. He played with Javier and stayed the night on weekends with cousins.

To Amelia, life felt normal again.

It wouldn't last.

Did she want to know?

Amelia's doctor sent her for a mammogram – and then a biopsy. On Feb. 1, 2013, she was diagnosed with cancer, invasive ductal carcinoma, unusual for a woman her age. She had a double mastectomy, chemotherapy and radiation, followed by hormone therapy to keep the cancer from coming back.

During a checkup at St. Jude in November 2014, Amelia told Juan's

doctor about her cancer. He asked if she would be interested in genetic testing through the Department of Genetics at St. Jude to look at possible hereditary predispositions to cancer. They wanted to test Javier, 6 at the time, too.

Juan had been tested. The results showed a mutation in a gene called *TP53*, which carries instructions for making a tumor-suppressing protein of the same name. *TP53* mutations are common in many different cancers and are associated with Li-Fraumeni syndrome.

People with Li-Fraumeni syndrome have a high likelihood of developing cancer. Half develop some type of cancer by 30. By 60, the risk soars to 80 to 90 percent.

Did she want to know? Amelia asked herself. It could explain Juan's brain cancer. Her breast cancer. What would it mean for Javier?

The results showed Amelia and Javier had the same *TP53* gene mutation.

During a follow-up visit at St. Jude in July 2016, doctors discovered Juan's tumor had grown back. Surgeons removed it, followed by another 33 rounds of radiation. The next year,



Juan was treated at St. Jude for months with intravenous antibiotics for an infection. He was enrolled in two clinical trials.

But in June 2018, at home in Arizona, Juan had a seizure. The next day, he went into hospice. Amelia never left him.

She was the last person Juan saw.

"I was broken, still am, will always be," Amelia said. "However, I am grateful that St. Jude gave me time with Juan." Time to make memories. Time she was told he wouldn't get.

"I cherish every extra moment I had with my son," Amelia said.

The nurse

On the living room wall in Virginia Green's house in West Memphis, Arkansas, 1,434 miles from where the Salas family lives in Arizona, are framed family photos of children and grandchildren, and of Juan.

Virginia, a nurse, retired now after 39 years, met Juan at St. Jude in 2012.

Virginia told Juan she wouldn't start a test or procedure until he was ready. He'd smiled at her, their deal sealed. Juan insisted Virginia put in his intravenous lines. It didn't hurt when she did it.

Talking to Juan was like conversing with an adult, Virginia said. He wanted to know about day-to-day stuff. How her dad was. Movies she'd seen. Time spent with grandkids.

"He was beyond his years," Virginia said. "I think cancer causes our children to grow up fast."

When Virginia asked, "How do you feel today?" Juan would say, "Oh, I'm fine," even on the days she could

tell he was worried or hurting. Juan never complained.

"There were times like that when you just had to hug him and love on him and tell him, 'We're just going to take this thing one day at a time,'" Virginia said.

Nurses aren't supposed to get attached to patients. "It's hard not to do that," Virginia said.

She tells her children and grandchildren what she learned from Juan.

"He taught me to do everything in your power to make each day count," Virginia said. "He taught me to cherish everyday moments."

The runner

When Nicole DiSturco met Juan in 2014, while working in the Phoenix office of ALSAC, the fundraising and awareness organization for St. Jude, she thought he was brave to speak at the opening of the local St. Jude Walk/Run.

She realized he'd faced tougher challenges.

Nicole was at St. Jude for a meeting in July 2016 when Juan's tumor came back. She visited him after his surgery.

Juan still was at St. Jude when Nicole ran in the Rock 'n' Roll Las Vegas Marathon to raise money for St. Jude. She texted Juan a picture at the finish line: "This is for you."

"That's awesome. Thank you!" Juan texted back. "I love you."

Nicole still runs for Juan – and Javier, too – raising money for St. Jude in their names.

"I think about Juan every day," Nicole said. "Not only because I loved him

and I miss him and I don't want him to be forgotten, but because he serves as my inspiration to keep going."

Juan was the first child she knew who didn't survive cancer. For him, Nicole works even harder.

The police officer

Phoenix police officer Juan Salas had been on duty the night he got a call from his mother telling him that his young cousin who shared his name was in hospice. It wouldn't be long now, she said.

Juan, the officer, was a teenager when his cousin was diagnosed with cancer. They were close, even with eight years between them. The younger Juan stayed the night almost every weekend at his Aunt Susana's house.

The younger Juan didn't want anything to change. Pretend I don't have cancer, he told his cousins. "I'm a normal kid. I'm just living my life," he said. "Let's just keep living."

When Juan became a police officer in 2016, his young cousin gave him a coin he bought in the St. Jude gift shop. On one side was a police badge, a prayer on the other.

"It'll protect you," young Juan said. Juan put the coin in his wallet next to his badge.

The night his mother called, there was no pretending young Juan didn't have cancer. At his bedside, Juan opened his wallet, pushed aside the coin and took out his badge. He tucked it in his cousin's hand.

"He should have it," he told Amelia. Juan was braver than anyone he knew.

Juan thinks of his young cousin every day.

"I have to use what he taught me," Juan said. His cousin didn't let anything get him down. Not even cancer.

He tells his son, Nehemiah Juan, who's almost 2, about his brave young cousin.

"For me and for Juan, I'm raising my son, and I'm teaching him Juan's ways," Juan said. "I want him to be just like Juan."

The supporter

Heidi Guest was touched when Amelia asked her to give Juan's eulogy. She knew theirs was an unlikely friendship, an 11-year-old boy and beauty industry executive 41 years his senior.

"We were kindred spirits," Heidi said, "and we both knew it." Instantly.

Heidi, an on-air regular on the shopping channel QVC and longtime St. Jude supporter, met Juan in 2014 at a rally for the St. Jude Walk/Run at a Phoenix bowling alley.

"He talked about his St. Jude journey with reverence and respect, but it was not his life – it was his circumstances," Heidi said. "He refused to let those circumstances define him."

The two families spent time together. Heidi's husband promised to teach Juan to drive. Her son, Nick, tutored Juan, though more often the boys went for burgers and to the movies. "Mom," Nick told Heidi, "Juan just needs to be a kid." Juan's favorite superhero was

The Flash. He'd roll his eyes because Heidi couldn't remember which superheroes were Marvel Comics and which were DC Universe.

Heidi was in Philadelphia, filming at QVC, when her husband called to tell her Juan was in hospice. She took the next flight back.

At Juan's bedside, Heidi recited which superheroes were Marvel Comics – Spider-Man, Iron Man, Captain America – and which were DC Universe. Batman. Wonder Woman. The Flash.

Juan didn't open his eyes, but he smiled. She'd finally got it right.

Juan's eulogy was surprisingly easy to write. Heidi had learned so much from Juan.

"In just 15 years, Juan left an incredible legacy and many lessons," Heidi told the crowd in the Serenity Chapel at Greenwood Memory Lawn in Phoenix on June 14, 2018.

"Namely, how to comport yourself with grace, love and acceptance, even when life isn't fair, even when life is downright cruel."

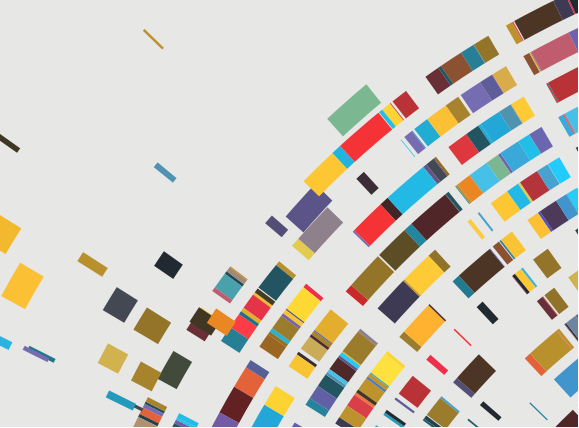
Don't complain. Juan never did. Lead by example. "It isn't what you say," Heidi said. "It's what you do." Cherish your family and friends. Don't let your circumstances, however dire, define you.

The brother

Javier was 4 when his brother Juan was diagnosed with cancer. He grew up with it.

On the days Juan didn't feel well, Javier stayed close to him. If Juan didn't feel like talking, Javier told him, "Just lift your finger. Up for yes, down for no."





**“In just
15 years,
Juan left an
incredible
legacy and
many lessons.”**

- Heidi Guest, St. Jude supporter



**Javier
and
Amelia**
.....

Javier never believed Juan would die. His brother had always been there.

On Javier's first day of kindergarten, Juan, then a worldly fifth-grader, walked him to his classroom and hugged him.

“I don't want to go,” Javier mumbled into his shirtfront.

“It's a thing you have to do, buddy,” Juan said. Juan promised he'd like school.

At home, Juan would ask, “Do you have homework?” No, Javier responded automatically.

Juan would rummage through Javier's backpack. “What's this then?” he'd ask.

Juan kept Javier out of trouble. He nudged him to sit still in church. If Javier spilled cereal on the kitchen floor, Juan would say, “Oh, sorry, Mom, that was me.”

“He wanted me to be successful,” Javier said. “He was my big brother. We loved each other. We had a bond.”

At the beach in Mexico, the boys jumped in the waves, side-by-side. They played video games and watched cartoons together.

A friend made Juan's favorite cartoon character T-shirt into a pillow. Javier keeps it on his bed.

“I'll never forget him because he was an important person in my life along with my mom,” Javier said. “I'm going to remember him.”

Juan taught Javier to make quesadillas – and more.

“I learned about staying positive, thinking about being kinder to everyone and to be grateful for my family,” Javier said.

In some ways, he's like his brother. He's kind to classmates and settles squabbles between his cousins. He works hard in school. He wants to be a doctor, like the ones at St. Jude who can make even the sickest patients smile.

Javier knows his chances of getting cancer are higher. He doesn't think about it much.

“You can't live life that way. If something does come up, I will accept it,” Javier said. “I'll be like my brother.”

That's part of Juan's legacy, too. Because of Juan, Javier is a St. Jude patient as part of a study. Twice a year, he undergoes scans and lab work at St. Jude so if any cancer develops, doctors will catch it early.

What St. Jude researchers are learning from genetic testing from patients like Juan could mean his legacy also includes saving children he never met. Juan's legacy may even include saving his brother.

FROM CLINICAL TRIALS TO CURES: A BREAKDOWN OF RESEARCH AT ST. JUDE

Kinlee's journey with **medulloblastoma** shows how research in the labs at St. Jude Children's Research Hospital can translate to better outcomes for patients.

By **Ruma Kumar** - ALSAC





It was summer in Georgia when the red clay ballfields emit unforgiving heat and dust. So, Nicole wasn't surprised when her 7-year-old daughter, a competitive softball player, complained that her head hurt and that she was tired, her vision hazy. After six straight tournament games, the mother herself had to admit the heat was getting to them both.

But then, even as summer slipped into autumn, the headaches persisted. They were worse, more frequent. And in one game, running to home plate, Kinlee lost her balance, fell and crawled to base, dizzy and disoriented. Afterward ...→

she was so nauseous and shaky on her feet that she missed school and skipped games with her beloved team.

Nicole knew then Kinlee's condition was serious. But when she and her husband took Kinlee to the hospital in Atlanta, nothing could have braced them for the diagnosis doctors delivered.

Medulloblastoma.

Fewer than 500 children in the United States are diagnosed with this type of brain cancer each year, and in the fall of 2017, Kinlee was one of them. Kinlee had a tumor the size of a golf ball in her brain and she'd need immediate surgery.

"Never in a million years did I ever think that they were going to tell my husband and me that Kinlee has brain cancer. Never ever," Nicole said. "Right then and there, my entire world just completely shattered."

"I fell to the floor," she said.

As this one Georgia couple buckled beneath the weight of a difficult diagnosis and imminent surgery, doctors and scientists 400 miles away at St. Jude Children's Research Hospital in Memphis were developing ways to better understand, classify and treat medulloblastoma.

The disease had proved inscrutable for even the world's most renowned cancer doctors and researchers for decades, and stubbornly posted dismal survival rates despite seminal advances in surgery and radiation techniques. But St. Jude's brain tumor program, running since 1985, had seen promising gains in a series of clinical trials since 1996 that better defined the disease and its effects on patients.

A clinical trial is a carefully planned research study to test new medicines, experimental combinations of

therapies or procedures. Right now, at St. Jude, over 135 clinical trials are helping turn scientists' discoveries into new, better treatments for children with cancer and other life-threatening diseases both on the Memphis campus and around the world. The medulloblastoma trials are part of that body of work.



St. Jude doctors treating medulloblastoma increasingly rely on proton therapy, seen here in 2015, which is less likely to damage nearby healthy tissues.

These trials seek to answer key questions:

- What is medulloblastoma at a molecular level?
- Does it behave differently in some patients and if it does, why is it more aggressive in some kids and not others?
- Could radiation therapy and chemotherapy be reduced, even eliminated, based on the type of medulloblastoma a child has, to diminish the serious side effects kids often suffer?
- How do you kill a disease, save a child and preserve good quality of life simultaneously?

Giles W. Robinson, MD, a neuro-oncologist and associate faculty member at St. Jude, is one of the doctors leading research in this area. Near the end of 2017, a family from Georgia signed their daughter up for Robinson's clinical trial.

They signed on because they had heard St. Jude was among the few pediatric hospitals in the country offering the more precise proton radiation to treat medulloblastoma. Traditional radiation delivers x-rays, or beams of photons, to the tumor and beyond it. It kills tumors, yes, but also wreaks havoc on nearby healthy tissues and organs, causing significant side effects.

But this family learned that St. Jude doctors treating medulloblastoma increasingly relied on proton therapy, which delivers a beam of proton particles that stops at the tumor, so it's less likely to damage nearby healthy tissues. Medulloblastoma tumors are mostly in children's developing brains and spines, so it's particularly important to preserve healthy tissues that are critical to learning, movement and coordination.

This family told St. Jude staff in the brain tumor program about their little girl, how she was a gifted reader in school and a strong, talented softball player. The family wanted to treat their daughter in a place that would not only save her, but help her retain some of the qualities that made her the athlete and star student she'd always been. Her name was Kinlee.

Part 2: The science behind the cures

Dr. Robinson hadn't expected to settle at St. Jude. He had planned to stay in Denver, Colorado, where he was training, or return to the Northeast and work in hospitals there, putting down roots close to family. But then he received a letter from St. Jude. It was an invitation to see if he might want to train at one of the most prestigious childhood cancer research hospitals.

Not wanting to waste the opportunity to study and learn how to treat the diseases he was most interested in, he came to Memphis nearly 16 years ago. He never left.

Robinson was moved by the patient care he witnessed and impressed by the legion of loyal donors who continuously support the work taking place in the labs and clinics. He was eager to work with the dogged researchers he believed would develop the unique and powerful therapies necessary to ultimately arrive at a cure for this disease.

“What makes us unique is that we conceive, launch and run our own clinical trials,” Robinson said.

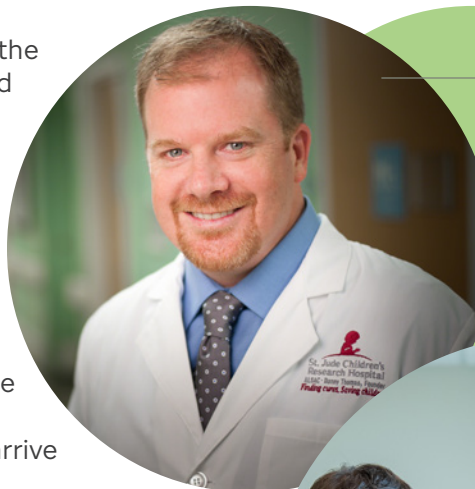
This model, he said, allows St. Jude to bring patients and collaborators care that is not available anywhere else. There’s a sense of urgency behind this work, too. After decades of steady rise – in part facilitated by research led at St. Jude – cure rates for pediatric cancer plateaued over the last decade. So, St. Jude increased investment in basic science research and clinical trials to develop newer, more effective and less toxic therapies hoping to boost cure rates.

This robust investment in research gives St. Jude scientists and doctors data, projects, grants and publications that share knowledge of the latest findings with colleagues and clinics across the world. It also leads to in-house discoveries that cultivate future clinical trials.

Between 2012 and 2021, there was a total of 4200 participants on St. Jude sponsored interventional trials. This is a 27 percent increase over the number of participants in these types of trials between 2002-2011.

Part 3: Evolving the standards of care

In the clinical trial Robinson has run alongside his mentor Amar Gajjar, MD, since 2012, the agents they use



Giles W. Robinson, MD, a neuro-oncologist and associate faculty member at St. Jude.



Paul A. Northcott, PhD, Robinson and Amar Gajjar, MD, are part of a team of doctors and scientists leading research into medulloblastoma.

to treat medulloblastoma haven’t drastically changed – they still rely on a combination of surgery, radiation and chemotherapy – but they’ve reduced the doses. In some cases, substantially.

In the current trial, Robinson said, St. Jude is testing the reduced dose of radiation on a subset of medulloblastoma patients whose disease is biologically more sensitive to therapy. In this way, Robinson predicts that they can still kill the disease while reducing harmful, long-term side effects on children’s physical appearance and movement, cognitive ability and endocrine system.

Robinson sees the proof of these efforts when kids return for checkups a few years after their treatment. Ten years ago, when

kids who had survived came back for checkups, they still carried the physical scars and signs of treatment. Their hair had not fully grown back. Their back was hunched, impacted by several rounds of radiation to their spine. They had a strained gait and experienced delays in learning.

These days, when Robinson’s patients who got lower dosing return for post-treatment checkups, they are virtually indistinguishable from their siblings. They’re doing well in school, applying for colleges and jobs. They’re playing sports and lifting weights.

“I get great satisfaction in seeing these patients come back to us and they are living full and healthy lives, doing things we never thought possible,” Robinson said.

This is the type of progress that drew Kinlee’s family to seek care from St. Jude.

They were cautiously optimistic, but not naïve. This would not be easy. Kinlee would be on an arduous protocol involving 30 radiation therapy sessions, four cycles of chemotherapy, blood and platelet transfusions and countless scans to track improvement and decline along the way.

“During that time, I was just, honestly, a lost soul. My daughter had cancer. We’re picking up and moving from Georgia to Tennessee. Like, what are we going to do? What’s going to happen? I’m scared to death. And I’m just overwhelmed with so many emotions,” Nicole said as she recalled the early days of the decision to join a clinical trial at St. Jude.

“So when St. Jude kind of stepped in, it was like a godsend for us,” Nicole said. “They were able to answer any and every question that we needed. I could

email them or call them and I would get answers right then and there.”

On this clinical trial, named SJMB12, Kinlee was about to leverage brain tumor research, some of it 21 years in the making and the result of global collaborations with doctors and scientists from Canada, Europe, Australia and New Zealand.

From this research, Robinson knew that the type of medulloblastoma Kinlee had offered a good prognosis, and had designed the trial to reduce and tailor therapy for tumors like Kinlee’s, to be less toxic.

Whereas medulloblastoma had once been regarded as a single entity and treated as one big, bad disease, research from the scientific community, which included many St. Jude doctors and scientists like Robinson, Gajjar, Paul Northcott, PhD, and David Ellison, MD, PhD, showed it could actually be divided into distinct molecular groups that behave differently in the body.

These molecular groups were given names, some funny, like: WNT (pronounced wint), Sonic Hedgehog, Group 3 and Group 4 to help distinguish them. WNT had the best prognosis and occurred in majority females between the ages of 6-12, while Sonic Hedgehog occurred predominantly in children younger than 5. Group 3 was aggressive and frequently had metastasized, or spread, at diagnosis, while Group 4 was the most common of all, accounting for nearly 40 percent of medulloblastoma.

Doctors such as Robinson, who had been used to treating every medulloblastoma patient in the same way, increasingly realized they could use these molecular groupings to adjust and modify treatment. This was the impetus behind the SJMB12 trial that was the first to deploy therapy based on molecular classification.

Here, Robinson and Gajjar backed off on radiation therapy to the WNT cases, and incorporated new medicines that had traditionally been used for lung and pancreatic cancer, for instance, for the resistant Group 3 tumors. This has allowed St. Jude to offer state-of-the-art therapy to new patients that is more promising and often less toxic than the standard therapy they would otherwise be offered.

“We know we’re treating many medulloblastoma patients with too much therapy and we know if we can sensibly back off even a little bit to those that don’t need it, then that’s what’s going to allow these patients to grow and thrive,” Robinson said.

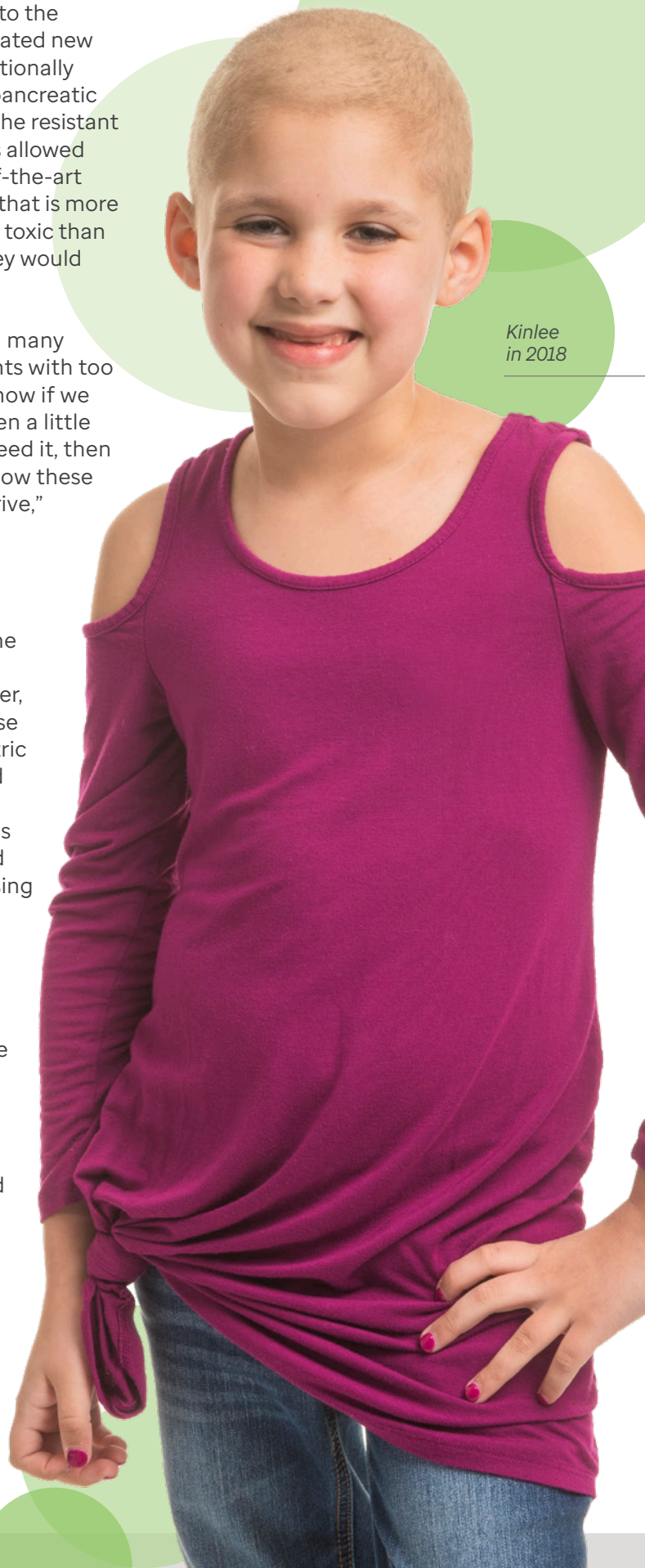
Part 4: Kinlee’s story

As Kinlee prepared for the clinical trial protocol St. Jude developed for her, child life specialists – case workers who help pediatric patients understand and cope with the complex aspects of their diagnosis and treatment – showed her how cancer works using colorful modeling clay.

They rolled clay into tiny balls shaped like tumor cells, malformed and abundant, mimicking the way cancer multiplies in a body. They told her about the tattoos and lines she’d need drawn on her body for MRIs and CT scans. They talked of radiation and about the nausea she’d experience with chemotherapy.

“Obviously, being a child going through harsh treatment, it’s very scary. But I was very curious, too, to see

Kinlee
in 2018



what it was going to be like. I was 7, and was curious and into everything,” said Kinlee.

She remembers it crisply though it was four years ago. Chemotherapy hit her harder than the effects of radiation. Nausea and vomiting made her too weak to climb into bed. She remembers the nurses tilting the bed to help her get in. She suffered complications with her port and was tethered to intravenous tubes for much of her treatment, needles and medical tape tugging and pinching at her sallow skin.

“I have very tiny veins. And so, they kept poking different places. They tried my feet, my wrists, my forearms, everything they could imagine,” she remembers.

Her stocky, muscular build turned wiry and thin as she lost weight and needed a feeding tube.

Reflecting on those difficult times, Nicole posted a message to her friends on social media: *Many nights I laid in a shower and cried for what seemed hours. Many nights, I waited until Kinlee would finally get comfortable for a few hours and sleep to have my break down.*

And though outwardly it seemed Kinlee was not tolerating the treatment, Nicole remembers the doctors offering optimistic outlooks for Kinlee’s response to the therapy they were trying. Despite appearances, the medulloblastoma was not detectable, they reassured her. They shared charts and graphs with numbers and values that offered early proof Kinlee was overcoming cancer.

“Throughout the entire journey, we had the utmost information on what was going on, what was next, what was about to happen.

Seven months after she began the trial, Kinlee was declared cancer-free.

Even if there was something that we didn’t fully understand, they would go print something for us, highlight it, talk to us again to make sure that we understood,” Nicole said. “Communication was key for my husband and I during her treatment.”

Kinlee would start to regain her strength and health over the following months and years, but she needed help getting there.

St. Jude provided Kinlee with a nutritionist and physical therapist, with helpful cooking lessons and exercises offered at the hospital and in patient housing. Eye doctors and specialists to check hearing also treated Kinlee at St. Jude to be sure they helped her manage any side effects of the treatment.

Seven months after she began the trial, Kinlee was declared cancer-free. Scans showed no evidence of disease. She returned to her home in suburban Atlanta with her family and gingerly navigated re-entry to a life that cancer had abruptly halted.

Kinlee couldn’t continue playing with her softball team, which had advanced in her absence. Undeterred, she took up cheerleading. With her mother supporting her as assistant coach, Kinlee doesn’t hold back in training, perfecting her kicks and jumps like the

other kids on the squad. At home, she roughhouses with the best of them, wrestling a little brother she calls “a handful,” and chasing after her energetic goldendoodle, Tinnie.

On quiet afternoons, she sketches superhero cartoon characters. She prefers to draw the villains, concentrating on their motivations and features. Like the doctors who cured her cancer, she’s fascinated by what can go awry in a person.

How and why does darkness grow in a person, suddenly corrupting all that is healthy and good? How does it become strong? What does it take to vanquish it?

Kinlee’s mother, Nicole, considers the determination it took for her family to come out the other side and thinks of the next family preparing to travel the same road they did.

“There’s somebody walking through these doors right now who was just diagnosed,” she said. “And just by us committing and doing a clinical trial, going through everything we did four years ago, we raised that standard to where people can learn from our treatment. Just to know you were part of that, as a mother, to look back on that, it’s very fulfilling.

“When I think of clinical trial, I think of research, research and more research. The more that we do research, the closer we are to finding a cure.”



Research on medulloblastoma at St. Jude is possible because of generous supporters like you. stjude.org/donate

At St. Jude, Dr. Amar Gajjar's

Work Reveals a Lifetime of Progress for Brain Cancer Patients

By Ruma Kumar - ALSAC

Gajjar honored for his work to transform how doctors around the world understand and treat medulloblastoma.

Before he was a world-renowned pediatric brain tumor expert, Amar Gajjar, MD, was a newly trained physician and young father curious about how he could make a difference in the vague and little understood field of childhood brain cancer.

It was 1989. He had a toddler daughter and wife, and had joined St. Jude Children's Research Hospital fresh out of medical training programs in Oklahoma and Florida. He had immigrated to the U.S. from Mumbai, India, roughly a decade earlier, emerging from a populous city on the Arabian Sea more renowned for maritime commerce and the glittering Bollywood movie industry than healthcare and academics.

But he was a serious sort with a mind for science and problem solving. Back then, the brain tumor program at St. Jude was in its infancy, said Gajjar, who is now Chair of the Department of Pediatric Medicine and Director of the Division of Neuro-Oncology. It served about six patients a year. They used mostly CT scans in those days. There was only one MRI machine available to get more detailed images of the brain, and it was housed in a trailer on the grounds.

With limited imaging available, surgery was based "on visual guidance," recalled Gajjar, with surgeons doing their best to remove tumors they could see with the naked eye. Chemotherapy use was just beginning. Radiation therapy was unrefined, sending rays of photons indiscriminately and in high doses throughout the body, killing tumors but also harming healthy organs and tissues with it. Fewer than half of the children survived their disease, and those that did emerged with serious physical and mental handicaps.

"When I was training, my mentor told me, 'You need to take this on as a challenge and make this a career for yourself,' and that's how I started focusing on this disease," he said.





***It has been
a dramatic,
exponential increase
in knowledge
in a relatively
short time.***

- Amar Gajjar, MD
Chair of Pediatric Medicine at St. Jude

For the next 30 years, Gajjar would lead the development of innovative clinical protocols that have nearly doubled survival rates in some patients by providing risk-adapted, targeted therapies for medulloblastoma, the most common malignant brain tumor in children. He has shared data with and collaborated on research studies with scientists around the world.

Within seven years of joining, he developed a clinical trial named SJMB96 that sought to ameliorate the effects of craniospinal radiation for newly diagnosed medulloblastoma patients while improving survival rates that were around 50 percent.

He remembers the very first patient he enrolled into that research study, a child from East Tennessee whose father was a dentist and whose mother was pregnant with her fourth child.

Hearing the diagnosis, “the father was in a complete state of shock,” Gajjar recalled. “And as always happens in tough situations, mothers get tough and take control.”

He asked her if she’d be open to trying out a novel protocol of treatment testing newly adjusted doses of chemotherapy and radiation for her son. She asked him how many children they’d treated using this new approach.

“Your son will be the first,” he remembers telling her.

“And without batting an eyelid, she said, ‘let’s go for it,’” he said. “That’s the faith that has been reposed to us by these parents.”

On that study, he enrolled 134 patients. The lessons Gajjar and his colleagues received on the side effects of treatments and how medulloblastoma behaves differently in each patient informed a successive study in 2003, where 330 patients were enrolled. He then opened SJMB12, a study which has enrolled more than 650 patients to date and is wrapping up. All along, Gajjar has tirelessly advocated for the better therapies he believes St. Jude offers. He counsels patient families whenever they call him, late in the evenings after he’s left clinic and even mid-travel, pausing in airports and hotel corridors to answer questions.

As the studies have grown in size, so has the body of knowledge about this type of brain tumor, and not just at St. Jude, but around the world.

In 2006, Gajjar and his team published a paper showing early evidence medulloblastoma was not one big disease, but a tumor with four distinct molecular groups that behave differently in patients and responded to varying treatment combinations of radiation and chemotherapy. Other programs in Europe and Canada have confirmed the findings.

“So now we are developing newer therapies, targeted therapies based on risk,” he said. “It has been a dramatic, exponential increase in knowledge in a relatively short time.”

Thanks to these new findings, patients with lower risk medulloblastoma now receive less chemotherapy, just four months compared to one year, leading to fewer long-term side effects such as hearing loss, bone marrow suppression and second malignancies.

During his time at St. Jude, Gajjar has helped lead a program that uses sophisticated imaging to diagnose

and track medulloblastoma and other brain tumors. He collaborates with a team of neuro-radiologists trained to pick up the subtlest changes in the tumor.

Over the last decade, Gajjar has also focused on efforts to remediate neurocognitive side effects from radiation treatment. In collaboration with Dr. Heather Conklin, PhD, strategies such as reading interventions have been a part of his medulloblastoma clinical trials. He also works with patients and their local schools to ensure academic support in their hometowns.

Throughout his career, he has authored more than 370 papers, many of which have contributed to the improved clinical care of children with medulloblastoma and other pediatric brain tumors. And all the while, he has steadily progressed in his career at St. Jude. He is the Scott and Tracy Hamilton Endowed Chair in Brain Tumor Research. He is also Co-leader of the Neurobiology & Brain Tumor Program at St. Jude.

But he’s ill at ease with titles and accolades. Asked about his progress, he brings the conversation back to the children he has served.

“It’s been an amazing journey,” Gajjar said. “For our average risk patients, we’ve reduced treatment significantly. Now we’ve got children who are completely intact neuro-cognitively. They’re in college, they’ve got jobs. You can’t even tell they had medulloblastoma.”

Now, he issues challenges to the next wave of young doctors and scientists to continue to build on the foundational work he has done.

“My challenge to my junior staff is put your neck out there and do work that is paradigm changing,” he said. “Devise new therapies for high-risk patients and try to pull them up using the technology available to us.”

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FROM CRAWLING TO RUNNING

By Kristina Goetz - ALSAC

A HALF MARATHON



T Tyler fell asleep in his first-grade class, out of character for the kid who loved karate, soccer and was such a climber his family called him “spider monkey.”

Tyler said he didn't want to play anymore.

Toward the end of 2012, his teacher, a nun at a small Catholic school where his mom Michelle also taught, told her: *Something isn't right.*

Tyler's arms and legs started hurting. He woke up in the middle of the night, crying with pain, his bed sheets soaked in sweat. Just after the turn of the new year, Tyler's face didn't look right either. He was pale all the time.

Michelle took him to the doctor.

“I kept taking him back and telling them something wasn't right,” Michelle said. “Something is absolutely not right with this child. And we kept leaving with the same thing: He's fine. He's 6 years old. He's seeking attention because of his cousin. That's all it is. It's just growing pains.”

Tyler's 9-year-old cousin, who had been diagnosed with pediatric melanoma, had been a patient at St. Jude Children's Research Hospital. She was doing well. But Tyler's symptoms did not abate. And on the night of January 31, 2013, everything changed.

Tyler screamed in pain. He couldn't stop crying. His fingers and toes were swollen into a curled position. His legs and arms started to swell. He could no longer put weight on them. He had to crawl. He laid in the hallway floor.

Michelle picked him up and rocked him. She would call the doctor's office again in the morning. She didn't know what else to do.

When morning came, Michelle called the doctor's office. But they said he might have potassium deficiency, to give him a banana. They told her to give it a few more days, that he was ok. But Michelle couldn't wait any longer. She drove Tyler to the emergency room.

By this point, he was lethargic and hadn't walked in 24 hours.

Doctors admitted Tyler and ran every blood test imaginable – from potassium levels to strains of the flu.

The next morning, doctors said someone from St. Jude would come to talk to them. Michelle's heart dropped. She called her husband and sister and told them to get to the hospital as fast as they could.

“By the time this sweet little resident came over, we were all in the room together,” Michelle remembered. “And she said, ‘We think he has cancer. We think it's a form of leukemia. ALL, which is acute lymphoblastic leukemia.’ And she said, ‘We don't know the extent of anything else, but we're going to transfer you over to St. Jude right now.’”



Tyler in
2017

“All I could think of is that they had just saved my niece's life... They're gonna save his.” ◀ Michelle, Tyler's mom

“And then I look up, and here’s this healthy, you know, strong, healthy child – young man now – running to me,” she said. “And thriving because of St. Jude.” ◀ Michelle, Tyler’s mom

Tyler took the five-minute ride in an ambulance.

“As terrified as I was – as uncertain going into this unknown – all I could think of is that they had just saved my niece’s life,” Michelle said. “They just saved her life. They’re gonna save his.”

When Michelle walked through the doors, she was flooded with calm.

“Because I was like, you know, this is the best place in the world,” she said. “This is the place where everybody wants to be if their child has any form of a catastrophic illness. This is where they choose to be – at St. Jude.”

The official diagnosis came the morning of February 4, 2013. Tyler had ALL.

He was whisked to surgery, and the family was surrounded by nurses, doctors – and constant reassurance that they would do whatever it took to save this boy no matter the cost. The protocol would last three years.

There were so many ups and downs. Some 1,200 doses of chemotherapy, his mom said. Bone breaks from brittle bones. Occupational therapy. Physical therapy. Going to school right there at St. Jude. And child life specialists from St. Jude going to his small Catholic school to explain to kids that what Tyler had was not contagious.

“So, we fast forward a little bit to two years and seven months later,” Michelle said. “It’s August of 2015. And Tyler – two years, seven months in. We’re going through chemotherapy. We were knocking through it. And it just seems like it’s taking forever to get to the end line.”



Tyler had developed an infection on exactly one half of his body. Specialists were puzzled. Then his doctor decided it was the chemotherapy itself that was feeding the infection. Michelle was shocked. They had 16 to 20 weeks of protocol to go. But the doctor said it was time to stop.

“This chemotherapy – even though it is something toxic going into his body – it is his lifeline,” Michelle remembered thinking. “It’s keeping the cancer gone. It’s keeping him alive. It’s helping him survive. And now they’re taking that out of the mix. And I thought, ‘Oh my gosh, what if we go in to do the bone marrow and the brain scans and the spinal fluid taps and all this and there’s still cancer there? Then what do we do?’”

The answer came late at night in a phone call from a nurse practitioner on Michelle’s birthday. The minimal residual disease test was negative. No cancer was detected.

Tyler’s scans have been clear ever since.

Michelle reflects daily on the promises the doctor made that first night: That he would do everything in his power to save her son and St. Jude would not send her a bill for treatment.

“He never said, ‘Well, I’m not going to get this chemotherapy because your insurance won’t pay for it,’” Michelle said. “Or, ‘I’m not going to order this test or this many rounds of therapy for monetary reasons.’ He said, ‘I’m going to do what it takes to make sure that he thrives.’”

“And Tyler is thriving.”

In December 2021, Tyler ran the St. Jude half marathon through the streets of Memphis and through the campus of St. Jude – his second time running the race.

“I want to show the other patients of St. Jude that they can do it,” he said. “It doesn’t limit you just because you have cancer. Even after treatment you can work hard, and you’ll be able to do the things that I do one day.”

Michelle always had hope that Tyler would be healthy, but she was never sure what that would look like.

Standing at the finish line that Saturday, she saw him turn the corner and sprint down the last stretch. She flashed back to all the times she held him when he had chemotherapy. The days he threw up. The ones he cried.

“And then I look up, and here’s this healthy, you know, strong, healthy child – young man now – running to me,” she said. “And thriving because of St. Jude.”

When Tyler crossed the finish line, Michelle was the one to put the medal around his neck.

After hugs and celebration, he turned to her and said:

“I’m running the full next year.”

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Immunocompromised During COVID-19,

.....

LUXE CAME TO ST. JUDE FOR A CURE

.....

Luxe had a failing immune system as the COVID-19 pandemic swept the world. St. Jude helped heal her and kept her safe.

By **Kelly COX** - ALSAC

No one knows how long 6-year-old Luxe was on the edge of disaster every normal day.

The dangers? Her kindergarten classroom. Her loosening baby teeth. Cheerleading with the church's youth athletic program, jumping up and down beside the basketball court. Even the busy home where strep throat had recently sickened her three siblings, but somehow, not Luxe.

All this represents incredible luck. Because, unbeknownst to everyone, Luxe was walking around with a crippled immune system and a platelet count so low, her blood could not properly clot. Had she caught a virus, lost a tooth, taken a tumble, it would have been a serious risk to her life.

"A normal number for platelets is 250,000 to 450,000," said her mom, Meagan. "The pediatrician took a blood sample and hers was less than 10,000. Her only option was a bone marrow transplant."

Shutdown

It's hardly uncommon for 6-year-old kids to have bruises. But that day in February, Luxe's legs sticking out of the purple and gold cheer uniform were black and blue. Meagan took her to the doctor, expecting low iron. Instead, Luxe was diagnosed with severe aplastic anemia. Her bone marrow (the body's producer of red blood cells to carry oxygen, white blood cells to fight infection and platelets to stop bleeding and to respond to immune threats) was a factory in shutdown.

And here's another reason, in retrospect, that Luxe was lucky. All of this was discovered less than a month before COVID-19 became a global crisis.

By March 2020, Luxe was at St. Jude Children's Research Hospital, where pandemic precautions were already in place, preparing to receive her brother's stem cells.

On March 12, the day after the World Health Organization officially declared COVID-19 a pandemic, St. Jude implemented the St. Jude Emergency Operations Plan. Behind the scenes, changes were far-reaching and nearly instantaneous. The campus was closed to all but essential personnel and sectorized into clinical and nonclinical zones, with restricted access. St. Jude quickly developed a comprehensive COVID-19 screening program that included regular testing of all employees on campus. 3D printers across campus were repurposed to churn out personal protective equipment. Routine patient care was provided, whenever possible, at St. Jude housing instead of the hospital itself.

If it was among the worst times to be immunocompromised, to Meagan, it was one of the best places. “We had a child with no immune system, and now we are in a pandemic. St. Jude did a wonderful job in trying to keep COVID out of the hospital. They made sure our child was safe.”

And there was another comfort: During this uncertain time for both the world and Luxe’s family, St. Jude went above and beyond just standard medical care.

The Luxe family was surprised by how much St. Jude provided. “We knew the medical bills were taken care of and we knew they had housing for families, but we did not know they provided groceries, gas reimbursement and transportation from lodging to the hospital,” Meagan said.

Patients typically undergo chemotherapy and radiation therapy to disable their own bone marrow prior to transplant. In Luxe’s case, said Meagan, “her body basically did the work.” She required many platelet and blood transfusions, but just a few days of chemotherapy before the procedure.

After her transplant, Luxe remained inpatient for 100 days, then in an apartment in St. Jude housing, in near total isolation until May. Shut down were the playgrounds, the common dining room, the music room, the game room. It was a big change, coming from a bustling family of six. But Luxe took it in stride. Though outgoing, “she is also very much happy to be in her own world,” said Meagan’s brother, Chase. “Luxe can go in a room and just be by herself and play for hours on end.”

In July 2020, Luxe was released to go home. In April 2021, it was deemed safe for her to re-enter normal life – or

as normal as what most everyone else was doing, as COVID-19 infection rates in the U.S. stubbornly hung on.

“A Brother Is Born For A Time Of Adversity”

Even though Luxe enjoyed living as an only child at St. Jude “a little too much,” joked Meagan, her little brother, Asher, played a key role in her healing. All her siblings were tested, but 4-year-old Asher was the best match to be her donor.

Meagan and the kids’ dad, Landon, explained it to Asher like this: Here was his chance to be a real-life superhero, and save his sister’s life. “Of course, there was no doubt in his mind,” said Meagan, “he wanted to do it. He would tell everybody that he was a superhero. We tried to explain as much as possible what the procedure was going to be, and he never acted scared. The only time he actually shed a tear was when they put his IV in.”

When Asher’s role was complete, the kids’ Uncle Chase, in his own role as a brother in time of adversity, picked the little superhero up and drove him the seven-and-a-half hours home.



That phrase from Proverbs – “a brother is born for a time of adversity” – resonates for Chase, a pastor. After Luxe’s diagnosis, he spent a lot of hours frankly angry and unable to focus on his work. But then he remembered: He was powerless to change the circumstances, but he wasn’t powerless full stop. He refocused his energies on being a spiritual and practical help to Meagan and Landon in their time of need. And with Luxe out of danger, Chase’s gratitude to St. Jude led him to compete in the St. Jude IRONMAN 70.3 Memphis as – not a superhero, which is Asher’s territory – but a St. Jude Hero, raising funds for the research hospital.

“Seeing the blessing that St. Jude was to my family, how they cared for them even in the craziest season ever with COVID, I wasn’t going to pass up the opportunity to race in Memphis on behalf of St. Jude,” he said.

“You just have to say thank you. There’s a few things in life that we get to be proud of and this kind of fell in my lap, this brother-sister relationship. And Asher, he was born a donor match for Luxe. It was just him being him that helped save her life. We didn’t do anything outside of what we were born to do and we got to be part of an extraordinary outcome.”

QUINCY: FINDING HEALING AT ST. JUDE

When Quincy couldn't shake his stomach trouble, his pediatrician had a feeling something more than a virus might be the cause. Sure enough, scans showed Quincy had a mass on his right kidney — a type of renal cancer called Wilms tumor.

He was referred immediately to St. Jude Children's Research Hospital for treatment. "It's definitely a whole other world inside these doors," said Quincy's mom. "You get a sense that everybody is here fighting the same fight. Everybody has the same goal and everybody wants the best for the kids." Quincy's treatment included surgery to remove the affected kidney and chemotherapy. He celebrated his last dose of chemotherapy in August 2018.

Quincy's family use their talent and their faith to inspire by leading worship through music at churches in their area. In addition to being musical, Quincy is wildly imaginative. "He's that guy who lightens the mood just because you never know what's gonna come out of his mouth. If you're having a bad day, he'll be the one to bring you out of that slump," said his dad. "He's basically everything I have always imagined in a son."

ST. JUDE'S

OF ST. JUDE

MAGGIE CUPIT-LINK, MD: WORKING FOR 'THE KIDS WHO INSPIRED ME'

For Maggie Cupit-Link, the world was just starting to open up.

Leaving her small town behind, she started classes at Rhodes College and gained a summer research job at St. Jude Children's Research Hospital. No small feat for a college freshman.

Shockingly, on what would have been her first day as a researcher, Maggie entered the St. Jude campus as a patient diagnosed with Ewing sarcoma. Heartbroken, but not defeated, she found that the challenges and adversity that took so much also provided purpose.

After finishing treatment at St. Jude, Maggie returned to college and completed medical school. Armed with a new calling and greater understanding, she now works for St. Jude and is eager to give back.

"I wanted to be a doctor for the kids who inspired me so much," she said.





GLORIA DE DIOS: BUILDING A 'MINI ST. JUDE' IN GUATEMALA

When Gloria de Dios started out, she was one woman crying over a laptop, wondering if cancer in children could even be cured. In her native Guatemala, children were being treated with adult doses of chemotherapy, kept away from their parents and loved ones during treatment. Worse yet, many of the children suffering from cancer would never even be diagnosed.

She knew something had to change. "It's not fair that we lose a child for lack of resources," she said. "It's all about dignity, because they deserve a second chance in life."

Since 1998, de Dios has been involved in a fundraising foundation called AYUVI, a St. Jude partner in the mountains of Guatemala that treats children with cancer. Under her leadership, fundraising has skyrocketed from \$3 million to \$11 million since 2007, and the survival rate at her clinic – which she calls a "mini St. Jude" – has risen from 20 percent to almost 70 percent.

"Having St. Jude Children's Research Hospital by my side makes me feel safe. Its international outreach program has helped us in so many ways, but if I must choose one, it is how the staff gave us the recipe on how to raise funds to save children's lives."

TYLUR FRENCH: SUPPORTING ST. JUDE THROUGH ART

When an opportunity to work with St. Jude Children's Research Hospital and Carnival Cruise Line popped up, Memphis sculptor Tylur French did not hesitate to sign on. This is the artist who calls his work "jubilant" after all. And bold.

In one of his well-known hometown pieces, he soldered more than 300 bikes together, painting them in bright blues and yellows and pinks to form a mammoth arched gateway for a treasured park. On another project for St. Jude, he and his team meticulously attached millions of shimmering sequins to large panels on a five-story interior courtyard for patients and families to see. The sequins, in bright magentas, greens and golds, sway in the breeze, reflecting light (and hope) for the in-patient families who look into the courtyard as they head to their rooms to rest from treatment.

For Carnival Cruise Line, which has long been a partner of St. Jude, French worked on four installations for the cruise line's newest ship, Mardi Gras. He reproduced St. Jude patients' drawings in steel, epoxy, resin and the multicolor glimmering sequins he used for the courtyard on campus.

"Whatever role we as an art studio can play to help that mission, we're incredibly grateful to be a part of it," French said. "This is what I'm really supposed to be doing."





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St. Jude mom Jayne: Danny Thomas' dream inspires and saves lives

Jayne found hope at St. Jude for her daughter Claire, who was diagnosed with medulloblastoma. Her family wants to be part of ensuring St. Jude is a place of hope far into the future.



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