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ST. JUDE



inspire

WINTER 2023

Special Moments

...

St. Jude treated Eri'Elle's cancer, now she can walk again

Celebration Day

Tina's quinceañera was possible thanks to St. Jude donors.

Special Homecoming

Luke gets a police escort home from St. Jude.

Strides in Research

Kids like Za'Mya benefit from advancements in treating sickle cell disease.

A woman with long brown hair, wearing a light blue surgical mask and a grey tweed jacket with the name 'Libby' embroidered on the left chest, is leaning over a large, tan-colored medical model. She is looking down at the model with a focused expression. The background is a grey wall with colorful geometric shapes: a yellow triangle on the left, a purple triangle in the center, and a green shape on the right. The model she is interacting with appears to be a large, tan-colored medical model, possibly a torso or a limb, used for educational purposes.

Play therapy

Za'Mya helps prepare a doll for a scan, similar to the one she has to have. As part of their treatment at St. Jude, children learn about tests and medical treatment through play and other therapeutic activities. Read more about Za'Mya's story on page 24.



Your gift will help more patients like
Za'Mya get the treatment they need.
stjude.org/donate



Eri'Elle took her first steps — for the second time — and Tina danced. Ian teed off with a celebrity and Luke was escorted home like a celebrity himself.

These are moments of a lifetime.
Moments of a second lifetime.

Special moments celebrated by moms and dads, grandparents and siblings, and all of us at St. Jude Children's Research Hospital and ALSAC the fundraising awareness organization for St. Jude.

And we hope you'll celebrate them with us. Because the truth is, they don't happen without generous supporters like you.

Thanks to your support, research and treatments have been advanced over 60 years to help cure the tumors that affected these four children.

Eri'Elle had a tumor pressing on her spine that impeded her walking. At St. Jude, treatment saved her life and saw her up and around again. Her mom still cries every time she tells the story of those second first steps.

Tina was diagnosed with medulloblastoma, a brain tumor, at just 10 years old. She received chemotherapy and proton therapy at St. Jude and last spring celebrated her quinceañera by dancing with her dad.

Ian struggled with golf as a 6-year-old, the effects of a brain tumor and treatment. But he had someone he wanted to

impress off the tee — country rocker Darius Rucker. And eventually, he would.

And Luke had the ride of a lifetime when his dad's friends and colleagues — Louisiana state troopers — met the family at the state line and escorted them in a limousine with blue lights leading the way, all the way home.

Thanks to you and our community of supporters around the world, the six-year, \$12.9 billion strategic plan St. Jude is in the midst of will help even more kids like these.

The historic plan — the largest single investment in St. Jude history — will focus more resources on difficult-to-treat cancers, those with little or no chance at survival.

That's why your ongoing support is so important, because every child — every mom and dad, grandparent and sibling — deserves hope and the special moments that make up a lifetime of memories.

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

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Research Hospital**
Finding cures. Saving children.
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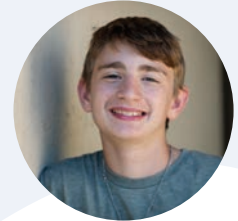
After being sidelined because of a malignant rhabdoid tumor pressed against her spine, Eri'Elle had to learn to walk again.



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St. Jude has one of the largest sickle cell programs in the country and is making progress toward a cure for patients like Za'Mya.



You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate



JEAN PIERRE heads to COLLEGE

By **Monsy Alvarado** - ALSAC

Jean Pierre made a request of his parents months after COVID-19 caused worldwide shutdowns.

He wanted to leave the Costa Rican coastal town they live in and move more than four hours away to the capital of San Jose to finish his high school education. He wanted more intense studies at an international bilingual school that would offer more science courses and prepare him better for college.

"I didn't feel I was reaching my full potential, so I convinced my parents to let me go to San Jose," he said. "At the new school, I get to take physics and chemistry."

The teen, the oldest of four boys, and his father, Manfred, credit his independence to his fight against a brain tumor which

he was diagnosed with as a 3-year-old. He was treated at St. Jude Children's Research Hospital.

"Ever since I was a child, I have to remember to take my medicines, at what time and how much of it," he said. "I think it just made me more responsible."

Jean Pierre was taught early on about the medications he was taking, their purpose and what he needed to do to keep healthy, including what he should eat and what sort of physical activity he needed to do. So even though it is hard to let children move away from home, Manfred said he thought his son was ready.

"Those things made him mature, and he always wants to improve himself," Manfred said. "He is also a person who always wants to help because of all he has received from St. Jude."

Jean Pierre was born in Louisiana. His parents were about to relocate to their native country of Costa Rica when doctors discovered the brain tumor after their son experienced regular headaches and was always fatigued. He had a hard time communicating and had a growing thirst that could not be quenched.

He was diagnosed with craniopharyngioma, a brain tumor that grows slowly but can cause serious illness. Jean Pierre's tumor was found in the pituitary gland, a tiny but important part of the brain that produces hormones which help you grow.



The family first went to a local hospital where Jean Pierre underwent surgery, but after finding out about St. Jude, they were referred to the research hospital in Memphis. There, Jean Pierre received radiation therapy every day for three months, his father said. He later received speech and physical therapy.

"Until we got to St. Jude, that is when we really understood what was happening, where the tumor was and how dangerous it was," Manfred said.

Jean Pierre graduated from high school this year, and started classes at Penn State University where he wants to pursue a degree in computer engineering. His love of building and design, he said, was sparked at St. Jude.

When he was a boy, he often played with colorful plastic building blocks

as he waited for a doctor's appointment or his radiation treatment to begin at the hospital. Manfred remembers hospital staff bringing his son building blocks when the waiting took longer than expected.

A few years later, Jean Pierre participated in the first Lego League event, an annual competition where participants research, problem-solve and then build and program a robot.

Through the years, Jean Pierre estimates he has built hundreds of Lego® building kits, many of which he purchased on annual trips to Memphis. His favorites are of Star Wars.

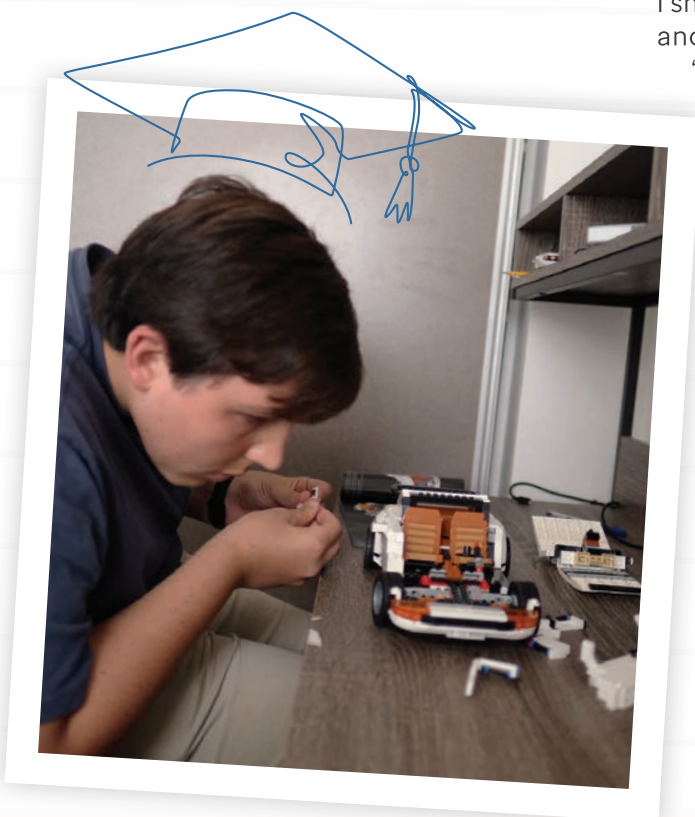
As he prepared to move out of the country for college, he said he was well prepared for the challenges ahead.

"St. Jude gave me a second chance and it's something I should take advantage of and not waste it," he said.

"It's also showed me to be more positive about life and do everything to the maximum."

His father said even though he was excited to have celebrated his son's high school graduation, the biggest milestone of Jean Pierre's life this year is that he no longer has to return to St. Jude annually for checkups. He had his last regular checkup earlier this year.

"Graduation from high school is pretty good we know, but graduation from St. Jude is amazing," Manfred said.





A large, colorful graphic with the words "FIRST STEPS" in a playful, multi-colored font. The letters are in shades of red, blue, green, and grey. To the left of the text, there is a hand reaching out towards the word "STEPS". Above the text, there are several small, colorful stars and dots in shades of blue, orange, and green. A large blue star is positioned to the right of the word "FIRST".

FIRST STEPS

FOR THE SECOND TIME

St. Jude mom cheers as Eri'Elle learns to walk again

By **Linda A. Moore - ALSAC**

Angel knows exactly when her now 3-year-old daughter, Eri'Elle, took her first steps.

"She walked two weeks after her first birthday," Angel recalled.

As a baby, Eri'Elle was smart, playful, happy and never stopped moving. As she grew from baby to toddler, that didn't change.

Eri'Elle kept moving, Angel said, until she couldn't. They were rushed to St. Jude Children's Research Hospital in Memphis, where her "St. Jude baby" battled a life-threatening tumor. And it's where

Angel rejoiced to see Eri'Elle's first steps – for a second time.

In late September of 2021, Angel made several trips with Eri'Elle to her local hospital for persistent constipation. But, in a span of two weeks Eri'Elle had gone from an active toddler to a child in pain who couldn't walk.

"In the blink of an eye, everything changed," Angel said.

Her local hospital in Louisiana did scans and sent them to a hospital in a larger city for more extensive tests. Doctors there gave Angel life-changing news.

“She came and told me my baby had a tumor pressed up against her spine and that was making her not walk,” Angel said.

Doctors there couldn’t treat Eri’Elle. But St. Jude could.

“When do we leave?” Angel asked.

“Right now,” she was told.

Angel called her mother, Addie, who was looking after her two older daughters. She signed some papers and with just “the clothes on her back,” left at 3 a.m. by ambulance with Eri’Elle for St. Jude.

Angel was overwhelmed by everything, but was grateful that she never received a bill from St. Jude for treatment, travel, housing or food so she could focus on Eri’Elle. “They were concerned about me as well,” she said.

Tests started immediately. Eri’Elle was diagnosed with a rare and

aggressive malignant rhabdoid tumor on her spine.

Eri’Elle underwent two operations last January, including one to remove the tumor.

“My baby is a warrior because she never let any of it get her down,” Angel said.

And as Eri’Elle grew stronger, she begged to do more.

“She kept saying, ‘Momma, I wanna walk,’” Angel said.

On Feb. 18, 2022, at 2:41 p.m. at their Target House apartment, Eri’Elle took her first steps – for the second time.

In the video capturing that moment, Angel cautions Eri’Elle to take her time.

“Take my time. Take my time,” Eri’Elle said excitedly as she balanced on still shaky legs and walked.

Witnessing those first steps was extraordinary.

“By the time we got to that point, I was happy because, when we made it to St. Jude, my baby couldn’t sit up. She couldn’t feel her legs,” said Angel, who cries while telling the story.

Angel had come to terms with the possibility that Eri’Elle might never walk again. So, the transition from a wheelchair to a walker was prayed-for progress.

“By the time she got to using the walker, I was just ecstatic, grateful and thanking God that things were moving up,” Angel said.

She now shares her St. Jude testimony with everyone.


“I thank God for the people he put in our lives to get us to that point. Because if it weren’t for those



See Eri'Elle's first
steps for the second
time on video.







*“If it were not for St. Jude,
we would not have been able to afford
the treatment to save this baby’s life.”*

– Addie, Eri’Elle’s grandmother

researchers and those doctors and the people that do the genetics and nurses, my baby wouldn’t have come this far,” Angel said.

Eri’Elle loved everyone who cared for her. Her physical therapy was playtime.

“She’d go down to radiation and she’d know everybody by name,” Angel said.

When someone there asked if she wanted to be a nurse.

“No,” Angel said, “She said she wants to be a doctor.”

“She has her own little ID with her little picture on it. She’s such a character,” said Addie, Eri’Elle’s grandmother.

“The fact that this amazing care is offered for free and I do not have to scrimp and save, we are beyond blessed,” Angel said.

Both Angel and Addie knew about St. Jude. A member of Addie’s prayer group had a grandchild who was treated there. And she has bought tickets for the St. Jude Dream Home® Giveaway.

“If it were not for St. Jude, we would not have been able to afford the treatment to save this baby’s life. It’s a wonderful thing,” Addie said. “The treatment this child had and it (did) not cost a penny, that is a miracle in and of itself.”

Angel is a self-described “straightforward parent” and didn’t sugarcoat Eri’Elle’s diagnosis for her daughters, now 12 and 10. And Addie is a breast cancer survivor.

Her oldest daughter cried. Her middle daughter declared that their little sister would beat the cancer. They all prayed.

Thanks to technology, Addie said, the girls were able see and talk to Angel and Eri’Elle every day.

During their nearly eight months at St. Jude, Eri’Elle and her mother left Memphis only once, for a Christmas visit. Eri’Elle’s grandmother, Addie, and Addie’s sister, Henrine, made the nearly five-hour drive to Memphis to collect them on Dec. 23 and the family drove home to Louisiana that same day – a 10-hour round trip.

“The girls were so surprised because their mom and their sister had come home for Christmas,” Addie said.

It was a short trip. Eri’Elle and Angel were back at St. Jude the day after Christmas.

“I didn’t know my daughter was as strong as she was until she went to be with her child all day every day for that long,” Addie said. “She basically carried that load by herself.”

Eri’Elle’s great aunt Henrine lives 83 miles away and stepped in often to help with Angel’s daughters. She took the girls to her house on odd weekends to give Angel’s parents a break. Now, Henrine is a monthly donor to St. Jude.

“Once Angel got to St. Jude and she was telling me all that they do up there, my goal, for as long as I can, is to contribute to St. Jude so that just like they helped Angel and Eri’Elle, they can help somebody else along the way,” Henrine said.

Right now, Eri’Elle goes back to St. Jude every three months for scans.

“She’s such an amazing child, so resilient,” her grandmother said.

Eri’Elle is an active 4-year-old who is spoiled by her big sisters while they all spoil a new baby brother.


“Now she’s older, so she’s more mature having to be at St. Jude and going through so much,” Angel said. “But she’s back being a little girl, just running around playing and jumping and enjoying life.”

And that’s why she will always love St. Jude.

“They gave me my baby back,” Angel said.



You can help ensure patients like Eri’Elle get the chance to pursue their dreams. stjude.org/donate

A young girl is sitting on a lush green lawn, wearing a light pink, tulle quinceañera dress adorned with small white floral decorations. The background is a soft-focus green field.

Tina's quinceañera: *A tradition* of a lifetime

After overcoming a cancer diagnosis at age 10, this St. Jude patient and her family celebrated her 15th birthday in style.

By **Monsy Alvarado** - ALSAC





Dressed in a mauve-colored ball gown and sparkly tiara, Tina made her grand appearance on a second-floor balcony and waved at family and friends, some of whom had traveled long distances to celebrate her 15th birthday.

Tina had wanted to forego the elaborate birthday celebration at first. She likes things simple, and certainly did not feel comfortable being the center of attention. But as she looked at her parents, smiles wide, she was happy that she had conceded to having a “quinceañera,” like those celebrated with family and friends in her native country of Venezuela.

A few years ago, Tina’s future had been uncertain when she was diagnosed with a brain tumor. She was treated at St. Jude Children’s Research Hospital. Her parents helped her through the most difficult times of treatment and never left her side.

“This is also a very big moment for my parents because they once thought that I wouldn’t have something like this,” she said. “I wanted to give that gift to my parents.”

On this sunny Saturday afternoon in South Florida, her mother, Marina, and her father, Vicente,

beamed with pride. When Tina danced the waltz with her father, Marina looked up at the sky with emotion. It was a moment she had dreamed of for years, and one that at times she and her husband feared they would not see.

“For me it was important to see her dance, to see her smile, to see her enjoy herself,” Marina said. “And that is something that one longs for when one asks and prays to see her well, to see her healthy.”

Seeing Tina “look like a princess,” brought tears to the eyes of some of the guests as well.

“We are celebrating Tina’s life, faith and the love that we have for her, and that is why we are here so happy and euphoric,” said family friend Maria Alejandra Colmenares, who attended the celebration with her husband, Carlos Lobo.

Unexpected diagnosis

Tina had always been a healthy girl. But when she was 10 years old, she started having a lot of headaches and vomiting. Afterward, she lost her balance easily; she tripped and fell. In class, the teachers noticed she was no longer writing straight.

Her parents took her to the hospital and after several tests she was diagnosed with medulloblastoma,

a rapidly growing brain tumor of the cerebellum.

“At that moment our life was gone,” Marina said. “You just can’t believe it ... it was very painful.”

Tina didn’t know very much about what the diagnosis meant but had heard about cancer before at school.

“Normally, it’s associated with something very sad, people normally associate it with death,” she said.

Tina underwent surgery to remove the tumor at a local hospital in Florida, but Carlos and Maria urged them to look at St. Jude. They had read about the work the research hospital did with childhood cancers. Marina had previously donated to St. Jude but hadn’t thought of the hospital as a possibility for her daughter.

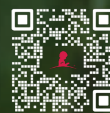
Days later, after several calls and conversations, they were referred to St. Jude.

“We felt that God sent us to this hospital and the people there took our pain and turned it into hope,” Marina said.

Tina received treatment for eight months, which included chemotherapy and proton radiation, before her cancer went into remission.



To see a video of Tina's
storybook quinceañera.



Her parents never received a bill for treatment, travel, housing or food from St. Jude.

“At first, I couldn’t believe that Tina had cancer,” Vicente recalled. “And to know that there are people who support St. Jude to help families like ours, it’s the best thing.”

Today, Tina returns to St. Jude regularly for checkups.

“I always think that without St. Jude the story might have been different,” Marina said.

Tina’s celebration

In Venezuela, as well as in other Latin American countries, the quinceañera symbolizes the transition of a girl into womanhood. Besides the traditional dance of the waltz, the birthday girl, “la Quinceañera,” dances with her brothers and other relatives. The celebration includes a meal and speeches as well. Many of the festivities end with “La Hora Loca” – The Crazy Hour – where guests dance with props such as party hats and glowing lights to inspire others to join in the fun.

The venue was bustling with activity hours before the celebration was set to begin. Marina had chosen the site because of its lush gardens, which she thought would be perfect for an outdoor celebration and pictures.

Aura Molinares, one of the event planners, was busy decorating tables throughout. She placed a pink book on a table near the entrance, which guests would be asked to sign. She then set up tables for the cocktail hour and for dinner. Pink balloons and pink-and-white rose petals could be seen strewn throughout the outdoors, complementing the natural red, pink and yellow flowers in the gardens.

Aura had heard of Tina’s cancer battle when her parents hired her for her services a few weeks prior. She and her partner had been supporters of St. Jude and felt an immediate connection to Tina and her story. On this day, she hung a special custom-made sign with Tina’s name in lights on the balcony as a surprise gift for the teenager.

“This is a special day for her, and we wanted to make it extra special,” Aura said.

Several feet away, indoors, Tina sat happily on a wooden chair as a stylist brushed and curled her hair. Her long, dark tresses were soon styled into a half-up do, something simple so she could dance.

Her mother was nearby, taking in the moment. Years ago, Tina had lost her hair due to chemotherapy. Marina remembered how sad Tina had been when she saw her hair falling out little by little. The only thing she and her husband could do at the time, Marina recalled, was to shave their heads.

“We wanted her to see that people, that human beings, are more than

hair, and that we were there by her side,” Marina said.

But today, Tina’s hair was long and healthy, and it looked beautiful. The hair stylist finished her hair by placing the tiara on her head.

Tina’s debut

A few moments later, once her hair and makeup were complete, all eyes were on Tina. Her strapless dress with flowers fit just as she had hoped. Photographers, videographers and some family and friends watched as she posed for a photo shoot before she made her appearance on the balcony.

She knew the importance of the day.

“Not so long ago, I was in a hospital, and I had cancer and it shows I won that battle,” Tina said.


The quinceañera was all she had hoped for. She dined with friends, she hugged her family members, she took pictures with her grandmother who had traveled from Venezuela, and her brother, Brandon, who had arrived for the weekend from Germany. She laughed and she danced. Merengue and salsa and some bachata were on the playlist.

“I like to dance,” she said. “I don’t know how to dance very much, but whatever comes out will make me happy. I am having a good time.”

Among the highlights of Tina’s quinceañera for Marina and Vicente was seeing their daughter enjoy herself like any other teenager.

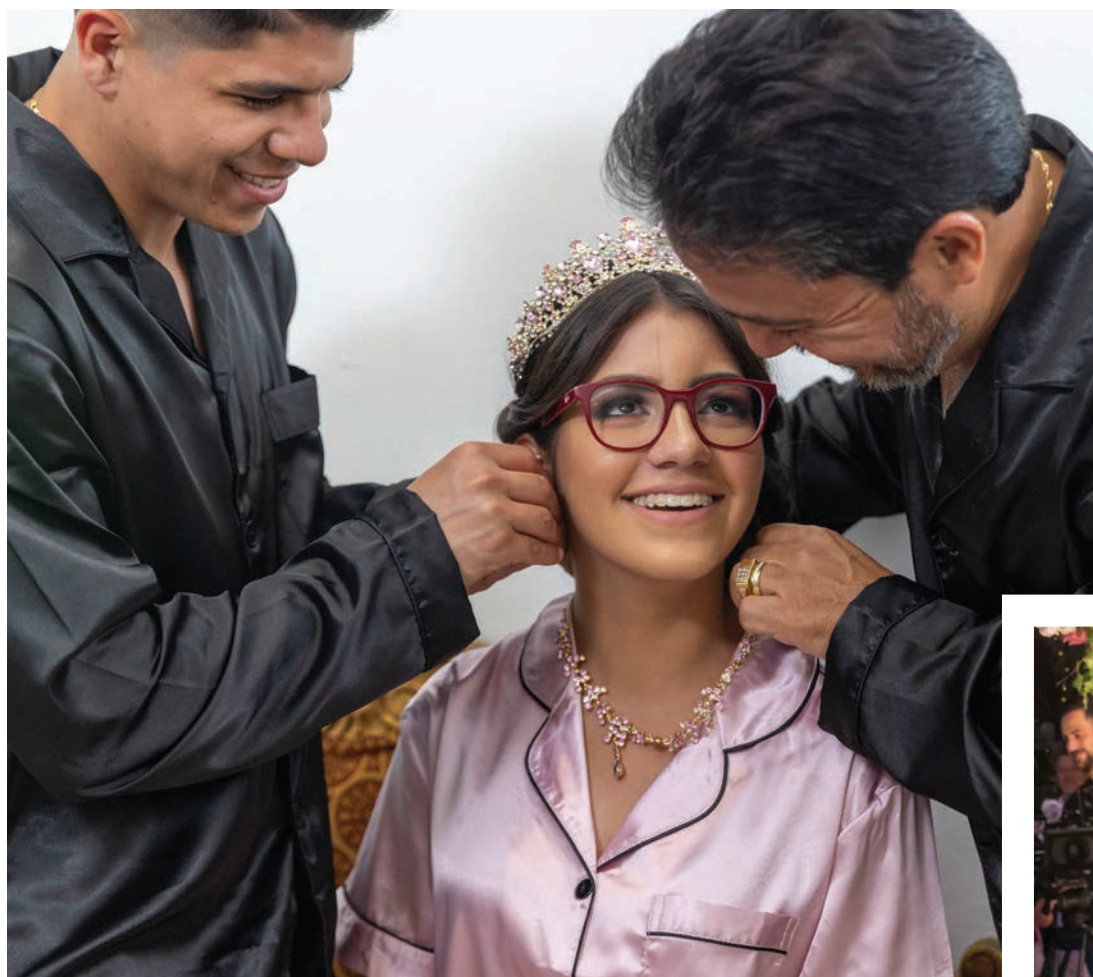
“Seeing her with that look in her eye that illuminates her entire face makes me very happy, especially because we were able to get here,” Marina said.





*“I always think
that without
St. Jude the story
might have been
different.”*

– Marina, Tina’s mom



Tina celebrated her
quinceañera. You can help
other St. Jude patients enjoy
their special milestones, too.
stjude.org/donate

Ian gets a second shot

St. Jude brain cancer survivor excels on and off golf course.

By **Betsy Taylor - ALSAC**

At the Darius Rucker and Friends golf fundraiser in June 2014, Ian, a novice golfer, was there to represent St. Jude Children's Research Hospital. The 6-year-old St. Jude brain cancer survivor had gotten to meet "Mr. Darius" himself, as Ian called him, and he liked the man right away.

He'd been invited to grab a club and drive off the tee, and Mr. Darius was watching, so he wanted to do a good job. He grabbed his little club, took his shot, and, well...

The ball didn't go far. It dribbled off the tee. No way around it, it was not a good shot.

His cheeks burning red, Ian got back into the golf cart with his parents and said, "I've got to get better at golf so I don't embarrass myself when I come back."

That statement says a few things about Ian and what drives him: He wants to be able to hang with friends. To the best of his abilities, he wants to do a good job. He's willing to work hard at the things he loves.

He just wants to take his shot. St. Jude had given him his first one.

Beast of a tumor

When Ian was 16 months old, his parents noticed one of his eyes pointing inward, and when they touched the soft spot on his head, it felt swollen. A CT scan soon after revealed the presence of a mass behind his right eye.

When Ian's mom, Anna, heard, "I couldn't talk, I was crying so hard."

It took a 12-hour surgery to remove the tumor, and the pathology showed he had a rare and aggressive brain cancer called a primitive neuroectodermal tumor.

The oncologist near their home in Tennessee did not sound hopeful and Ian was given a 50/50 chance of survival.

That's what brought them to St. Jude, with its reputation for helping children who have rare cancers.

In the time between Ian's surgery and when he got to St. Jude, his tumor had grown back – an aggressive beast of a tumor.

At St. Jude, he underwent a second surgery to fully remove it, as well as six rounds of chemotherapy. He also received proton radiation, which directs the radiation exactly where needed, sparing the healthy brain tissue that surrounds the tumor bed.

Afterward, he continued on six months of oral chemotherapy. For several years his scans were clear, and his parents praised God.

Better luck next hole

What if Ian's first try at golf had been good?

What if the ball had gotten into the hole on his first attempt or been close enough for his shot to be indicative of some natural gifts?

Well, that would have been wonderful, of course. But that's not what happened. That's not Ian's story.



What happened is this: He tried harder with renewed purpose. Ian's parents enrolled him in junior golf lessons, and he began to play on the course with his dad.

Then, in 2018, his cancer came back. It would require another surgery and more treatment, but "St. Jude was with us every step of the way," said Anna.

Even during relapse cancer treatment, Ian practiced golf and put in the time. It was hard sometimes, and Ian, at 10 years old and now a two-time cancer survivor, had come to the decision that it was important to say this out loud.

Because he was a little bit older and little more aware this time, he said, "You know, I am a little bit different. Things are a little bit harder for me, and I've got to acknowledge that and accept that, but not let it keep me from doing things."

Little by little, year after year, Ian has gotten better. He joined a Junior PGA group and began competing so he can gauge how he's progressing against the other golfers.

But he's not a competitive guy, Anna insists. Golf, the way Ian plays it, is about friendship and camaraderie.

"If the kid next to him is on the other team, and they shank it into the

woods, he'll say, 'Great job. Better luck next time.' It's so cute, and it's so his personality. He's such an encourager...

"He's not hard on himself either. Even when he doesn't do well, he's just like, 'Oh well. Better luck next hole.'"

Now he's 14 years old, cancer free, a high school freshman, and he's just been named the manager of his high school golf team. His family has a St. Jude Heroes team, and every year he attends the Darius & Friends golf fundraiser for St. Jude to hit a few balls with Mr. Darius.

350 friends

They say the difference between a happy ending and a sad one is where you choose to stop the story.

Earlier this year, Ian had been experiencing some treatable medical issues. Not a happy ending, but just wait.

His parents took a calculated risk, adjusted his medication and decided to let him go to sleepaway camp anyway. He would be there with 350 kids from a new church his family had joined, most of them strangers.

He could do this, his parents believed, but in the days before the camp began Anna was a nervous wreck. "I just prayed, 'Lord, just please help my son find one or two really good friends.'"

For the first few days she heard nothing from camp, and then on the last night she got a text from one of the leaders saying, "You've got to watch this," with a video link.

The video showed Ian walking onstage to do a lip synch battle to a TobyMac song called "Scars." But before he began to perform, Ian had something he wanted to share with everyone.

"Hey, my name's Ian. So, I'm a two-time cancer survivor...", he proceeded to tell his story, "...and this song 'Scars' resonates with me and my life, and I just wanted to share it with y'all."

Then he bursts into the song in the lip synch battle and starts dancing for all he's worth.

"And I was just like bawling," said Anna, "and everybody in the audience is chanting his name, like, 'Ian! Ian! Ian!' And I'm like, 'Oh my gosh, I just asked for two friends, and you just gave him 350.'"

"And the fact he was just so comfortable getting up there and weaving his story, but not making it just about that. And I'm like, 'Oh my gosh, we have come so far. It's so amazing to see him grow up and just become his own little person and be so brave, I tell ya.'"



Ian excels in golf. Help other St. Jude patients reach their potential by donating today. stjude.org/donate



Welcome Home Rally

After treatment at St. Jude, Luke gets a police escort home

By Karina Bland - ALSAC



Luke counted down the hours of the drive from Memphis to Shreveport, Louisiana, punching his dad's arm every hour and announcing, "Five more hours."

Another punch and, "Four more hours."

They had left early that morning in his dad's mud-colored truck that Luke hoped to finagle when he was old enough to drive. He pressed his feet against the floorboards as if that could make his state trooper dad go faster.

Punch. "Three more hours."

When they crossed the Louisiana state line, Luke and his dad did double-takes, trying to take in what they saw. "Wait, what is going on here?" Luke asked.

Uniformed officers were lined up on the side of the road, some standing next to SUVs, red or blue lights rotating atop, and others astride motorcycles.

They were there for Luke.

"I just lost it at that point," Luke said. "I was like, 'This is *crazy*.'"

His dad, Barry, a Louisiana State Trooper for 25 years, and Luke were ushered into the back of a white limousine, a driver in jacket and tie holding open the door. Luke had never ridden in a limo before. He pulled a root beer from the cooler, slid across the leather seat and stretched out his legs.

Punch. "One more hour."

It was the ride of a lifetime. After almost eight months of cancer treatment at St. Jude Children's Research Hospital, Luke was almost home.

'No rhyme or reason'

Luke had started vomiting in January 2021. He'd vomit all day Sunday, be fine Monday and Tuesday, and then throw up after dinner on Wednesday.

"There was no pattern," Barry said. "No rhyme or reason."

Luke's pediatrician thought it was a virus. It got so bad that Barry took Luke to the emergency room. An ultrasound of his stomach and blood tests showed nothing wrong.

But Barry told his wife, Jenn, "I'm afraid there is something very, very wrong." He felt like it was something to do with Luke's head. Something serious.

"Don't think that," Jenn said.

In March 2021, tests at a pediatric gastroenterologist showed sludge in Luke's gallbladder. He had it removed in May.

Three days after the surgery, Luke was in the hospital, the four incisions on his abdomen straining each time he retched.

'Can we look at his head?'

Because he'd had that feeling, Barry asked Luke's doctor, "Can we look at his head?" Luke was wheeled away for a computerized tomography or CT scan.

Luke's mom, Laura, was there, so Barry left to shower. At home, his phone rang. It was Laura, crying. She choked out the words: "Luke has a brain tumor."

"It felt like all the air in the house got sucked out," Barry said. "It was complete terror."

On his phone's screen, Barry looked at the images from Luke's CT scan. There was no missing it: a white mass against the gray of Luke's brain, and the size of a golf ball.

He and Jenn rushed to the hospital.

The doctor had only told Luke, "There's a spot on your head." Now, Luke sat on his hospital bed, feeling his scalp for lumps. He asked his stepmother, who's a nurse, "Hey, Jenn, is this it?"

"No, baby," she told him. "That's not it."

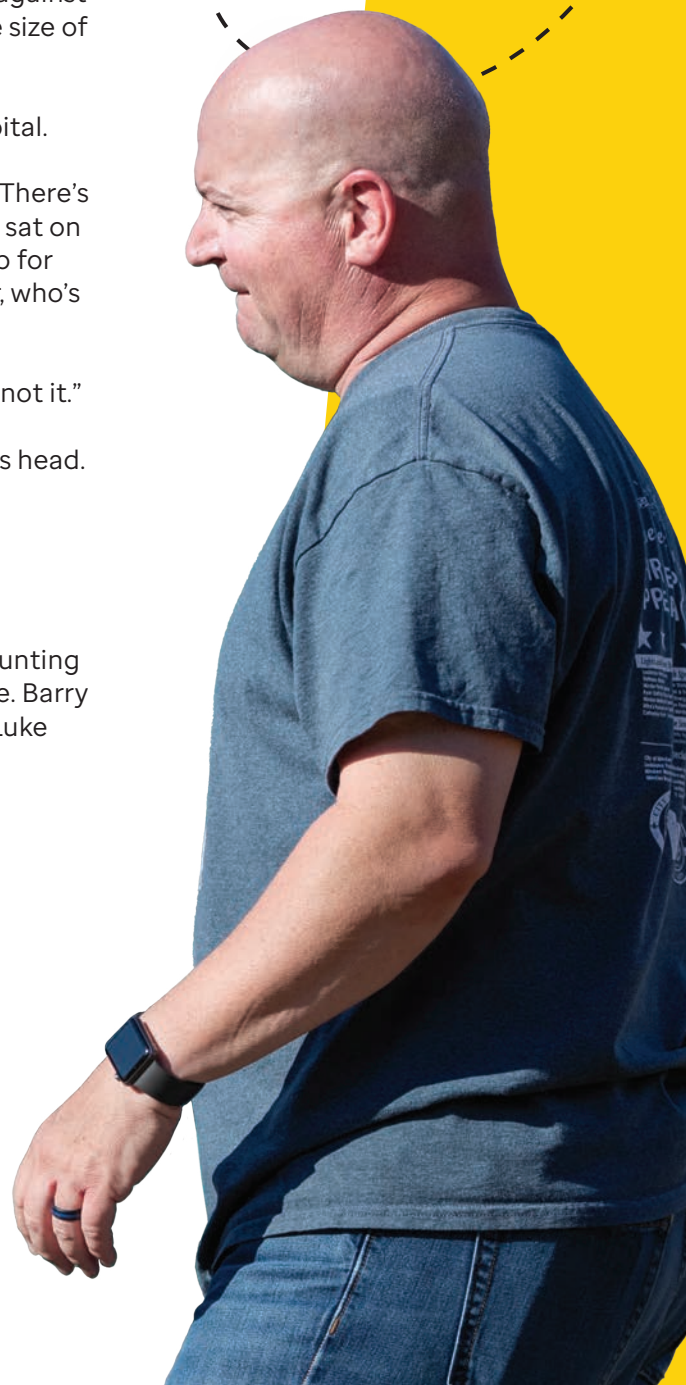
Luke dropped his hands from his head. "Is it in my brain?"

"Yeah, baby, it's in your brain."

Two days later, Luke's family sat in the hospital waiting room, counting down the hours. One. Two. Three. Barry would have given anything for Luke to be there, punching his arm.

Four. Five. Six hours later, the doctor came out of the operating room, grinning. She'd removed the entire medulloblastoma, a rare cancerous brain tumor. Luke's tumor had put pressure on his brain, triggering the vomiting.

While Luke was in the intensive care unit, his



“Let’s get through Monday and then we’ll deal with Tuesday. Fight for that day to get to the next.”

– Barry, Luke’s dad

doctor contacted St. Jude, where she had completed a fellowship under Amar Gajjar, MD, a world-renowned pediatric brain tumor expert.

Survival rates for medulloblastoma are 70 percent, or 60 percent if it spreads. Luke needed treatment to target any remaining cancer cells.

Finding hope at St. Jude

Luke had seen commercials for St. Jude.

“I thought it was a place kids go when they’re really, really sick,” he said. He thought, “It must be bad if that’s where I’m going.”

The first time he met Dr. Gajjar, Luke said the doctor put his hand on his shoulder and promised he would be OK.

“That was all I needed to hear,” Barry said. “We were where we were supposed to be.”

Luke’s cancer had not spread. He would need six weeks of radiation therapy and four months of chemotherapy.

Barry told Luke, “Bubba, this is going to suck. You’re not going to like it, but I promise you we’ll get through it.”

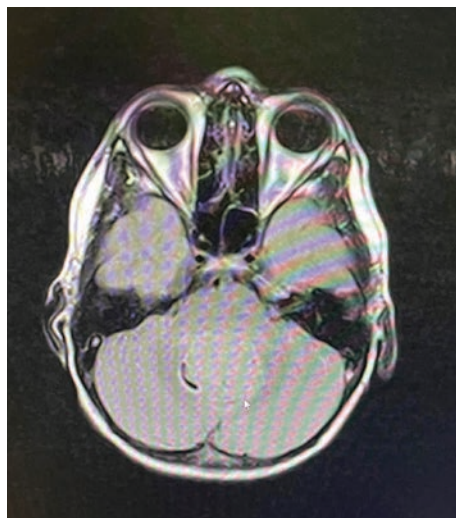
Still, there were times when Barry would tell Luke he needed a soda and walk down the hallway. He didn’t want his son to see him cry.

Luke was exhausted and nauseated. His hair fell out.

“That was ugly,” Barry said, nudging Luke.

“I looked better than him,” Luke said. Barry ran his hand over his bald head, chuckling.

Luke and his dad took it day-by-day instead of thinking of the months ahead. “Let’s get through Monday and then we’ll deal with Tuesday,”



Barry said. “Fight for that day to get to the next.”

Luke turned 15 in treatment. He was at St. Jude for Halloween and Thanksgiving. His last chemotherapy treatment was Dec. 22, 2021. His family put Christmas on hold.

“There are moments where it does strike you down and brings you way down to the bottom,” Luke said. “But there’s always a top. There’s always tomorrow. The better day is coming.”

The better day came on Jan. 12, 2022. Luke got to go home.

‘Welcome home, Luke’

As the motorcade pulled into Luke’s neighborhood, family and friends lining the streets cheered, holding up signs: “Welcome home, Luke” and “Fight like Luke.”

“I started tearing up,” Luke said. He got out of the limousine wearing a mask, a cap on his bald head, the port in his chest and feeding tube in his belly hidden under his sweatshirt.

Luke hugged family and friends and shook hands with the mayor. His dad told a local news station how grateful he was for St. Jude. “They saved our son,” Barry said.

So much about home was the same.

His chore list. Family dinners. His 16-year-old brother, Amos, dropping his dirty clothes on Luke’s side of their shared bedroom.

Some things were different.

Luke couldn’t go to school. A teacher came to his house. He had kept up with his freshman classmates with the help of

teachers at St. Jude, maintaining his straight-A average.

Luke couldn't play football, either. Not for at least a year, per doctor's orders.

His friends had changed, too. They'd gotten taller — one grew a mullet — and found new interests. "They kind of grew up without me," Luke said.

When Luke got home, he was thin and bald. The kid with cancer, something that set him apart when all he wanted was to fit in.

Luke was different, too. Going through what he went through changes you.

"It puts a whole different perspective on life," Luke said. Before he left St. Jude, a psychologist asked Luke how he would cope with friends who thought making a C in a class was the end of the world.

Luke still can sympathize. But he knows there are worse things.

"I had to come to grips with some things that I don't think most 15-year-olds have to come to grips with," Luke said. That life isn't always fair. That not everyone makes it.

A life to live

Luke gets nervous when he returns to St. Jude for check-ups. Not because of the MRIs or spinal taps, but the fear that his cancer might come back.

"I don't really think about it when I'm at home," Luke said. But on that six-hour drive to St. Jude with his dad, "It's all more real."

At Luke's checkup in August his scans were clear. Doctors took the port out of his chest.

Now nothing marked him as a kid with cancer.

His hair has grown back. He got taller and filled out.

A girl he's known since sixth grade and liked since they were freshman invited him to the movies. Elizabeth had texted Luke almost daily when he was at St. Jude.

He's learning to drive, and he's good at it, save one close call with some mailboxes. He's still got his eye on his dad's truck. "*My truck, you mean,*" Luke said. He turned 16.

The first day of his sophomore year, back at school in person, was perfect, even if he forgot his locker combination. His teachers were nice. The football coach invited him to condition with the team.

Barry and Luke are grateful for it all.

"We're beyond blessed for what we've come through," his dad said. "I get to keep my son."

"And that means I can keep beating him up," Luke said, and he punched his dad in the arm.



You can help ensure families like Luke's never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate



MAKING PROGRESS

in sickle cell disease research

By **Ruma Kumar and Yolanda Jones - ALSAC**

Pioneering
work at
St. Jude
provides
'promising'
path to a cure

Nytasha was worried when the nurses whisked away her daughter moments after she was born. They said the baby was anemic and had jaundice. There could be something wrong with her liver.

But a blood test soon revealed Nytasha's daughter, Za'Mya, was born with sickle cell anemia, one of the most common inherited blood disorders in the United States. It can occur in all races but is most common in the U.S. among African Americans and Hispanic Americans.

Za'Mya, who is now 7, was diagnosed in the first week of her life and was referred for care and treatment at St. Jude Children's Research Hospital, which runs one of the largest pediatric sickle cell programs in the largest sickle cell programs in the country, treating about 900 children a year.



Facts about Sickle Cell Disease

Doctors and researchers at St. Jude have helped to dramatically improve the care and understanding of sickle cell disease.



1962

St. Jude has been researching sickle cell disease since the hospital opened in 1962. The first research grant ever received by St. Jude was for the study of sickle cell disease.



1968

While at St. Jude, Dr. Rudolph Jackson developed community outreach programs and clinical protocols serving sickle cell-affected families.



1977

St. Jude launches the first major effort to understand the lifelong progression of sickle cell disease.



1983

St. Jude patient with sickle cell disease and cancer underwent a bone marrow transplant to target the cancer. The procedure also cured her sickle cell disease, making her the first person in the world cured of sickle cell disease through a bone marrow transplant.



Today:

St. Jude runs one of the largest pediatric sickle cell programs in the country, treating about 900 children a year.

Nytasha was aware she carried the sickle cell gene, but knew little about the disease, which forms hard fibers inside red blood cells causing them to distort from healthy, round and plump into sickle or banana shapes. The abnormally shaped red blood cells cannot move through blood vessels easily, so they get stuck, preventing the crucial delivery of oxygen to some organs and tissues and causing debilitating, sometimes life-threatening, pain crises.

For Za'Mya, the pain comes unexpectedly and throbs along her legs, but sometimes in her chest, too, forcing the family to rush to the hospital for urgent treatment.

"You know, she rarely cries, even though I know she's hurting like crazy," Nytasha said. "She's very strong for her to be so young and going through what she goes through. She makes me brave."

Over the last 60 years, doctors and researchers at St. Jude have set the stage to dramatically improve the care and understanding of sickle cell disease.

It was on this campus in Memphis where an African American doctor, Rudolph Jackson, developed community outreach programs and clinical protocols serving sickle cell-affected families in 1968. In a few years, Jackson's pioneering work had amassed such recognition and stature that the federal government asked him to help establish a national protocol for the treatment and care of sickle cell patients.

A St. Jude patient was the first in the world to be cured of sickle cell

anemia through a stem cell/bone marrow transplant. And work led by scientists and researchers at St. Jude also showed that using the drug hydroxyurea daily could boost average hemoglobin levels, thus severely reducing the frequency of hospitalization for pain crises.

Recently, St. Jude partnered with other top institutions in the country through its Research Collaboratives program to develop and refine novel gene therapies that would allow doctors to edit the genes



There are more than 100,000 patients affected by sickle cell disease in the U.S.



While new therapies and screenings have reduced the chances of early death and disease caused by sickle cell disease, life expectancy remains in the mid-40s.



“She’s going to get married. She’s going to have me some grandbabies. We are going to take trips. She’s going to be a doctor. She’s going to do everything she wants to do...and more.”

– Nytasha, Za’Mya’s mom

responsible for sickle cell in fetuses, allowing babies prone to the disease to be born healthy. Published early results of gene editing studies are “very promising,” said Clifford Takemoto, MD, Director of Clinical Hematology at St. Jude and Lemuel Diggs Endowed Chair in Sickle Cell Disease.

St. Jude also recently opened a telehealth clinic for sickle cell disease patients in Tupelo, Miss., helping patients who live too far from the main campus in Memphis to easily attend appointments.

Still, there is much work left to do to improve the lives of the more than 100,000 patients affected by sickle cell in the U.S., and the tens of thousands with it around the world, particularly in Africa, Takemoto said.

“I will say that there has been progress made in terms of understanding and knowing that if we give something very simple like penicillin to babies, that infants that used to die early on, that doesn’t happen anymore, so that is much better and children are living and doing well,” Takemoto said.

Takemoto added that other screening measures have also been developed that identify children at risk for other major life-threatening conditions such as stroke. So now, therapies can be implemented before children experience such devastating complications. Using these new therapies and screenings, doctors and scientists

have markedly reduced the chances of early death and disease caused by sickle cell. That is, until adulthood.

“That’s where things have not changed much,” Takemoto said, stressing the need for continued research in this area. “This is a condition where the life expectancy is still in the mid-40s.”

These realities weigh on Nytasha’s mind. She asks lots of questions at clinic visits about Za’Mya’s prognosis, which looks encouraging now, and has enrolled her older sons in trials at St. Jude so they will know more about the disease for which they carry a gene when it comes time for them to have children.

Recently, she brought Za’Mya to the St. Jude campus to meet the crew members of a new space mission to benefit the research hospital. The 7-year-old was shy with the astronauts as they asked her questions, but proudly showed them a rocket she painted in vibrant pinks and yellows.

Sitting there, surrounded by folks talking about the stars and heavens, Nytasha couldn’t help but share what she dreams for her daughter.

“She’s going to get married. She’s going to have me some grandbabies. We are going to take trips. She’s going to be a doctor. She’s going to do everything she wants to do...and more,” Nytasha said.



Ensuring more patients like
Za'Mya get the treatment
they need is possible
because of generous
supporters like you.
stjude.org/donate

Finding ‘some way to help’

Dixie Mills supports St. Jude as a Partner in Hope.

By Yolanda Jones - ALSAC

It was seeing the children and their parents on TV, then hearing their grateful voices talk about the lifesaving impact of St. Jude Children’s Research Hospital supporters, that stirred Dixie Mills to action.

The commercials moved Dixie, who knew of her own family members’ struggles with cancer, including her parents and a young nephew. So, Dixie decided to embark on her own journey of support as a monthly St. Jude Partner in Hope, contributing what she could to help children with cancer and other life-threatening diseases.

“I didn’t know much about the children at St. Jude until the ads captured my full attention,” Dixie says, 15 years later. “I thought, ‘I’m missing out here on some way to help.’ So, I got involved and I’m so glad I did.”

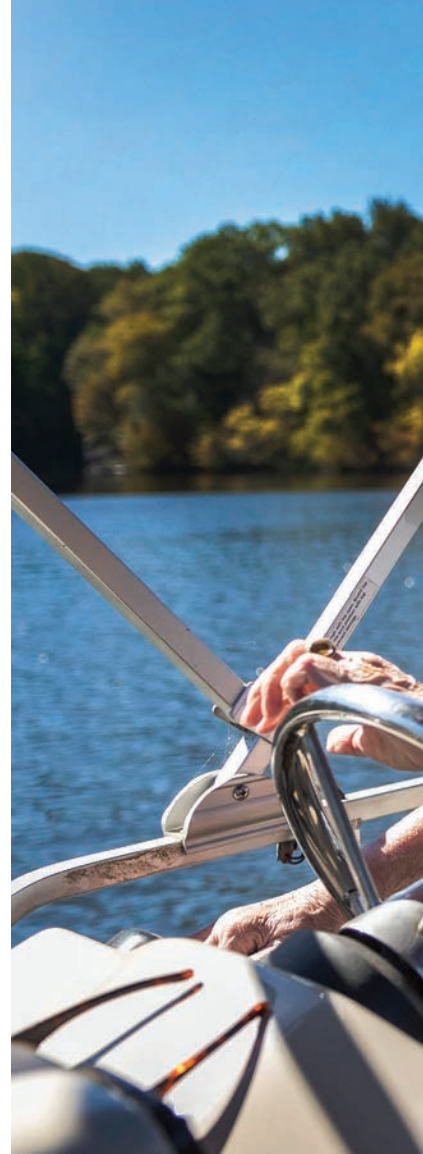
*“I became active
in all things
St. Jude because
I just didn’t want
to disappoint
the children.”*

– Dixie Mills, St. Jude Partner in Hope

including the FedEx St. Jude Championship golf tournament, where she met fellow supporters also motivated to do their part to further the St. Jude mission: Finding cures. Saving children.®

Becoming a St. Jude Partner in Hope meant Dixie began receiving regular updates on St. Jude patients, like those whose cancer journeys had touched her heart. Those hopeful updates often included examples of how St. Jude could use donations to help provide a new toy (\$15), help feed a St. Jude family for one day (\$35) or help provide 12 IVs to patients (\$50).

Dixie also began attending St. Jude events in her area,





Now in her 80s and living in Mississippi, Dixie says, “I became active in all things St. Jude because I just didn’t want to disappoint the children.”

Retired now, Dixie had several colorful careers – in construction, as a veterinarian tech and even showing horses – but spent her last 30 years selling supplemental insurance plans.

When her only son died of cancer in 2017, Dixie decided to make an even bigger commitment by designating St. Jude in her will as a beneficiary of her life insurance policy – so her legacy can help the next generation of children.

“I have no family left except for what I do for St. Jude,” says Dixie, who made sure to notify St. Jude of the plan so the research hospital could better plan for the future. “I have had it real hard at times in my life, but I worked hard, and I have been blessed in my life. So, I wanted to bless others like at St. Jude.”

Dixie remains very active, living with her cat Mya (whose meows sound like an opera singer) and spending time on the lake with her fishing and pontoon boats. When she plays shuffleboard twice a week at the local VFW, she often wears a “This Shirt Saves Lives” T-shirt she received as a St. Jude Partner in Hope.

Dixie still has goals to reach on her “bucket list,” like ziplining and whitewater rafting. But instead of checking adventures off her list on her most recent birthday, Dixie asked friends to donate to St. Jude on a Facebook fundraising page she set up.

“I can’t do like the astronauts and raise all that money, but I give monthly what I can,” Dixie says, in reference to the all-civilian Inspiration4 mission to orbit Earth in 2021, benefiting St. Jude. “It is important to me to give because the kids at St. Jude motivate me every day. Believe me, I’ll get to my bucket list, but the kids come first.”

GIFT GUIDE

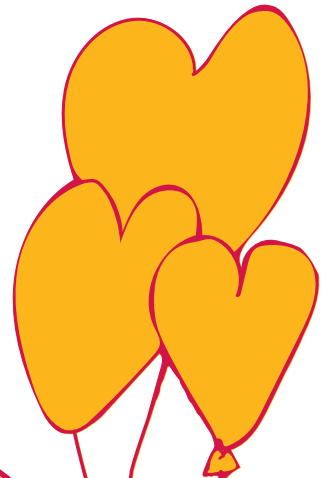
Give a gift that gives back
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St. Jude Heart Gnome Beige
472600000 \$8.00



St. Jude Heart Gnome Brown
472700000 \$8.00



St. Jude Heart and
Pearl Bracelet
686200000 \$18.00



St. Jude Red Faded Block
Letter Sweatshirt
9335RED \$46.00



St. Jude patient Addison
and mom, Kellie.

I Love Us Heart Frame
472800000 \$10.00



Art by St. Jude patient Ty
shop online at stjude.org/giftshopinspire

Save the Date for St. Jude Kids



St. Jude patient **Charlie**, leukemia

Please join us February 7, 2023 for a very special Partners in Hope Virtual Summit. We look forward to sharing a beautiful mission moment, exciting hospital updates and information on how support like yours is helping change the lives of St. Jude patients and families.



Scan the QR code to register for the St. Jude **Partners in Hope** Virtual Summit on February 7 or visit stjude.org/pihevent.





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Marina's Journey

Not long before Marina, the baby of the family, was diagnosed with eye cancer, her father lost his leg in an accident. Suddenly, the family was dealing with two crises, and having to make do on a single income. A referral to St. Jude Children's Research Hospital made all the difference. "There's no way I could have afforded treatment otherwise," said Marina's mom.

Still, retinoblastoma is a frightening diagnosis. "I was just terrified," said her mom. "I was afraid for my daughter's life, and I was afraid for her to be in any kind of pain."

Despite receiving systemic chemotherapy and **chemotherapy** injections in her right eye, Marina remained her cheerful, affectionate and playful self with everyone, including her St. Jude care team. Ultimately, Marina's care team determined her eye had to be removed. But her mom said she has adapted wonderfully. She continues to visit St. Jude for checkups.



Thank you for helping St. Jude patients like Marina through your generous monthly gifts as a loyal Partners in Hope friend. St. Jude won't stop until no child dies from cancer – we hope you won't either. To help us get closer to that day, please consider giving an additional, one-time gift by scanning the QR code or go online to stjude.org/hope.

