

● ST. JUDE

inspire



FALL 2024

St. Jude Family

Generations before James became a patient, his great-great grandfather supported St. Jude.



Moving forward

Yarianis has a new dream after cancer treatment at St. Jude

History-maker

St. Jude patient was the first person ever cured of sickle cell disease

Improving patient outcomes

St. Jude is targeting tough-to-treat pediatric cancers

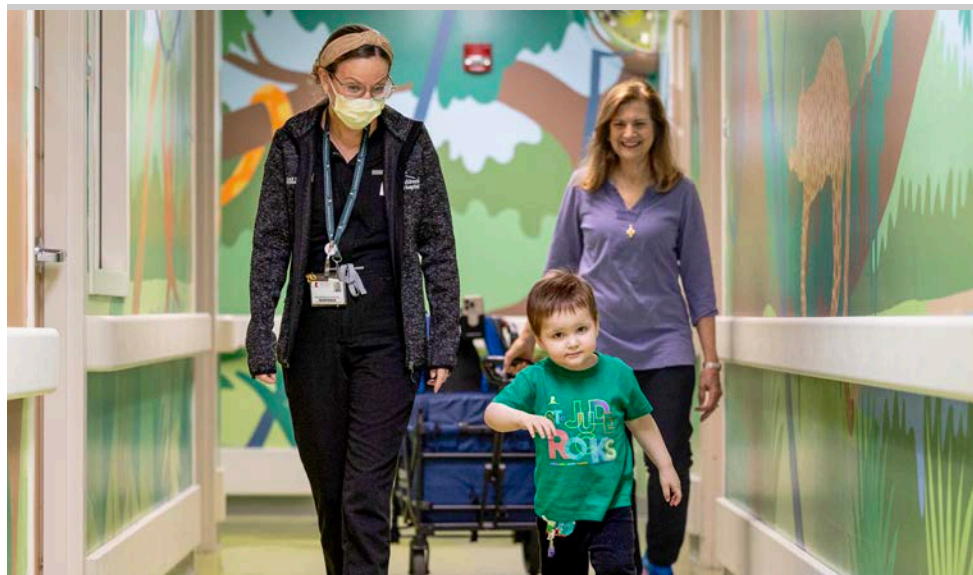
HERO

MOMENT

A rabid Dallas Cowboys fan, Matthew grew up watching legendary quarterback Tony Romo play. He never missed a game, not even when he was 8 and in treatment at St. Jude Children's Research Hospital® for medulloblastoma, a cancerous brain tumor.

Matthew, now 27, got the chance to meet Romo in February at the 19th Annual Legends for Charity® Dinner in Las Vegas. The event has raised more than \$14 million for St. Jude since 2005. Matthew never dreamed he'd meet his hero. Turns out, Romo thinks kids at St. Jude, like Matthew, are the heroes.





At the heart of St. Jude Children's Research Hospital® is something so fundamental and essential — family.

As supporters of this mission, you are all part of our St. Jude family. We are a family united by a common goal to care for kids with cancer and other catastrophic diseases. Ours is a family of individual supporters, doctors, nurses, researchers, caregivers, patients and corporate partners like Domino's. The Domino's Village housing facility is a place for families to rest and heal together. And with their generous new commitment to raise \$300 million by 2034, Domino's is helping St. Jude offer hope and healing for generations to come.

Speaking of generations, in this issue of St. Jude Inspire you'll read about a family that's been looking out for each other — and for St. Jude patients — for more than 60 years.

James was diagnosed with neuroblastoma, a devastating cancer of the nerve cells, when he was just 3 months old. For most families, that diagnosis might be their initiation to our mission. But James' great-great-grandfather, Jack, a Lebanese immigrant, supported St. Jude from the very beginning as president of the Nashville chapter of ALSAC.

James' parents, Amy and Rob, volunteered at St. Jude patient family housing facility Target House before they were even dating.

And now, their son has found the lifesaving treatment his family never hoped they'd need at the institution his ancestors helped build.

Amy said, "You see so many people here, meet so many people from completely different backgrounds, don't speak the same languages, but we all want the same thing. We all want our children to have long, meaningful lives."

What's more, they all become family while they're here — bound by the unifying vision that no child should die in the dawn of life.

I hope you'll read and share these stories with your own families. With your advocacy and support, we hope that one day we'll see all kids with cancer, no matter where they are, live long, meaningful lives.

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

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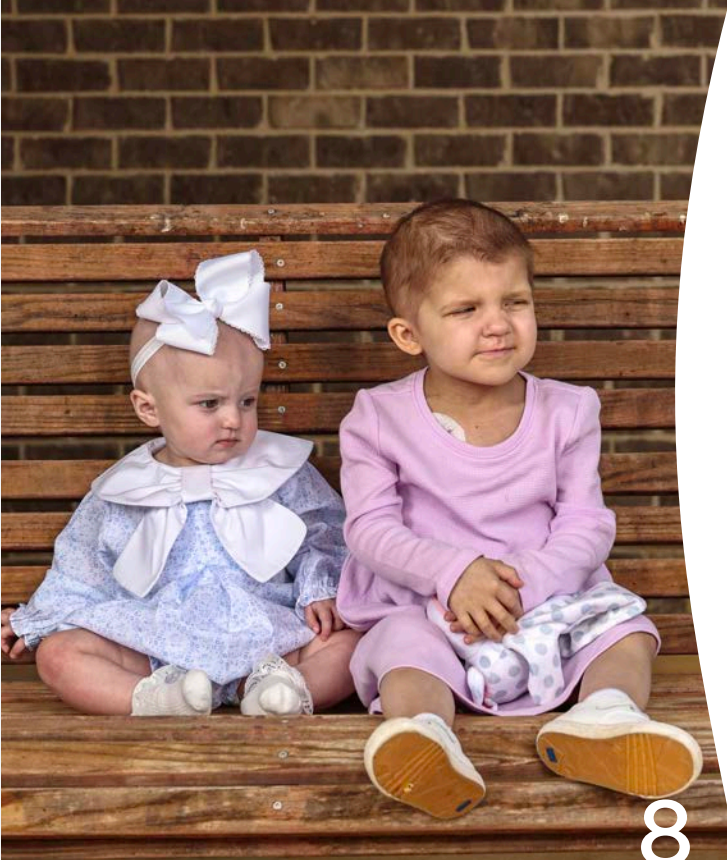
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Together, we can help cure childhood cancer.
Donate at stjude.org/ImpactGiving

chance

ST. JUDE GAVE US OUR

When my son, Chance, was diagnosed with a cancerous brain tumor, St. Jude offered a way forward.

By **Trish** - Chance's mom

Becoming a first-time mother in my 40s was a long-awaited dream come true. When my son was born, I named him Chance. I could not have predicted just how much he'd live up to the name.

Five days before he turned 5 years old, Chance was diagnosed with brain cancer.

In the weeks leading up to his diagnosis, we had been to his pediatrician, a gastrointestinal specialist, and admitted to the hospital, all because Chance was vomiting every day. This little boy held a barf bucket in his lap for six weeks. The doctors were attentive, but Chance was getting no relief. My mind understood medical mysteries take time to solve, but my gut felt a sense of urgency that something serious was wrong.

On the Fourth of July, Chance was feeling good for the first time in

weeks, so we attended a charity celebration with friends. Looking back at video from that day, I can see now that Chance was having balance issues. But in that moment, watching the fireworks with my happy boy, life was perfect. I went to sleep with thanks in my heart that we had turned a corner.

The next morning, Chance woke up screaming. We rushed him to the emergency room and by 8:30 a.m., the life we had known was over. It was a tumor, a huge brain tumor. The next day, we learned it was medulloblastoma, an aggressive brain cancer.

There are no words to describe what that feels like as a parent. I had dreamed of and hoped for and wanted this child for so long and, just like that, it appeared it was over. I had lived decades without him before he was born, but it felt like I couldn't live even minutes without him now. Five years with him wasn't nearly enough.

Chance had emergency brain



surgery. Surgeries on this part of the brain can result in serious side effects, and this was the case with Chance. My brilliant child, who loved hiking and was always making up songs, lost his mobility and ability to speak. I thought it was the beginning of the end.

Thankfully, we were referred to St. Jude Children's Research Hospital® to join a clinical trial for his particular cancer.

At St. Jude, Chance received proton therapy to his brain and spine and months of chemotherapy. His care team showed him so much kindness and respect, and they extended the

same regard to me. Although I'm just a mommy, these world-class experts valued the expertise I brought to the table regarding this individual child. We were no longer victims, but warriors taking on a seemingly unstoppable foe, but we had the most experienced team on earth and, most importantly, we had hope.

I wish there was a way I could bottle that feeling, when you have hope. Hope is the greatest gift you can give a parent in this situation. That's why it's so important to me that St. Jude is a research hospital, and that we have had the opportunity to participate in that research. No matter what happens to us, we are going to be part of the solution for someone.

When we got to St. Jude, Chance could not walk, talk, swallow or hold his head up. Eleven months later, on the day before his 6th birthday, he walked out of there. He still uses a walker and struggles with tasks of everyday living, like buttoning his clothes, but he has grit unparalleled by any human I know. St. Jude gave him another shot at living and he's running with it.

Chance's determination is unflinching in the face of challenges, and so is St. Jude. These kids with cancer need a cure. Until there is a cure, they just need a chance. St. Jude gives them that chance.

When the love of your life has such difficult odds, the greatest gift anyone can give you is hope. That's what St. Jude has given us. St. Jude gave us our Chance.



Join St. Jude in our mission to cure childhood cancer and help patients like Chance get the treatment they need. [st.jude.org/ImpactGiving](https://www.stjude.org/ImpactGiving)

Targeting tough-to-treat pediatric cancers

Dr. Julie R. Park helps lead St. Jude efforts to improve patient outcomes.

By **Ruma Kumar** - ALSAC

When Gideon's parents found bruises on his body and a lump on his head, they took their baby to the pediatrician.

In the clinic, his doctor also felt a mass in Gideon's abdomen. Gideon was referred to St. Jude Children's Research Hospital® where tests determined he had high-risk neuroblastoma, an aggressive and rare type of cancer that almost always affects children.

He started therapy at St. Jude three days after his visit to the pediatrician. Scans showed the cancer had spread throughout his body, even causing the lump on his head. But quickly, his treatment began to work. In addition to chemotherapy, Gideon had surgery, a bone marrow transplant and radiation therapy at St. Jude. He also received a novel antibody therapy manufactured on the St. Jude campus.

After more than a year of treatment, Gideon went home with no evidence of cancer in January 2017. Survivors

of childhood cancer like Gideon who are treated at St. Jude receive long-term follow-up care. So, until he turns 18, Gideon visits St. Jude once a year for checkups at the After Completion of Therapy (ACT) Clinic. Hopeful stories like Gideon's fuel the work of clinicians and researchers like Julie R. Park, MD, who is now Chair of the Department of Oncology at St. Jude. She took over the leadership post in January 2023, leaving Seattle where she had spent 30 years working to develop new therapies and improve survival rates for children with cancer.

Park is also the Associate Director for Translational Research in the Comprehensive Care Center at St. Jude. She works with teams of doctors and researchers who perform translational research – that is, how to turn the cutting edge, innovative work done in the labs of St. Jude into more effective treatments in clinics that treat kids with pediatric cancers. Through these roles, Park is hoping to chart substantial progress in tough-to-treat pediatric cancers like neuroblastoma.

She assumed the role as Chair after the esteemed St. Jude oncologist Ching-Hon Pui, MD. Pui is internationally renowned for his work to improve survival rates and the quality of life for kids with acute lymphoblastic leukemia (ALL). He continues his clinical and research work to improve outcomes in

patients with ALL, with a focus on clinical research in the Asia-Pacific region for St. Jude Global.

Park grew up in Rhode Island and received her early medical training at the University of Vermont in Burlington, Vermont. She completed her medical training in pediatrics and pediatric hematology/oncology in Seattle, Washington.



That's also the place that first sparked her interest in pediatric cancer research. "I found my true love in what I wanted to do: to treat children with cancer and improve their outcomes," Park said.

That principle still drives her. Especially when she thinks of cases like Gideon's.

"Neuroblastoma, I think, is the most fascinating and yet most frustrating cancer we treat in childhood," Park said.

Children can be diagnosed with neuroblastoma as early as the day they're born, Park said, but the average age for diagnosis is 2. Neuroblastoma is a difficult disease to detect in early stages and doesn't follow predictable patterns in how it behaves in children, she said.

Some children with neuroblastoma can have widespread disease, including nodules under their skin and enlarged livers, but remarkably, the disease resolves on its own. Under the microscope, those neuroblastoma cells look just like any other cancer, and yet they go away on their own, Park said. On the other hand, there are children with widespread disease in their bones and their bone marrow, and in these children, neuroblastoma does not go away on its own. In fact, if left untreated, the children with this form of neuroblastoma will likely die, Park said.

"And what we don't understand is what causes the spontaneous regression of neuroblastoma in some children and not others," Park said.

She points to a curve on a graph that shows survival rates climbing over the last 20 years. But that improvement is not nearly as dramatic as she'd like.

"I found my true love in what I wanted to do: to treat children with cancer and improve their outcomes."

– Dr. Julie R. Park
Chair, St. Jude Department of Oncology

"We are treating these children with the most intensive therapy we have at our disposal and yet in some cases, 50 percent of them will not survive. That's just not acceptable," Park said. "And those surviving still have multiple long term health effects because of the intensity of the treatment. We have to do better for them."

Fortunately, Park is overseeing further research on one of the biggest advancements in neuroblastoma research today:

how to harness the power of the immune system to detect and kill neuroblastoma cells.

"There are antibodies that are proteins that recognize tumor cells and stick to it. They're like a flag and tell the immune system be a Pac-Man and go gobble up that tumor cell," Park said, adding, "St. Jude has made its own antibody and very exciting trials have shown the addition of the antibodies early on in treatment may improve outcomes."

It was this earlier clinical trial – concluded before Park assumed her current roles and led by St. Jude oncologist Sara Federico, MD, and now-retired oncologist Wayne Furman, MD – that made it possible for Gideon to receive antibody therapy to treat his high-risk disease. Following the encouraging results of that clinical trial, Park said she's excited to join the team and help shepherd it through the next phase of trials and study.

Relying on antibody therapy more could potentially allow doctors to pull back on more toxic therapies like radiation and chemotherapy.

Cancer cells tell your body to bring in normal cells to protect them.

"I like to say it's like building a moat around the castle," she said. "The cancer cells signal to all the parts of our immune system to help protect them. Parts of the body that should not be doing this end up guarding the tumor cells to prevent the normal immune system from doing their job. We have to understand how and what the tumor cells are telling the rest of the body. It's called a tumor microenvironment. Why does the immune system become so ineffective when cancer cells are communicating with it? Why isn't it attacking?"

Until now, a variety of clinical trials studied these questions in isolation across various cancers. But Park envisions a more comprehensive platform of clinical trials that study and share everything from why some kids are more likely to develop cancer to the molecular underpinnings of tumors, or the immunologic effect of tumors, and better understanding tumor microenvironments so doctors can manipulate their weaknesses to destroy them more effectively.

It's the kind of ambitious, far-reaching work only possible at a place like St. Jude, Park said. Thanks to generous donors, researchers have the freedom to study, collaborate and communicate across and outside their individual disciplines and expertise to share information about what they learn about the complex nature of the worst diseases to threaten children's lives.

"We should learn from each patient so we can continue to develop new treatments and therapies," Park said.

Her vision for the future: oncology that is built on collaboration and innovation.

"Researchers have to collaborate both internally and externally so that we can get cures faster for kids with cancer."



Together, we can help cure childhood cancer. Your gift helps oncologists like Dr. Park continue their lifesaving work. stjude.org/ImpactGiving

Lifelong FRIENDS

FACE THEIR GREATEST CHALLENGE

Christine and Anna Marie have daughters with the same cancer diagnosis and are now St. Jude moms together.

By **Linda A. Moore** - ALSAC

They don't remember when they met. Anna Marie and Christine were born about two weeks apart and grew up in the same small Mississippi town. Their families were friendly, and they all attended the same church.

Christine and Anna Marie had tea parties and sleepovers. They made prank phone calls and got equal punishments after they ordered 20 pizzas once as a joke.

"That was Anna Marie," Christine said. "I blame every bit of it on her."

"Our moms made us pay for them," Anna Marie recalls.

Later, they went to college together and are now both teachers.

Christine married Anna Marie's cousin Bryson. It's a rare day that they don't talk or text or both.

These lifelong friends have shared so much. Now, both have daughters (fourth cousins) who are patients at St. Jude Children's Research Hospital®. They're St. Jude moms – together.

In early 2023, Anna Marie's daughter, Logan, now 4, and Christine's newborn daughter, McClain, were both diagnosed with neuroblastoma.

Neuroblastoma is a very rare type of cancerous tumor that almost always affects children. Tumors generally develop in the adrenal glands, located on top of the kidneys. It accounts for 50 percent of cancers in infants, making it the most common tumor in infants less than a year old.

As difficult as this situation is, these friends are grateful to have each other. "I hate that we had to have each other. It's terrible that we are both here, but it's wonderful at the same time," Christine said.

Logan's Story

After 2-year-old Logan complained of leg pain and spiked low-grade fevers, her parents took her to their pediatrician. As Logan's symptoms persisted over a two-week period, her pediatrician sent her to the emergency room at their local hospital where she was admitted for treatment. From there, she was transferred by ambulance to a children's hospital two hours away. Anna Marie rode with Logan, while Jake, Logan's dad, followed on ice-slick roads in his truck.

At the hospital, an MRI scan showed a mass on Logan's right adrenal gland. Because the scan results suggested a possible diagnosis of neuroblastoma,



Lifelong friends Christine (left), with her daughter McClain, and Anna Marie, with her daughter Logan, have added to their long list of milestones together – they are now both St. Jude moms.

Logan was transferred to St. Jude that same day for diagnosis and to begin care.

“From a mom’s standpoint, my heart was breaking for her,” Anna Marie said. “My heart was breaking for my child. There were so many emotions going on at that point.”

McClain’s Story

Thirty-six weeks into her pregnancy, Christine saw a specialist for an ultrasound. The scan showed a mass on the baby’s right adrenal gland. Christine and her husband Bryson were also sent to the children’s hospital two hours away.

Two weeks after that fateful ultrasound, on Feb. 3, 2023, McClain was born weighing less than six pounds.

At 9 days old, McClain was referred to St. Jude. Over the course of her treatment, she’s had surgery and chemotherapy. By McClain’s first birthday, she was out of treatment and at home for a celebration.

“I feel like she didn’t really have a babyhood,” Christine said. “That makes me sad. That whole year was kind of surreal. I was (at St. Jude) every minute of every day. But now, it’s like it didn’t even happen.”

Everyone is in this fight

Having both girls at St. Jude was a lot to process. But the two families found ways to come together to support each other, being there for surgeries, tests and scans.

Jake was the first person Christine and Bryson saw on their first day at St. Jude. When Christine checked in to family housing at St. Jude, Anna Marie was the first person to knock on her door.

Back home in Mississippi, the dads are grateful they were close enough to St. Jude to drive in when



(above) St. Jude patient McClain is all smiles with her mom Christine following a check up at St. Jude in August of 2023. (right) St. Jude patient Logan snuggles with her mom Anna Marie during an appointment at St. Jude in January 2024.

needed. The grandparents from all sides have been a godsend.

“The unfortunate thing is, in a way life stops, but in a way, it has to keep going,” said Jake, a police officer.

Whenever Anna Marie is away with Logan, he’s been home working and looking after their 8-year-old son, Earlea, and 7-year-old daughter, Elizee.

“They just know their sister’s really sick and momma’s got to be away for a while,” he said.

Logan is still in treatment but has been able to spend time at home, play with her siblings and make demands on how high her brother should push her swing.

Meanwhile, Bryson, a lineman for a power company, has also been

caring for Bryar, their 4-year-old son while mom has been at St. Jude with McClain.

It’s a relief now to watch McClain play with her brother, test her balance and hang on to furniture as she moves through the living room.

“She’s been through so much at her age,” Bryson said. “You really want her to be into everything.”

St. Jude donors make it possible

Jake knows of other St. Jude patients in their town.

He didn’t know about the commitment St. Jude provides to families.

Families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

“I had no idea until we got there,” Jake said. “Thank you is not enough.”

Christine and Anna Marie joke about how they imagine their daughters will be when they’re older and this journey is behind them. They hope McClain and Logan will be close.

“They’re going to be a force to be reckoned with,” Anna Marie said.



Together, with St. Jude, you can support treatment for patients like Logan and McClain.
stjude.org/ImpactGiving



My heart was breaking for my child. There were so many emotions going on.

– Anna Marie, Logan’s mom



Family of Support

James is receiving treatment from the organization where his great-great grandfather served as one of its early champions.

By **Kelly Cox** - ALSAC

It would have taken about five days to cross the Atlantic Ocean then. Aboard the ship was a little boy known as Jack, born in Zahle, Lebanon, in 1907, and bound for his new home, the United States. He would settle in Tennessee, start a business, raise a family and remain as proud of his Lebanese roots as he was in love with his new country.

In the spirit of giving back to his new nation, he sought to do something for others. When he learned his famous fellow Lebanese American, Danny Thomas, was raising money to build a hospital for catastrophically ill children, Jack got involved.

Jack P. Wehby became president of the Nashville chapter of American Lebanese Syrian Associated Charities

(ALSAC), the fundraising and awareness organization for St. Jude Children's Research Hospital®. This hospital would be unlike any other. It would be guided by the belief that no child should die in the dawn of life. It would tackle diseases deemed incurable, such as childhood leukemia, and it would accept patients regardless of their race, religion or a family's ability to pay.

Four generations later, Jack's great-great-grandson James would receive treatment there, not once but twice.

But Jack and James aren't single points of contact that root this family to St. Jude. In fact, there is a web of connection to St. Jude across the generations, a familial culture of caring in which each generation was paying it forward, without knowing they were.

Close to Home

"My great-papa would be so proud of James because he's such a fighter," said Amy, Jack's great-granddaughter and James' mom.

"I call him 'Mr. Mischievous,'" said James' dad, Rob. "He just loves to get into everything. He loves slides.





He loves running outside. He loves singing and dancing. His dancing is great because he just dances like nobody's watching."

James, now 3 years old, was first diagnosed in 2021 at 3 months old with neuroblastoma, a cancer arising from nerve cells. He was referred to St. Jude immediately.

"It was heartbreaking," said Rob. "You feel powerless. You're scared, you're worried. It's just a whole lot to take in."

"Who wouldn't want to be part of something bigger to give families and children hope?"

– Rob, James' dad

James underwent months of chemotherapy at St. Jude. Amy has photos of him smiling in his hospital crib, playful and happy despite the illness, despite the treatment. James was able to complete treatment and go home before his 1st birthday. Amy and Rob took the kids to the beach, and soon learned James, their youngest, was going to be a big brother himself. It was a year of "normal family stuff," said Rob.

Then, at one of James' regular checkups at St. Jude, scans showed his cancer was back.

Amy and Rob knew relapse was possible, but it still took them off-guard. Now they needed St. Jude for a second time.

Full Circle

When James' family returned for treatment, they stayed in an apartment at Target House, a housing option provided to patients and families.

It was their first time there as a St. Jude family, and yet it was familiar, because before they were even dating, Rob and Amy both volunteered at Target House.

"Amy, of course, has her own story with her family history," said Rob. "My family has always been huge supporters. Just seeing my mom and dad always donating to St. Jude and being part of that made me want to be part of something like that."

Amy and Rob were in college then, and volunteering was a reminder there were more pressing things in life than exams. It felt good to reach outward with a helping hand.

Not long ago, Rob's social media archive offered up a 2010 photo of him and Amy at one of their volunteer events at Target House. It was a strange and unexpected feeling of coming full circle. This time instead of serving, they were being served. Rob said, "It's completely different being on the other side."

Rob's support of St. Jude was sort of an obvious choice because his parents had modeled it. "Who wouldn't want to be part of something bigger to give families and children hope?" he asked.

Now, he knows just how much that really means.

Looking at Legacy

"If I were to die tomorrow, I now know why I was born." – St. Jude founder Danny Thomas

When Amy thinks of her great-grandfather Jack's life,

and how his actions continue to touch her family now, she thinks about legacy.

“You know, he was tough,” she said. “My family’s tough. I just think like, how overwhelming to immigrate to a country, a foreign country, and to build this life. And I think I’ve found that within myself through James’ battle. I didn’t know how strong I am, honestly didn’t know if I had that same toughness. But it’s there, and I see it in James.”

St. Jude “is always going to be part of me and my family and our family history,” said Amy.

Moving forward, childhood cancer is part of it, too. When James first arrived at St. Jude, Amy and Rob were asked if there was any history of childhood cancer in the family. In their whole large family, there was none. But from that point forward, the answer became yes.

“My great-grandfather helped raise money for St. Jude in its infancy, and now he has a great-great grandson being treated there.”

– Amy, James’ mom

“Our lives were forever changed with James’ cancer diagnosis,” said Amy. “I sing the praises of St. Jude all the time because ... you don’t really know, I guess, until you’ve been through it. You see so many people here, meet so many people from completely different backgrounds, don’t speak the same languages, but we all want the same thing. We all want our children to have long, meaningful lives.”

“My great-grandfather helped raise money for St. Jude in its infancy, and now he has a great-great-grandson being treated there. It’s people like him that made St. Jude what it is today.

“We’re all here for a short while. And what’s going to be your mark? What’s going to be what you’re remembered by? Make it meaningful. Make it impactful.”

You may never know what impact your actions today will have on the future.”

James continues to receive treatment at St. Jude.

Jack, who started his life in Lebanon, died in Tennessee in 1998. His gravestone is inscribed with this epitaph: *I Tried*. In terms of making a difference, his family believes he more than succeeded.



You can help ensure families like James’ never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live. stjude.org/ImpactGiving



St. Jude patient
Kiara



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St. Jude family.**

**This holiday season,
we need you.**

Donate Now



stjude.org/givethanks

This holiday season, we give thanks for our family of corporate partners. Support St. Jude by giving online or in-store through these brands.



An Amazing Place Doing **AMAZING THINGS** for the Children

A family honors St. Jude and their daughter's legacy.

By **Yolanda Jones** - ALSAC

When Pat Wedner's daughter, Julie, was 5 years old, doctors diagnosed her with neuroblastoma, a cancer that starts in the nervous system, frequently in the nerve tissue of the adrenal glands above the kidneys, and can spread quickly.

Over the next few years, Julie, a smart and playful girl with expressive green eyes, underwent multiple surgeries, chemotherapy and other treatments.

Though she was never a patient at St. Jude Children's Research Hospital®, one of her doctors at her hometown hospital in St. Louis spent a yearlong sabbatical at St. Jude, and this made an impression on Julie's family.

As the years passed, Julie, the bubbly little girl who loved horses and her big sister, Kati, battled cancer with courage. Yet, just before her 11th birthday, she passed away from neuroblastoma.

Decades later, her family's gratitude to St. Jude has taken shape in a meaningful way. They established

the Julie Scannell Memorial Named Endowment Fund, a beacon of hope at St. Jude for other children facing the same fight.

The generous donations from their IRA account are not just financial support, they are a legacy that continues to inspire hope, healing and works towards a cure at St. Jude.

Her mother, Pat, speaks of their commitment with a voice that resonates with both sorrow and determination. "It is our desire not to see other children go through what Julie went through, for them to have a chance at life."

Jim Wedner, who married Pat after Julie's passing, echoed this sentiment. "Our decision to support St. Jude was a very simple one."

Jim, who is a doctor, has long admired the mission and research at St. Jude. He read an article in the Journal of Medical Oncology about St. Jude "moving the needle" on high-risk neuroblastoma research through a chemoimmunotherapy clinical trial, which spurred the couple to make their first gift establishing the endowment fund.

The family's call to action extended to friends, family members and others. They urged them to

“
It is our desire not to see other children go through what (my daughter) Julie went through, for them to have a chance at life.

– Pat Wedner,
St. Jude supporter

contribute to the endowment fund as a testament to Julie's life and a step forward in the fight against neuroblastoma – a disease that approximately 800 children, many of them under 5 years of age, are diagnosed with each year in this country. It is the most common solid tumor pediatric cancer. Patients with high-risk neuroblastoma undergo multiple rounds of chemotherapy, radiation, surgery and immunotherapy.

Thanks to medical advances and new research, the five-year survival rate is now over 90% for low- and intermediate-risk patients and around 50% for high-risk patients. All of which are a poignant reminder of the progress made and the lives saved.

Julie's sister, Kati Scannell Goffstein, has been motivated by the progress made over the past four decades.

"It is really hard when there's a diagnosis like this, and it's up and down and just never-ending, right? You know the pain of our family and my sister," Goffstein said. "You want somebody there fighting. My mom never gave up and I see St. Jude fighting. Never giving up."

With the goal of moving the needle even further on survival rates for pediatric cancers, St. Jude leads more clinical trials for childhood cancer than any other hospital in the United States. Sara Federico, MD, is the director of the Solid Tumor Division within the Department of Oncology, and she is currently leading

five clinical trials on approaches to treating neuroblastoma.

St. Jude researchers and doctors recognize they cannot stop or slow down until survival rates increase, relapse rates lower and the toxicity of treatment is reduced while finding optimal efficacy. St. Jude donors help make this work possible.

Pat and Jim have visited St. Jude many times including

last year during an annual event for supporters where they got to see a plaque on the endowment wall honoring Julie.

Pat loves that families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

"It is huge what St. Jude does to help families," said Pat. "This is an amazing place doing amazing things for the children."



Join the Wedners in helping to provide cutting-edge treatment to St. Jude patients. Together, we can help cure childhood cancer.
stjude.org/ImpactGiving

ST. JUDE Survivorship Portal

New data platform incorporates clinical and genomic information from thousands of cancer survivors.

By **Ruma Kumar** - ALSAC

Scientists from St. Jude Children's Research Hospital® have announced the first data portal for sharing and analyzing pediatric cancer survivorship data.

Details on the survivorship portal by St. Jude and its ability to facilitate breakthroughs in pediatric cancer survivorship research were published recently in *Cancer Discovery*, a journal of

the American Association for Cancer Research.

The portal integrates data involving whole genomic sequencing, treatment exposure and outcomes – creating an unprecedented research system that houses 400 million genetic variants from over 7,700 childhood cancer survivors.

“With the portal, with just one click, you can make new discoveries,” said co-corresponding author Jinghui Zhang, PhD, St. Jude Department of Computational Biology. “In the past, people would spend weeks downloading, analyzing, organizing and summarizing data into figures – now you can do all that in just minutes.”

The portal is free to use and open access as a part of the St. Jude Cloud ecosystem.

Research at St. Jude has been instrumental in increasing childhood cancer survival rates over the past 61 years, and today approximately 85 percent of childhood cancer patients in the U.S. are successfully treated and alive five years post-diagnosis. Research at St. Jude has shown that experiencing cancer as a child can have long-term implications on the survivor's health, placing increased focus on finding interventions to improve and maintain the quality of life for survivors and developing new cancer therapy with reduced toxicity.

St. Jude is amassing a wealth of survivorship data through two key efforts: the Childhood Cancer Survivor Study, a collaborative

“With the portal, with just one click, you can make new discoveries.”

– Jinghui Zhang, PhD
St. Jude Department of Computational Biology

1

Platinum chemotherapy has been used for decades to treat cancer and is known to cause hearing damage, but the data in the portal were able to show that not all types cause the same amount of damage.

effort representing 31 institutions spanning North America and compiling data on a range of childhood cancers, and the St. Jude Lifetime Cohort Study (St. Jude LIFE). St. Jude LIFE is a long-term follow-up study for St. Jude patients where participants are brought back to the hospital every five years for an assessment.

All the data generated from those two cohorts can now be found in the Portal, providing new insights and greater understanding in the way childhood cancer treatments affect survivors later in life.

“There are half-a-billion clinical data points in the portal, hundreds of terabytes of genetic data supported by dynamic and interactive visualization analysis,” said Xin

2

Gene mutations are associated with placing cancer survivors of African ancestry at greater risk for developing heart disease later in life.

Zhou, PhD, St. Jude Department of Computational Biology.

“We aren't just sharing data,” said Yutaka Yasui, PhD, St. Jude Department of Epidemiology and Cancer Control. “We are facilitating the analysis and visualization of data and making it free to anyone – that's a tremendous resource for the cancer survivorship community.”

3

Some new findings from the data in the Portal include:

A novel association was discovered between mental health, age and limb amputation. Receiving an amputation at an older age (teenage compared to earlier childhood) is associated with increased resilience against poor mental health.



Your gift helps fuel the lifesaving work of St. Jude around the world.
stjude.org/ImpactGiving



Triumph OVER

ADVERSITY



Yarianis finds new purpose after cancer treatment at St. Jude.

By **Monsy Alvarado** - ALSAC

Move forward. One day at a time. Yarianis thought those words as she stared at the steps of the two-story rental her family was staying in during Christmas of 2023. She was determined to climb the entire flight of stairs – 18 steps in all – on her own.

Those words always steadied her through volleyball matches and practices that hadn't gone her way.

It was difficult going up and down the steps without assistance on that day. At St. Jude Children's Research Hospital®, where she was receiving physical therapy as part of her treatment for bone cancer, she always had a physical therapist with her to help. Not being able to move her left leg like before was a source of frustration for the teen athlete from Puerto Rico who, prior to her cancer diagnosis, not only excelled in volleyball but had reached international levels of competition.

"I said, 'Let me see if I can go up using both my legs, and when I

saw I could do it with both my legs, it was very emotional because I wasn't able to do it before,'" Yarianis recalled.

Yarianis' moment on the stairs was just one significant step in her arduous road to recovery. Each day has brought new challenges, yet Yarianis has faced them with the same unwavering determination that fueled her volleyball career. She looks forward to her physical therapy sessions at home in Puerto Rico, where she works hard to regain more of her strength.

"Every time I arrive, they have something new for me because of the things I can do and because they raise the level of physical therapy," she said. "I'm excited to find out what new thing I'm going to do."

Her parents, Yamilka and Jose, are grateful for each new stage in her recovery and in her life. Yarianis graduated high school in the spring of 2024, attended a graduation dinner with her parents and is making plans for her future.

"The most important thing is that she is doing well," Yamilka said, "and we are so grateful to St. Jude: She is the girl that she used to be, active and slowly returning to the life she had."

She is the girl that she used to be: active and slowly returning to the life she had.

- Yamilka, Yarianis' mom

A swollen leg

Before her diagnosis, Yarianis had trained relentlessly for volleyball. The early morning exercises and long hours of practice and games after school had paid off.

At 17, the 6-foot-tall middle blocker was a member of the Puerto Rico women's national under-19 in international women's volleyball competitions.

In 2022, Yarianis and her teammates beat Mexico in the quarterfinals at the Girls U19 Pan American Cup. In that match, Yarianis showcased her prowess with a match-high four blocks. The win qualified Puerto Rico for one of four spots available to teams from The North, Central American and Caribbean Volleyball Confederation for the 2023 International Volleyball Federation World Championship.

A few months later, during her junior year in high school, Yarianis accepted a scholarship offer to play volleyball at a university in Ohio, where she intended to pursue a degree in psychology.

Her academic and sports aspirations seemed to be on track and going better than she or her family had dreamed.

Yarianis was even invited to talk about her college acceptances and future volleyball plans on a Puerto Rican sports show. One of the show's interviewers described Yarianis and other players who had been offered scholarships as the pride of Puerto Rico.

"My daughter is so loved by Puerto Rico. She has had so much success in volleyball and had so much support from the fans," Yamilka said. "There were big expectations."

Yarianis continued her training to play in the Pan American Cup in 2023, an event that also serves as Pan American Games classification. Maybe the Olympics would be in her future one day, she thought.

Then one morning, during her exercise routine, Yarianis felt pain in her left leg. A few weeks later, she began to feel tired quicker at practice. Her left knee became swollen. She was told at first the swelling was due to too much training. She rested. It didn't get better.

After a visit to an orthopedic doctor, an X-ray followed by a CT scan, MRI scan and a biopsy, Yarianis was diagnosed with osteosarcoma, a cancer of the bone.

Yamilka, an intensive care nurse, immediately thought the worst.

"I just started to cry. I had lost my mom to cancer and now I had to face this with my daughter," she said.

Treatment miles away

Doctors in Puerto Rico told Yarianis and her family that she needed to seek treatment right away. She was referred to St. Jude.

"They explained to us that it was an aggressive cancer and it could spread to my lungs," Yarianis said. "Everything was so fast and I didn't really have time to process it, but it was not something that discouraged me. Instead, I was ready to face the process to come."

Yarianis felt hopeful. Even though she would be away from most of her friends and family, she was confident St. Jude would provide her with good care.

"When I arrived at St. Jude, I felt sure that I would get the support I needed," she said.

At St. Jude, Yarianis learned the cancer had spread to her lungs.

Because the disease had metastasized to her lungs, Yarianis' osteosarcoma diagnosis was considered high-risk. In April 2023, within days of her arrival at St. Jude, surgeons performed a lung resection to remove the cancerous nodule.

Yarianis also began chemotherapy within days of her arrival. Chemotherapy for osteosarcoma aims to treat the primary tumor as well as prevent new disease in the lungs and other bones. In preparation for her eventual leg surgery, she started physical therapy in early April to learn not to use her left leg after surgery to allow for recovery. Four months later, surgeons performed limb-sparing surgery.

Following decades of advances in limb-sparing surgical techniques, approximately 90-95 percent of St. Jude patients with osteosarcoma undergo some type of limb-sparing procedure. Through these procedures, surgeons work to remove tumors without harming nearby nerves, blood vessels and organs. They must remove the entire cancer as well as a small area of normal tissue around it to ensure no cancer is left behind. Through grafts or prosthetic implants, like

the hinged knee prosthesis Yarianis received, patients are able to use their limb for everyday activities such as walking and helping sustain their quality of life after treatment.

St. Jude surgeons continue to explore new limb-sparing techniques to improve survival and help children live normal lives after treatment.

Yarianis' operation was a success. Recovery, however, was difficult.

"It was a huge operation," she said. "And during physical therapy I had to take medicine to help with the pain. I think the pain was the most difficult."

Despite the pain, Yarianis set goals for herself. She reminded herself: Move forward. One day at a time.

At first, physical therapy required her to do exercises sitting or lying down. Later, she used a bicycle. Then, finally, she took steps with physical therapists standing by her side. In October, three months after surgery, Yarianis took her first steps by herself.

"I was very excited that I was going to start walking," she said.

After conquering the stairs in December during a brief getaway from Memphis, Yarianis returned to

St. Jude for more physical therapy and to complete her chemotherapy. She went home in February 2024, and within weeks was back in school. Her classmates welcomed her with open arms and in June she graduated from high school and enjoyed her senior prom.

Yarianis is not playing volleyball these days, but she hasn't left the court entirely. She has enrolled in

coaching courses, aiming to mentor younger volleyball players. She will not go to Ohio for college, and instead will start classes at a university in Puerto Rico. Her career goals also have shifted – she now aspires to become a physical therapist. Her dream? To work at St. Jude.

She's moving forward. One day at a time.

I just started to cry. I had lost my mom to cancer and now I had to face this with my daughter.

– Yamilka, Yarianis' mom



Together, with St. Jude, you can help patients like Yarianis celebrate more victories. stjude.org/ImpactGiving



DOMINO'S HISTORIC \$300 MILLION GOAL FOR ST. JUDE

The record commitment is the latest
in 20 years of giving.

By **ALSAC staff**

Domino's®, the largest pizza company in the world, together with its franchisees, recently announced the largest corporate or private financial commitment to a children's hospital: a pledge to bring its fundraising total to \$300 million by 2034 to benefit the lifesaving mission of St. Jude Children's Research Hospital®.

This record commitment was delivered by Domino's CEO Russell Weiner to more than 9,000 Domino's

franchisees and their team members during the company's 2024 Worldwide Rally in Las Vegas. This commitment will help ensure families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

"Our new Hungry for More growth strategy means more stores and more sales, providing even more opportunities for customers to donate to St. Jude," said Weiner. "Since 2004 we've made it possible for millions of customers to simply donate a dollar or two, or round up their change, to help the children of St. Jude and their families, for which I am so grateful.

"Over the past 20 years those dollars and pennies have totaled over \$126 million and by 2034 we believe we can get to \$300 million raised by our customers for St. Jude."

St. Jude founder Danny Thomas famously said, "I'd rather have a million people give me a dollar than one give me a million. Then you've got a million people involved." Domino's embraces this concept in its fundraising by participating in the annual St. Jude Thanks and Giving® campaign, where customers can add a small donation to their order.

Domino's also supports St. Jude year-round by providing customers the ability to round up their change to advance ongoing work by St. Jude to accelerate research and treatment of childhood cancer and other life-threatening diseases.

"We are incredibly grateful for this momentous and historic \$300 million pledge from our compassionate and purpose-driven friends at Domino's," said Richard C. Shadyac Jr., president and CEO of ALSAC, the fundraising and awareness organization for St. Jude.

"This record-setting commitment is yet another step in the longstanding partnership with Domino's that supports St. Jude in so many ways – all which helps advance treatments and research to raise survival rates for children around the world with cancer and other life-threatening diseases. By giving customers the opportunity to donate at checkout, Domino's enables them to live charitably – to make small acts for good that, collectively, will make a difference for families all across the globe."

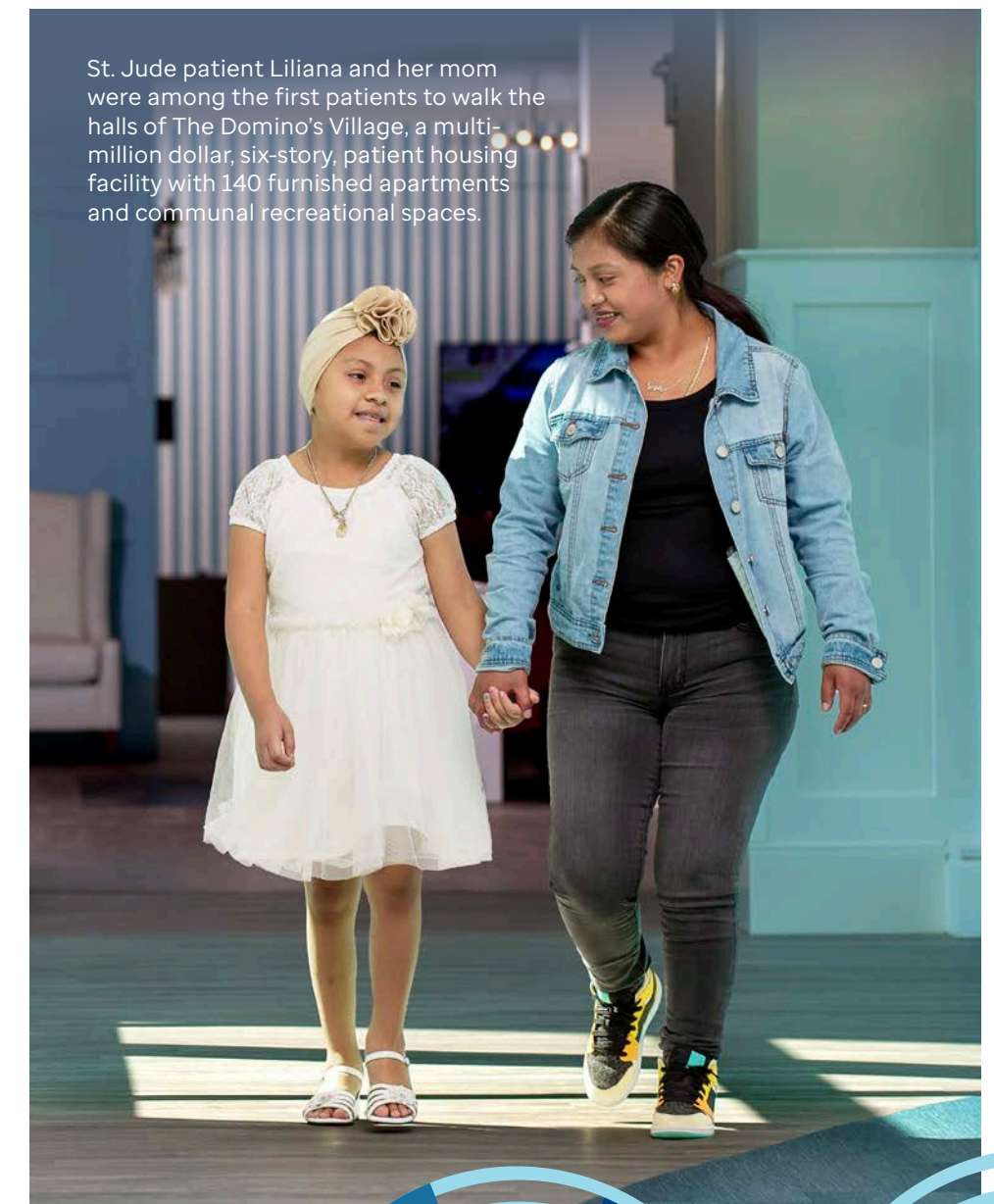
Domino's became a St. Jude partner in 2004, raising more than \$191,000 in that first year. This new commitment comes on the heels

of the September 2023 opening of The Domino's Village, a multi-million dollar, six-story, 307,000-square-foot housing facility for patients and their families with 140 furnished apartments and communal recreation spaces. The facility was funded by Domino's as part of a 10-year, \$100 million commitment to St. Jude announced in 2020. In addition, Domino's continues to have a prominent presence on the St. Jude campus with the Assessment and Triage Clinic Delivered by Domino's and the Domino's Event Center.



You can join partners like Domino's in helping ensure families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live. stjude.org/ImpactGiving

St. Jude patient Liliana and her mom were among the first patients to walk the halls of The Domino's Village, a multi-million dollar, six-story, patient housing facility with 140 furnished apartments and communal recreational spaces.



Meet the Artist Aspen



Meeting her now, one would never guess Aspen had such a difficult start in life. She is bubbly, happy, creative and smart. Yet her cancer journey began before she was even 2 years old, when she was diagnosed with stage IV neuroblastoma.

Aspen underwent lengthy treatment in the Philippines, which stabilized but did not eradicate the cancer. Soon, it was spreading again, and Aspen's doctors referred her to St. Jude Children's Research Hospital®, 8,000 miles from home.

Aspen received two more years of cancer treatment. Being able to leave her hospital bed at St. Jude and go to the playroom was a moment Aspen will never forget. Her colorful acrylic on canvas is a reminder of that special time. "The girl is me and there is a nurse," she said. "It reminds me of the window where I painted."

Aspen's favorite things to draw are "puppies mostly," as well as buildings and her family. She says being creative makes her feel happy and interested. When not making art, Aspen can often be found playing with Mr. Chocolate, her pet guinea pig.



Your gift helps allow patients like Aspen to keep creating masterpieces.
stjude.org/ImpactGiving

FIRST TO BE CURED

Cancer treatment at St. Jude also cured her sickle cell disease. Now, Kimberlin relishes every day.

By **Ruma Kumar** - ALSAC

On quiet afternoons, when she's singing to the baby granddaughter in her arms, Kimberlin doesn't feel like part of medical history. She feels like a proud grandmother holding a gift. It is a gift she was not sure she'd live long enough to have.

In 1983, when she was 8 years old, something remarkable happened to Kimberlin. A bone marrow transplant, which doctors at St. Jude Children's Research Hospital® had intended to treat her acute myeloid leukemia, cured not only the cancer, but her sickle cell disease as well.

Since then, Kimberlin has been known as the first person in the world to be cured of sickle cell disease, the most common inherited blood disorder in the United States, affecting about 100,000 Americans and millions more worldwide.

The debilitating condition warps normally round red blood cells

into crescent-shaped brittle ones that have trouble moving through blood vessels, disrupting the critical delivery of oxygen to tissues and organs. Sickle cell disease often leads to pain crises, organ damage and higher risk of stroke and heart disease.

According to the CDC, sickle cell disease is most common among people with ancestors from sub-Saharan Africa, South America, the Caribbean, Central America, Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy. In the United States, it predominantly impacts those of African descent, with about one out of 365 African American babies afflicted.

"People ask me if I feel like a hero," Kimberlin said. "But on most days, I don't think of myself as one. I just live every day to the fullest with gratitude and faith."

Cancer, sickle cell and answered prayers

Kimberlin was diagnosed with sickle cell disease when she was

2 years old. She remembers suffering from pain crises nearly every other week throughout her early childhood. She remembers writhing and crying as her arms and legs experienced "excruciating unbearable pain," she said.

"My parents and grandmother prayed and took turns rubbing my arms and legs," Kimberlin recalls. And when the pain got too bad for the Baton Rouge, Louisiana native, they would seek help from the local emergency room.

"The nurses at Our Lady of The Lake Hospital knew me well," she said.

She missed school and playtime with friends.

"Up to that point, life for me was filled with lots of pain and hospital stays," she said.

But then at 8 years old, Kimberlin endured a particularly difficult pain crisis, one that felt different from the others and brought with it a level of fatigue and weakness she had not experienced before.

When her parents took her to the local hospital to manage the pain



I just remember my parents and grandmother saying it was like their prayers had been answered. It felt like a miracle.

– St. Jude patient Kimberlin

this time, the doctors and scans found something else that was contributing to her anguish: acute myeloid leukemia.

That's when she was referred to St. Jude.

In addition to a protocol of chemotherapy and radiation therapy, doctors at St. Jude also determined she could benefit from a bone marrow transplant. The transplant would help the body replace blood-forming cells killed off by chemotherapy with healthy ones to rejuvenate the bone marrow. And as good fortune would have it, Kimberlin's brother Shongo was a bone marrow match.

After the transplant, doctors were pleased to see that it not only cured the cancer in her blood, but also the sickle cell disease.

"I just remember my parents and grandmother saying it was like their prayers had been answered. It felt like a miracle," Kimberlin said.

New Era of Hope

Even now, 41 years after Kimberlin's procedure, bone marrow transplant remains the primary cure for sickle cell disease. But its use is limited because of the challenge in finding a matched donor – barely 20 percent of sickle cell patients find an eligible bone marrow match.

And even when matches are found, the health complications that are associated with the conditioning process that prepares the patient for transplant, as well as the procedure itself, can be difficult and sometimes even life threatening.

That's why doctors and scientists at St. Jude continue looking for ways to refine the process to cure more patients while causing less toxic side effects.



The hope is to someday provide all patients with what Kimberlin experienced: a cure for sickle cell disease.

One such effort is the ongoing Sickle Cell Disease Hematopoietic Cell Transplantation (SCDHCT) study at St. Jude, led by Akshay Sharma, MBBS., MSc., designed to answer the question: What if researchers can find a way to cure children of their severe sickle cell disease with a transplant while using a gentler chemotherapy and radiation conditioning regimen than standard transplants? With this goal, the clinical trial is studying the results for patients under age 25 who have severe sickle cell disease.

This clinical trial includes enrolled patients, who, like Kimberlin, have fully matched sibling donors, as well as those who have half-matched, or haploidentical, donors. The latter option increases the odds of finding a suitable donor as one's parents are always a haploidentical match.

Ongoing research like the SCDHCT trial and other efforts underway at St. Jude aim to cure more children, like Kimberlin, with fewer complications.

When Sharma saw patients being treated on SCDHCT clinical trial go on to lead 'normal' lives, he said, "It's very fulfilling as a physician and researcher to see that our trial is helping kids get back to being kids again. They are my inspiration."

St. Jude is also at the forefront of another effort to explore multiple approaches to treat and potentially cure sickle cell disease using gene therapy. Gene therapy treatments, including two that were recently approved by the U.S. Food and Drug Administration for use in patients 12 and older, appear to hold the potential to cure sickle cell disease for even more patients.



In addition to ongoing laboratory research on multiple different approaches to using gene therapy for sickle cell disease, St. Jude will soon launch its own gene therapy clinical trial for sickle cell patients who do not have a matched donor. Because gene therapy does not require a donor, this next frontier in sickle cell disease treatment is hoped to be a one-time treatment and cure for individuals with sickle cell disease.

Kimberlin may have been the first to be cured of sickle cell disease, but St. Jude is working to make sure more children will not only be treated for but cured of this disease, and experience fewer complications in the process.

Kimberlin Today

Kimberlin returned to St. Jude for checkups after the bone marrow transplant in 1983, at first a couple of times a year and then annually until she was 18 years old.

"St. Jude just teaches you to be strong, determined," Kimberlin said. "Every minute you are there, every day, you see people working hard to help you."

She was able to claim the kind of normalcy she didn't have in early childhood.

She went to high school, graduated and went to college in Louisiana and earned a degree in child development. She taught first grade for a bit and later ran a childcare center for more than 11 years.

Kimberlin, who lives in Texas now, has been happily married for over 19 years, has three children ages 22 to 14, and until recently, was a beloved middle school registrar.

"I've had the joy of having an amazing partner, being a mother, helping children, which makes me so happy, and now being a grandmother, and none of it could have happened without St. Jude," Kimberlin said. "That's the simple truth. I love St. Jude."



Your gift helps ensure that St. Jude keeps advancing research and discoveries that can help make lifesaving cures like Kimberlin's possible.
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Yara's St. Jude Village

Yara was hospitalized after an RSV infection led to a range of complications. After tests revealed her bone marrow was hypocellular – lacking stem cells – Yara was transferred to St. Jude Children's Research Hospital® for treatment and monitoring.

Genetic testing led doctors to diagnose Yara with SAMD9L syndrome. This rare condition affects the bone marrow's ability to produce healthy cells. Some patients with SAMD9L may experience a spontaneous improvement over time and even a natural recovery. However, for others, the bone marrow failure can worsen, and they might develop a condition that can progress to leukemia. At St. Jude, doctors continue to monitor Yara closely.

"They say it takes a village to raise a child. St. Jude is part of our village, and they are the healthcare part of our village. We can just make sure she is happy, and they make sure she's healthy," said her mom



You help bring hope and healing to patients like Yara when you support St. Jude. Did you know many ways to give with non-cash assets – like stocks and IRAs – may present unique opportunities to save on taxes while furthering the St. Jude mission? Donate today at stjude.org/ImpactGiving