

● ST. JUDE ●



inspire

SPRING 2024

Home again

Beckett is back with his family after treatment at St. Jude.

Hope for Ava

Doctors in the Bahamas referred her to St. Jude

Grateful grandparents

Longtime St. Jude donors are thankful after their granddaughter was saved at St. Jude

Sibling benefits

The St. Jude sickle cell program helps kids like Franser and Kendall



VOICE OF COMFORT

Grammy Award-winning country music artist Carly Pearce performs for St. Jude cancer survivors and clinical staff.

Ashley McTyre, enjoying the show with her daughter, is both: a St. Jude cancer survivor and a St. Jude nurse. She was referred to St. Jude at the age of 10 for treatment of osteosarcoma, a type of bone cancer. The relationships she formed with her care team inspired her to pursue a career in medicine. Today, Ashley works as a nurse practitioner, delivering the same level of care and support to St. Jude kids that she herself experienced.

“My hope for this place is that one day we will be able to put me out of a job because we can find a cure for cancer,” said Ashley, “and no child ever has to go through the things I’ve experienced and that kids right now are fighting through.”



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](https://www.stjude.org/ImpactGiving)



To this day, I'm still amazed by the optimism exhibited by parents of St. Jude patients.

Even through the darkest days, hours when hopelessness threatens to take over, the spark of hope is always there to light the way.

I'm inspired by moms like Tammie, who said of the support of family, friends and strangers, "You definitely see the good in the world."

That spark from Tammie, who has seen the worst. Her son Beckett was only 3 years old when he was diagnosed with atypical teratoid rhabdoid tumor (ATRT), a rare and aggressive cancerous tumor of the brain and spinal cord.

She and her husband brought Beckett to St. Jude, 11 hours from their home. Eleven hours away from their other children and their routine, their lives that had, up until the moment of diagnosis, held only promise.

At St. Jude they found hope. They found a community to lean on. They found the good in the world.

In this issue of St. Jude Inspire, you'll find uplifting stories like Beckett's and Madelyn's. Stories of hope and healing, but also of family and community – the twin helixes in our mission's DNA.

Madelyn was treated at St. Jude for a rhabdoid tumor of the kidney and

was cheered on by the University of Alabama softball team whose coach was a family friend.

Teamwork. Another spark of light from St. Jude and Dr. Sara Federico, a member of the St. Jude faculty doing incredible research into solid tumors, who has said, "At St. Jude, we don't care who cures cancer, we just need to advance the cure."

Those cures are advanced thanks to generous supporters, donors like Jaime and Irma in Puerto Rico who have made a monthly gift to St. Jude for years. Years of giving because, Jaime said, he wanted to give thanks for his seven healthy children. But then his granddaughter became a St. Jude patient. Never was that hope brought so close to home.

In this issue we celebrate the hope, the teamwork, the spark and the light supporters like you give the St. Jude family.

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

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St. Jude is helping two siblings live their childhood to the fullest.



You can 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. Donate today at stjude.org/ImpactGiving



Generosity comes

FULL CIRCLE

By **Monsy Alvarado** - ALSAC

Grandparents contributed to St. Jude for years, then their granddaughter became a patient.

Jaime of Puerto Rico became a supporter of St. Jude Children's Research Hospital® years ago to give thanks for his seven healthy children.

He started giving occasionally after seeing information on television, and then later became a St. Jude Partner in Hope® by giving monthly. When he signed up, he remembered a neighbor from years ago when he lived in New York who had a son with cancer and a colleague whose daughter had been living with muscular dystrophy. It was more reason to donate, he thought. His wife, Irma, was on board.

"I did research and looked into the hospital, and I was even more thankful, and I wanted to give consistently,"

he said. "I wanted to help other children and to improve their quality of life."

Jaime had never visited St. Jude, but as a donor he received mailings that gave him a glimpse into treatment and research breakthroughs. Jaime never imagined one day St. Jude would be a lifeline for someone in his family.

In 2020, his youngest daughter, Genesis, gave birth to twin girls, Janelle and Amalia. Jaime and Irma were elated as they watched the girls grow and often witnessed milestones while they babysat. But when the twins were more than a year old, Janelle started to regress in her development. The toddler who could



I never thought that my monthly donation would one day help my granddaughter, but that is the way it was. Not only my donations, but the donations of all those who give, and I'm thankful to them. Today it's Janelle, but tomorrow it will be another child.

- Jaime, Janelle's grandfather



once sit on her own would fall over. Janelle also could no longer stand, which was something she had been doing.

Tests later revealed that Janelle had medulloblastoma, a fast-growing brain tumor of the cerebellum. The cerebellum controls balance and coordinated movements.

Janelle underwent surgery in Puerto Rico to remove the tumor and was later referred to St. Jude.

"I thought, 'Thank you, God is good,'" Jaime recalled when he learned Janelle was going to be treated at St. Jude. "I never thought that my monthly donation would one day help my granddaughter, but that is the way it was. Not only my donations, but the donations of all those who give, and I'm thankful to them. Today it's Janelle, but tomorrow it will be another child."

Janelle traveled to Memphis with her mother and father, Jan Louis, while Amalia stayed in Puerto Rico with her grandparents. Jaime and Irma worried about the diagnosis and what was to come for their granddaughter.

"It was something very difficult for us, thinking about what we must go through, we knew that there were children who had gone through it. But you must live it to know the pain," Irma recently said as she sat in her daughter's living room.

At St. Jude, Janelle received chemotherapy for 16 months followed by six weeks of proton radiation therapy. She also underwent a procedure to replace a shunt in her brain.

Jaime and Irma video called their daughter daily to get updates on Janelle. They saw her improvements and looked forward to hearing



St. Jude patient Janelle and her parents attend one of her clinical appointments during treatment at St. Jude.

about the gains she made during physical therapy sessions.

"We saw the miracle in our granddaughter. I saw it and I continue to see it every day," Irma said. "Everything that Janelle needed, St. Jude gave her. The greatest gift that St. Jude has given me is the life of my granddaughter."

Janelle went home to Puerto Rico in June 2023 where her grandparents were waiting with open arms followed by an emotional gathering of family and friends. Janelle returns to Memphis for regular checkups.

"The pain and anguish I felt began to heal because Janelle was here, and Amalia is back with her parents and all four of them are together as a family," Irma said.

Jaime said Janelle is determined to walk again. She is crawling and often grabs someone's hand to practice her stride.

"It's so good to see her moving because there was a time that she wasn't able to," he said.

Jaime and Irma said they encourage others to donate to St. Jude. They talk about the work St. Jude does and their family's experience.

"To all those who support St. Jude, keep giving because you are giving life to children so they can live happy – not only my granddaughter, but all those children who are being treated at St. Jude," Irma said.



Your gift will help more patients like Janelle get the treatment they need.
stjude.org/ImpactGiving



HOME

AT LAST

After treatment for brain cancer at St. Jude, Beckett and his family celebrate everyday life.

By **Karina Bland** - ALSAC

Five months into treatment for brain cancer at St. Jude Children's Research Hospital®, 3-year-old Beckett was madly missing his brother and sisters back in Michigan.

He'd tear up, telling his mom and dad, "I just want my sissies back. I want my bro-bro back."

It had been almost two months since the kids' last visit to Memphis.

The results of Beckett's latest blood tests were good, meaning it was safe for him to travel. So, with six days until Beckett's next round of chemotherapy, his parents, Tammie and Brett, decided to make a surprise visit home.

Beckett comes from a blended family. The older three kids are Tammie's from her first marriage. Tammie and Brett married in 2019 and had Beckett. His brother and sisters adore him.

For the family of six, there's a comforting chaos to their life – work, school, homework, football practices and cheerleading competitions. They camp, hunt and fish together. Brett and Tammie play soccer on the same team. Their house is where everyone gathers.

Tammie and Brett miss it all. "Family is very big to both of us," Brett said.

He drove and Tammie rode in the back seat with Beckett, fielding video calls from the kids throughout



the 11-hour drive trying to protect their secret.

“Why are you in the car still?” Cadence, who’s 11, asked.

“We’re heading to Target,” Tammie told her.

“You just went to Target,” Cadence said.

Finally, they pulled up outside the older kids’ dad’s house. Tammie had texted ahead, asking him to send the kids out one at a time.

Paisley, who’s 9, was first. Spotting them, she sprinted across the lawn to hug Beckett. She likes to have Beckett all to herself, taking him out back to swing or play in another room. They crack each other up.

Next was Cadence, who mothers Beckett, carrying him on her hip, reading him books and tucking him into bed.

“Oh, my gosh!” Cadence yelled, running to hug Beckett. Sobbing, she picked him up. Beckett buried his face in her neck.

“Those are happy tears, Beckett,” Tammie told him.

And then Aaron, who’s 13, was tearing toward Beckett, who turned and ran, laughing. Aaron caught him easily and then hugged his mom. Aaron is Beckett’s protector, even more so now.

Tammie and Brett cried, too. Happy tears.

“It gives you a fresh sense of how important family is and how much we all mean to each other,” Brett said. “It brings new meaning to our family connections.”

In the five days they’d have together, they’d hold tight to one another and

hope and pray that one day Beckett would come home for good.

‘Mama, I dizzy’

It was late January 2023 when Beckett suddenly started getting lightheaded. He told Tammie, “Mama, I dizzy.”

At the pediatrician’s office, screenings showed nothing wrong. The doctor sent Beckett to a nearby hospital for a blood test that showed he was anemic. Beckett was prescribed daily iron supplements.



It gives you a fresh sense of how important family is and how much we all mean to each other.

– Brett, Beckett’s dad

A month later, Beckett still was dizzy and worse than before. In his safety seat in the back of the car, he said, “Dada, don’t turn.” Even that made him dizzy. He began throwing up.

Family and friends gathered to celebrate Beckett’s third birthday with a party on March 11 and a monster truck show the next day. Brett’s mom, a physician assistant, pointed out Beckett was leaning when he walked and cocking his head to one side.

The next morning, at 5 a.m., Brett’s mom texted Tammie and Brett, saying they should take Beckett to the emergency room. There, a CT scan showed a mass in Beckett’s brain.

He was transferred to a children’s hospital, where a more precise MRI confirmed a mass in his cerebellum, which primarily controls balance and movement.

In a 10-hour surgery the next morning, the surgeon removed part of the mass. After six days in intensive care, Tammie and Brett took Beckett home to await biopsy results.

“We were just a mess,” Brett said. Sleepless nights and terror-filled days but still there were kids to feed and get to school. Friends and family came to help.

The call came an agonizing three days later on March 22.

Beckett had an atypical teratoid rhabdoid tumor, or ATRT, a rare and fast-growing cancerous tumor of the brain and spinal cord. It is notoriously difficult to treat, and the long-term outlook for children with ATRT is usually poor.

“Our world completely shattered,” Tammie said. She wanted only to curl up with Beckett.

Brett scoured the internet for information about ATRT and the best treatment. Tammie’s mother suggested St. Jude. Tammie’s best friend turned up at 9 p.m. with the St. Jude website already pulled up on her laptop.

The next morning, Tammie and Brett got a call back, telling them Beckett had been referred to St. Jude.

“We decided there would be no more crying. No more feeling sorry

for ourselves,” Brett said. “It was time to be warriors and fight.”

‘Best possible outcome’

Three days later, on March 29, Tammie, Brett and Beckett drove 11 hours through the night, arriving at St. Jude a few hours before Beckett’s first appointment. The first few days were a blur of scans, lab work and assessments.

Beckett’s pediatric neuro-oncologist at St. Jude recommended a second surgery. On April 6, in a 5-hour surgery, the pediatric neurosurgeon removed the rest of the tumor. Tests showed no evidence of cancer anywhere else.

“It was the best possible outcome,” Tammie said. Beckett was up and walking the same day.

Tammie and Brett had seen information on TV for St. Jude and donated by rounding up at checkouts of businesses that support St. Jude.

But they didn’t understand what happened at St. Jude until they saw it themselves. “They’re changing people’s lives here,” Brett said.

Beckett would undergo 17 rounds of brain and spine radiation therapy and then 13 rounds of targeted radiation at the tumor site.

Then he’d get a break and get to go home for a month in June before starting chemotherapy.

The best medicine

In July, the whole family drove back to St. Jude so Aaron, Cadence and Paisley could visit for the first time.

”
**They're
changing
people's
lives here.**

– Brett, Beckett's dad

After that, the kids visited for a few days every month or so, traveling to St. Jude with Tammie’s parents. During those visits, Beckett was happier and, interestingly, Brett said healthier, his lab results consistently better when his brother and sister were with him.

“It even keeps us going,” Tammie said. Without the family together, Brett said it is easy to fall into autopilot – appointments, meals, sleep and repeat.

Beckett is almost always happy, except when he’s missing his siblings. Even chemotherapy doesn’t slow him down.

He loves monster trucks and construction vehicles. He’s bright, already learning to read and doing addition and subtraction. Not only can he count to 100, but he can also do it by 10s and 5s.

At Target House, a long-term residential patient facility where families never receive a bill from St. Jude for housing or food, Beckett opened the curtains in the

morning and told Brett, “Dada, wake up. It’s a beautiful day outside.”

Tammie marvels at Beckett’s resiliency. When she told Beckett he’d need lab work that day, he tapped the medical port in his chest and said, “Good thing I’m already accessed.”

But Beckett always asks when they’ll get to go home again.

Back in Michigan for the holiday

After the surprise trip home in August, Tammie, Brett and Beckett left the game where the girls were cheerleading at half-time on Aug. 27 to make the long drive back to St. Jude.

It would be almost three months before they would return to Michigan.

They’ve already missed so much. Birthdays. The girls’ cheerleading competitions. Aaron’s first day of junior high and his new braces.

Tammie misses hearing the kids yelling from upstairs, their bikes and scooters scattered across the yard, and the routines of daily life. Picking up the kids from school. Riding bikes around the neighborhood. Even cleaning the house.

Brett misses sitting on the back porch with a cup of coffee before work. Having friends and family over for a barbecue. Even mowing the grass.

After what they’ve been through, they’ll never take it for granted.

As excited as they are to go home, it’s scary, too. “We’re safe here,” Tammie said.

Beckett, now 4, has been cancer-free since his surgery in April. He celebrated his end of treatment with



a No More Chemo Party, a tradition at St. Jude, on Nov. 21 – two days before Thanksgiving.

He returns regularly to St. Jude for scans and lab work – reassurance that if his cancer returns, doctors will catch it early.

In the meantime, the family has resumed their life. Regular, glorious everyday life, with a new appreciation for all that entails.

The friends they made among the patient families who understood

what they were going through. “It’s a real community,” Tammie said.

The overwhelming support of family, friends and strangers. “You definitely see the good in the world,” Tammie said.

St. Jude and the people there who saved Beckett’s life – and the donors who make their work possible. “We are indebted to St. Jude for the rest of his life,” Tammie said.

The happy tears – and the hope.



Your donation can help ensure patients like Beckett get to spend more time with family. Donate today at stjude.org/ImpactGiving

HOPE

FOR SAVING



A hospital in the Bahamas referred Ava to St. Jude.

By **Kristina Goetz** - ALSAC

Lakesha was sitting in her kitchen when her daughter Ava walked in, her neck swollen on one side.

Concerned, Lakesha kept an eye on her daughter's condition for a couple of days before she took her 6-year-old to the doctor near their home in the Bahamas.

Ava was given antibiotics. And even though her bloodwork came back fine, it appeared to Lakesha that Ava's neck had gotten bigger.

Still looking for answers, the doctors ordered scans. That next day Lakesha got a call from the doctor.

It looked like cancer, possibly lymphoma. She needed to get Ava to the hospital and there was no time to waste. The scans showed masses in Ava's abdomen. Ava spent two days in the emergency room before she could be moved to the children's ward.

But in an unfortunate turn of events, Ava also had COVID-19. She and her mother had to be isolated for weeks. Following the isolation, a biopsy was taken. The initial diagnosis was non-Hodgkin lymphoma, but the sample was sent away for confirmation.

During these dark days, Lakesha could only visit her daughter an hour a day, a necessary hospital policy in her country, where there's little room for anyone other than patients. She would drop off food in the morning and stay an hour to

visit in the evening. Ava was in a room with four other patients and no TV. Lakesha made sure she had a tablet, phone and coloring books.

Lakesha couldn't be there for the first chemotherapy infusion. And Ava was nervous and didn't like to be away from "Mummy." On the day Ava was scheduled to start chemotherapy, the doctor said she needed to meet with Lakesha. They had received the final results of the biopsy.

Ava did not have lymphoma. She had neuroblastoma. Something they couldn't treat.

At the end of the meeting, the doctor told Lakesha she

Lakesha finally felt at ease. They were given housing at Tri Delta Place and Ava was back at the hospital later that day for tests.

St. Jude confirmed the diagnosis was neuroblastoma.

The doctor showed Lakesha Ava's scans.

"She said, 'Wherever you see red, it's cancer.' And when she pulled up that picture, the whole left side was red. Her neck was red, and she had two spots on her thigh bone, and she had a spot on her spine," Lakesha recalled.

And the doctor reassured Lakesha that she'd done nothing wrong.



When she said St. Jude would take her, I had so much hope."

- Lakesha, Ava's mom

had contacted St. Jude Children's Research Hospital® in the United States.

"When she said St. Jude would take her, I had so much hope. I think the word hope came out of my mouth," she said.

Within a few days, they were on a plane to Memphis.

"Everything fell into place."

They arrived at midnight and nurses were waiting at the hospital doors.

Still, that moment was her breaking point, she said.

Ava is her only child.

"Why? And that was my question for so long: Why? ... People have so many kids, and all of them are well," she said. "My one is sick."

After the first round of chemotherapy, Lakesha noticed Ava's neck went back to normal.

After Ava finished five rounds of chemotherapy, there was no evidence of disease.



“**Why? And that was my question for so long: Why? ... People have so many kids, and all of them are well. My one is sick.**”

– Lakesha, Ava’s mom

That good news came the second week of December in 2022. Ava had turned 7 in October.

“That was the best Christmas gift,” Lakesha said.

After more than a year at St. Jude, Ava is back home in the Bahamas. Now 8, all Ava wants is to go to the beach and for everyone in the family to be there together.

Lakesha no longer feels the need to pay close attention to Ava’s neck. Instead, she looks at Ava’s face, focuses on how tall she’s grown,

how mature she is and how big her personality has gotten.

“As a mother, your child having cancer is the last thing you want to hear. It’s the absolute last thing you want to hear about your child or any other child. But when you get here, and you see the doctors and

the nurses and the techs care about your child’s health just as much as you, it gives you a feeling that, ‘Hey, it’s gonna be ok,’” Lakesha said.

The folks at St. Jude are like family.

“You’re never going to forget them,” Lakesha said.



You can help ensure families like Ava’s 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

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St. Jude patient Hadleigh

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'THERE'S A LOT OF WORK THAT NEEDS TO BE DONE'

Dr. Sara Federico shares what inspires her as she focuses on curing some of the most challenging cancers affecting children.

By **Ruma Kumar** - ALSAC

Through her work at St. Jude Children's Research Hospital®, Sara Federico, MD, has helped define the treatment landscape for high-risk solid tumors in kids. This veteran clinician-scientist, who joined St. Jude in 2007, was recently named director of the research hospital's Solid Tumor Division within the Department of Oncology.

Federico is currently leading five clinical trials, including two pioneering new approaches to treat neuroblastoma. She recently spoke with St. Jude supporters about how they are helping St. Jude in its mission to help patients and improve survival rates.

Q: You like to say: "At St. Jude, we don't care who cures cancer, we just need to advance the cure." Could you expand on that sentiment?

A: When we think about what our founder Danny Thomas said, that "no child should die in the dawn of life," he didn't end that sentence

with "at St. Jude" or "in the United States". He meant anywhere. We owe it to our patients and their families to work together, both within the institution and outside of it, to push that cure rate forward. It's that kind of collaboration that gets better treatment into the hands of people that need it.

Q: You've been at St. Jude since your fellowship began in 2007, when patients with high-risk neuroblastoma had a 30 percent survival rate. By the time you finished your fellowship and joined the staff at St. Jude in 2011, 3-year event free survival rates for high-risk neuroblastoma had risen to 51 percent. What is neuroblastoma and how does your team work to make progress with improving cure rates?

A: Neuroblastoma is a cancer that starts in the nervous system. It's the second most common pediatric solid tumor, behind brain tumors, and in 50% of patients at the time of diagnosis their disease has already spread. Many of these patients are categorized as having high-risk neuroblastoma.

Thankfully we've been able to advance cure rates in high-risk neuroblastoma, but it's come at

a cost of having to add a lot more therapy to the patients to advance that cure.

A couple years back, we decided to test whether adding a certain type of antibody therapy to the beginning, the middle and the end of the treatment protocol would improve survival. Before that, we used to just add the antibody therapy to the end of treatment.

You may be wondering, "What is antibody therapy?" Well, imagine that tumor cells are like a circle with little flags hanging on them. An antibody goes around the body looking for that flag. Once it binds to that flag that's on a tumor cell it marks it for destruction. We then give medicines to make the immune system recognize the tumor plus antibody and destroy the cancer cell.

So, we conducted a trial (with a group of 64 patients here at St. Jude) and identified that giving antibody therapy with chemotherapy during the beginning of treatment as well as at the end was tolerated and more patients were cured. Now, the next step is to study if this treatment regimen, in a larger setting, has the same improved survival rate. So, that's the phase three study that will open this year.

Q: That's promising work. What drives you?

A: When I went into medicine, I really wanted to be able to look back and say, "Hmm, did I participate in anything that really helped children?" not just on an individual level, but as a group. When I selected oncology as my career, my dream was to advance cure rates, so that more children will have the chance to grow up and change the world. This is what drives me, and it's been thrilling to be a part of the research that helps advance cure rates for

high-risk neuroblastoma. But there is so much more work that needs to be done.

There are approximately 800 cases of neuroblastoma diagnosed per year in the United States. But worldwide, there are thousands of patients diagnosed with neuroblastoma every year and many of those patients don't have access to the therapy that we have here within the United States. Additionally, about 30 percent of patients who are diagnosed in the U.S. with high-risk neuroblastoma will relapse. Sadly, when patients relapse,

”

We owe it to our patients and their families to work together ... to push that cure rate forward.

- Dr. Sara Federico

it's much harder to get rid of the cancer. So, we can't slow down; there are still many more children that need better treatment.

Q: What is your why? What keeps you coming to St. Jude to work every single day?

A: (laughs) How much time do you have?

There's one patient story that sums up my why. This patient of mine was diagnosed with Ewing sarcoma as a teen. Ewing sarcoma is the second most common bone tumor in children and young adults. Unfortunately, if at the time you are diagnosed with Ewing sarcoma it's already spread, your chance of cure is only about 30 percent.

Well, that's the situation that this young man was in. He was diagnosed with metastatic Ewing sarcoma and unfortunately his aggressive cancer relapsed multiple times. He also happened to be a talented concert pianist who loved to play music at churches and travel around the country performing concerts. So, as we treated him in our clinic we always factored in his love for music and concert schedule. During the time he was treated for relapsed disease, through a partnership with our basic scientists, we identified a new therapy that had just come from the lab to the clinical space.

Thankfully it worked for a long period of time, and we were able to get his disease to stabilize. But eventually the Ewing sarcoma came back. And I will never forget when we got a call that he was traveling and was short of breath and needed to come back to St. Jude. I knew in my heart that this wasn't going to be good. He arrived that night and went straight to the intensive care unit. The next morning, we got a CT scan and I had to share with him that he was not going to survive his cancer much longer.

We were all having a very sad, tough moment. So, I asked him, "What can we do for you? I know I can't get rid of your cancer now, but what can we do to make your day better?" And he looked at me and said, "I need a piano."

So, I paused a moment and thought, "Okay, we're sitting in an ICU, but you need a piano, so ... let's do it." This is the spirit of St. Jude; you are able to walk out of that room, look around at your colleagues and say, "Okay, we've got to find him a piano."

A few hours later they were able to locate a piano and get it on wheels up to his room. That afternoon I was in a meeting when I received a page that said he was giving a concert in the ICU. So, I raced up to that room.

What a sight ... there was my patient, sitting on the edge of that bed playing the piano. Outside his room there was an arc of people: doctors, nurses, respiratory therapists and different staff that were all standing there soaking up the music. As he finished playing his song everybody erupted in applause and cheer. When he looked up and saw me, he invited me into his room to hear his own rendition of "Amazing Grace." That was a life-changing moment for me and one that reminded me of what makes St. Jude unique and so incredibly special.

We never give up. We never gave up on this patient. He was fighting for his life, and we were in it with him. We don't give up at the end. We take care of the whole patient, not just the disease. While this is not the ending that we wanted for this patient, I know that it was important to him to know that some of those clinical trials he participated in, while battling his relapses, helped other patients and have been developed into new clinical trials. That was his legacy and the amazing grace that he extended to us all.

These patients and these moments are my why.

”

We take care of the whole patient, not just the disease.

- Dr. Sara Federico

Q: What would you say to supporters who give to St. Jude and provide funding that fuels your research and patient care?

A: When I think of St. Jude, there are two sets of heroes that pop into my mind. Of course, first and foremost, are the patients and their families for having the courage to face what they go through every moment of every day. The second group of heroes, in my mind, are the St. Jude supporters because they give selflessly to advance cure rates and quality care for patients that they have never had the opportunity to meet. That is not lost on me, and I am so grateful for the supporter's dedication to provide patients the opportunity to celebrate more birthdays and grow up. And so, St. Jude supporters are always second on my hero list; we just couldn't do it without them.



You can help clinician-scientists like Dr. Federico continue their lifesaving work. stjude.org/ImpactGiving



A Symphony of Love and Care

Nebraska family turns their tragedy into a legacy of hope at St. Jude.

By **Bethany Horton** - ALSAC

Michael and Susan Ferris have supported St. Jude Children's Research Hospital® for over four decades, and by deciding to include St. Jude in their estate plans, their generosity will touch the lives of future generations of children.

Michael, a physician in Nebraska and one of six children, traces his St. Jude journey all the way back to 1972 – the year his youngest brother, Tom, was diagnosed with acute lymphoblastic leukemia, commonly called ALL.

That was the very same year St. Jude published a landmark study

showing a 50 percent survival rate could be achieved for ALL, using a combination of chemotherapy and radiation. So, there was hope when their family physician referred Tom for treatment at St. Jude.

“Mom brought Tom to St. Jude and had all of the tales to tell that a family who's been devastated by the disease, cancerous disease, had to tell,” said Michael. “Our family fell in love with the image of what St. Jude was to my family.”

Heartbreakingly, after nine months of treatment, Tom passed away. But the care and compassion the Ferris

family received at St. Jude would stay with their family forever and influence the man, and physician, Michael would become.

Years after his brother's death, Michael had the opportunity to visit St. Jude – this time as a medical student.

“I was a little apprehensive about how that might be, emotionally, but it was such a positive experience because St. Jude is a positive place,” he said. “It was a really great experience for me to work with the doctors who had treated my brother and to see the kind of love and care that he got here.”

When Michael met and married Susan, their shared desire to help children and families in need became a foundational value of their family. St. Jude, where collaborations helped lead the way to better survival rates for ALL and other catastrophic childhood diseases, was a pillar of the young couple's charitable giving.

“I describe St. Jude as a symphony of love and care. That happens because of collaboration and me, being in the medical field, I can tell you that as important as that is, that doesn't happen a lot,” Michael said. “In fact, I'm sure that St. Jude is unique on planet Earth for some of the things that they've been able to accomplish through that coordination between their clinical staff and their research scientists.”

As members of the Danny Thomas - St. Jude Society, a group of

”

Our family fell in love with the image of what St. Jude was to my family.

– Michael Ferris, St. Jude patient sibling and supporter

dedicated supporters that has included St. Jude in their estate plans, the Ferrises have had the opportunity to visit St. Jude several times.

“Even though we were all in, we've been all in all along. It's so impressive to come here and to see it and to feel it,” said Susan. “It just makes us want to go and round up our friends and family and say, ‘You need to join us in this effort.’”

Now, more than 50 years after his brother first came to St. Jude, Michael finds comfort in the progress he has witnessed. Today, 94 percent of St. Jude children with ALL will survive.

“We've been able to see that progression and the accomplishments that have happened,” Michael said. “That's because of all of the people who are part of the family and have given their dollars to St. Jude.”



You can join Michael and Susan Ferris in supporting the St. Jude mission. stjude.org/ImpactGiving

Lifelong lessons

St. Jude dad James shares how his daughter Emma changed him as a father.

I'm a schoolteacher. My wife is a schoolteacher. We know that teachers enter our lives in all kinds of ways, not just the classroom. And we knew, as we were expecting our first child, that our daughter was going to teach us a lot.

But we never dreamed some of those lessons would come through childhood cancer.

Our first and only child, Emma, became a St. Jude patient at 9 months old, after she was diagnosed with a cancerous brain tumor called ATRT, atypical teratoid rhabdoid tumor.

We had gone into her regular checkup thinking everything was alright. We'd never had a child before, so everything we were experiencing for the first time was normal to us. There was no big red flag. But when the doctor double-checked her growth percentiles, her head was larger than it should have been – from fluid buildup caused by the tumor, we would learn.

At the time that we caught it, in July 2021, it was way past catching it early.

Our baby needed brain surgery, but there was also the possibility she wouldn't make it to surgery. Our local children's hospital helped us make prints of her hands alongside our hands, in case we were taking home only mementos.

But Emma did make it to surgery, and surgeons were able to remove most of the tumor. She was then referred to St. Jude Children's Research Hospital® for cancer treatment.

Those first days, I was physically present, but mentally zombified. I was just trying to get my feet back underneath me. I felt like I had been knocked down, and it took days to get back up. But soon, we started to be flooded with the hope that comes from St. Jude.

Emma's treatment included chemotherapy, proton therapy and physical, occupational and speech therapies. She started improving.

There were moments where, as hard as it was to see our vulnerable little baby going through this, I was grateful that she was a baby. The older kids, the teens we meet at St. Jude, they're starting to have dreams and they're starting to go out and experience the world for themselves. They have aspirations, real things that they want to do that may be taken from them. With Emma, we could cuddle her, read her a book, play with her and make her happy.

And to be honest, I was grateful I didn't have to answer the question, "Why is this happening to me?" I have no idea how I would answer that question. I can only say that one of the biggest lessons of this experience has



been: You're in control of nothing. Only how you face what you have no control over is yours to decide.

Today, Emma's doing great. She's walking, talking, going down the playground slide, being a 3-year-old. The more confidence she gains, the more she tries, and the more she tries, the more she succeeds. Every time she does something new, the hope just goes through the roof again. And that's the most remarkable thing St. Jude has done for us.

But the second most remarkable thing is that, after Emma's yearlong treatment, we were able to just step right back into our life because St. Jude did not bill us for anything. I'm a young man. I have a young family. And I can tell you for certain, this would have been a financial struggle.

If not for St. Jude, I would have spent the rest of my life working extra to pay off medical debt, instead of spending time with my daughter. St. Jude was a life preserver in more ways than one. We have our daughter, and we still have the home we want to raise her in. If it wasn't for people's donations to St. Jude, we would have neither.

Another thing I learned from this experience is don't put it off. You think there's always another moment to do it later, or say it later, or live it later, but the truth is there may not be. Be present, right now. You can't take the future for granted.

But here's the other thing, the tricky thing: Have faith in the future anyway. I can't sit here and tell you for certain that I will walk my daughter down the aisle one day and deliver her into the next chapter of her life. I'm going to live my life like I will, but I'm going to treat each day with her like there's a possibility I won't be able to.

That's what this whole situation has done for me as a father. I will not waste a day.



You can help ensure more patients like Emma get to keep enjoying every day to the fullest.
stjude.org/ImpactGiving

Stronger than sickle cell disease

St. Jude is helping two siblings live their childhood to the fullest.

By **Ruma Kumar and Alban Zamora** - ALSAC

The first time Claudia heard of sickle cell disease, she was weeks away from giving birth to her first child, a son she would name Franser. Claudia said doctors told her blood tests showed her son was likely to be born with the genetic disorder.

Doctors told Claudia how the disease affects red blood cells, causing them to warp from healthy, round and plump to sickle or banana shapes. That distortion hinders those cells' ability to supply major organs with oxygen, leading to a host of lifelong health complications, including lung disease, heart disease, kidney

disease, stroke, frequent infections and pain crises.

But it was these words – there is no cure – that Claudia remembers most clearly.

"My whole world came crashing down around me," recalled Claudia.

Franser was born in 2016 with sickle cell disease as the doctors had predicted. The first two years of his life were the hardest, Claudia said, as fevers and rampant infections sent Franser frequently to emergency rooms.

Living in rural North Carolina at the time, Claudia also had a hard time finding clinics and doctors trained to treat those with sickle cell disease that could provide consistent care for Franser.

As this Honduran family struggled to cope with the debilitating impact of this genetic disorder, Dr. Mitchell Weiss, chair of the St. Jude

Department of Hematology, was assembling and growing a team of scientists and doctors at St. Jude Children's Research Hospital® to lead the next generation of work to better understand, treat and manage the myriad and lifelong effects of sickle cell disease.

He recruited top clinicians, bone marrow transplant experts and leaders in the field of gene expression to help develop new, more effective medicines and gene editing – key areas that represent a new era of hope for a cure to sickle cell disease.

St. Jude has been a leader in improving standards of care for people with sickle cell disease since its founding. The first grant the research hospital in Memphis ever received was for the study of sickle cell disease in 1958, and today, St. Jude has one of the largest sickle cell programs in the country, serving about 900 patients a year. St. Jude has been part of major advances in sickle cell disease treatment over the last 60 years and continues to explore new cutting-edge curative therapies for the disease.

When work opportunities led Claudia and her family to permanently resettle in Memphis in 2019, Claudia said she was relieved when a pediatrician referred her to St. Jude and told her about the sickle cell treatment program there.

Franser, who is 8, began going to St. Jude monthly for clinic visits to constantly monitor his health and symptoms. He was given medicine to take daily that helps control the sickling of red blood cells so that he has fewer side effects from the disease.

"My child already understands his condition and takes his medications dutifully," Claudia said. "He loves going to St. Jude because he knows

St. Jude mom Claudia was relieved when a pediatrician referred her to St. Jude and told her about the sickle cell treatment program there.



he will be able to play and receive so much love; he only gets a little nervous when they draw his blood.”

Two years ago, Claudia had a daughter, Kendall, who also was born with sickle cell disease. Now both siblings receive care from St. Jude.

“The most important thing for me is to see them grow, to see them play without fear and to know that I must be strong for them,” Claudia said.

Sickle cell research at St. Jude

Sickle cell disease is predominant among African Americans and those of African descent, but it is also common among those of South and Central American ancestry.

Claudia and her children were able to lean on research built

over more than half a century at St. Jude. “Sickle cell disease has disproportionately affected communities that are underserved and have been subjected to many inequalities,” said Dr. Clifford Takemoto, Chief of Clinical Hematology at St. Jude and Lemuel Diggs Endowed Chair in Sickle Cell Disease. He works closely with Dr. Weiss.

Inequities in healthcare among marginalized minority communities are something doctors at St. Jude recognized when the hospital opened in a segregated city as the first fully integrated children’s hospital in the South, and something they have worked to correct ever since.

It’s what motivated Takemoto to leave top research institutions and hospitals in Boston and Baltimore



The ultimate goal is that it could lead to cures with no risk and no side effects, which is perfect medicine, but that’s hard to attain right now.

– Mitchell Weiss, M.D., Ph.D.

and pursue work at St. Jude. “For someone like me who has spent my career caring for people with sickle cell disease, it is really a motivating factor because these communities deserve high quality comprehensive care. And unless you really fight for progress and for things that folks need, people will be forgotten,” Takemoto said.

The new generation of research and care centers around two key areas that offer promising steps toward a cure for patients with sickle cell disease: gene editing and bone marrow transplants, Takemoto said.

Sickle cell disease arises from the mutation of a single gene, and scientists are using new genetic engineering technology to find ways to correct that one error so that sickling of red blood cells doesn’t occur.

Results from a recent study led by St. Jude and the Broad Institute of MIT and Harvard showed the potential benefits of using gene editing to cure genetic anemias, but there is still much work to be done before it can move beyond research models in the lab to help patients in clinics.

“The ultimate goal is that it could lead to cures with no risk and no side effects, which is perfect medicine, but that’s hard to attain right now,” said Weiss.

St. Jude is involved with many clinical research studies to investigate a variety of treatments for sickle cell disease, including gene therapy and the use of medicines like hydroxyurea. This drug boosts the level of fetal hemoglobin. Studies have shown that patients with higher levels of this form of hemoglobin tend to have fewer symptoms of sickle cell disease.

St. Jude is also enhancing its bone marrow transplantation program to further improve outcomes for children with sickle cell disease. Although a bone marrow transplant is a potential cure for sickle cell disease, it is not an easy cure, and it has many complications. That is why St. Jude continues to research alternate approaches by creating new clinical trials, for instance, that improve the entire transplant process and identify ways to decrease transplant-related side effects in children. St. Jude also develops collaborative research partnerships with the National Institutes of Health and other institutions throughout the world.

“This is something that we couldn’t have done without the help of St. Jude and our donors, because bringing together expert researchers from across the country is expensive. St. Jude donor funds

are supporting this collaborative research, which advances progress more quickly than individual laboratories working in isolation,” Weiss said.

Franser and Kendall

Today, Franser loves spending time with his sister and his family. He also enjoys art class in school, particularly painting. Kendall is a rambunctious toddler.

“I am very happy with them. And I am trying to be a better mother every day so they can grow and become good people,” Claudia said. “I want them to respect their bodies and know that having sickle cell is a condition that they must learn to live with wherever they are.”

Kendall and Franser’s parents say they are deeply grateful for the health care and treatments the children have received at St. Jude.

“We want to thank all the people at St. Jude who keep supporting us,” Claudia said. “They should know that they are saving kids’ lives, like my two children, who are now stronger than this condition. I truly believe that one day, they will find the cure that will allow Kendall and Franser to live their lives without fear.”



You can help ensure families like Franser’s and Kendall’s 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



Rallying the team for Madelyn

Overcoming her cancer diagnosis took a strong team and St. Jude.

By **Betsy Taylor** - ALSAC

It all started with a text in March 2023 from Alyson Habetz to her childhood friend Duke.

They had grown up in the same small town in Louisiana and had attended high school together in the late 1980s. Duke knew Alyson could play baseball as good as any boy – or even better. They had been teammates, playing side by side. In that way that sports can do, the experience had bonded Alyson and Duke for life.

In March 2023, Alyson was finishing her 25-year career as assistant head coach of the University of Alabama women's softball team when she heard the news about Duke's daughter, Madelyn.

The 6-year-old was very sick and getting cancer treatment at St. Jude Children's Research Hospital®, so Alyson texted Duke to let him know she would be praying.

She asked him to tell Madelyn to watch the next game. Each time an Alabama player got a hit, she would do something special at first base to let Madelyn know: Coach loved her.

On game day, as Alyson greeted player after player after a hit, the camera panned to Alyson who tugged at her earlobe.

"I think this earlobe is a little longer now," said Alyson, "because I was pulling it the whole time."

Madelyn watched the game from her hospital room at St. Jude and was delighted.

Soon, the entire team was sending Madelyn messages of encouragement and her story became a featured part of the televised games.

It seemed like everyone was praying for Madelyn, which was good, her parents believed, because Madelyn needed all the prayers she could get.

A sick little girl

An ultrasound on March 9, 2023, revealed a tumor on her kidney that was double the size of the organ. More scans brought worse news: The cancer had spread to her lungs. Madelyn, at 6 years old, underwent a biopsy and spent three days recuperating in the ICU at a hospital near her home in Louisiana. She was referred to St. Jude where she became a patient. She wouldn't see home for another three-and-a-half months.

Trust in the team

Madelyn's team grew to include not only St. Jude, but all the members of the University of Alabama women's softball team, the coaches, their fans, the opposing teams. It grew to include anyone who happened to be watching TV when a game came on because there was Madelyn's story being told.

"The more prayers the better," said Duke.

As the players sent Madelyn best wishes by cell phone video, she was wishing them well, too. And a crazy thing happened – they couldn't stop winning.

Alyson believes it was because they were playing for something larger than themselves. They were playing for Madelyn.

As Madelyn received chemotherapy, the team tore its way through the Southeastern Conference (SEC), all the way to the Women's College World Series.

"When they did homeruns, those were the girls she was talking to on the phone and sending messages back and forth with, so she would get excited," said Duke. "We would all get excited."

Madelyn had a special connection with slugger Ashley Prange, whose jersey Madelyn wore during treatment.

After the team played in the SEC tournament in Arkansas, Ashley and Alyson skipped a flight home with the rest of the team and drove hours out of their way to go see Madelyn in Memphis.

Important scans

Six weeks after Madelyn began chemotherapy, she underwent her first set of scans since starting treatment.

"We hoped that the tumors in her lungs and in her kidneys hadn't increased," said Duke. "That way we could say, 'Hey, the chemo is working, and we can continue chemo.'"

Duke still gets emotional recounting the moment they learned the results: The main tumor had reduced significantly.

"And the spots in her lungs had gone from four to one," said Duke. "So, blessed is an understatement."

Three days later, Madelyn underwent a five-hour surgery during which

the surgeon removed her tumor, kidney, lymph nodes and part of a vein. Because some cancer was still present in her body, she received radiation and continued chemotherapy.

Madelyn was able to return home and receive her treatment from the St. Jude Baton Rouge Affiliate Clinic, with periodic trips to St. Jude for scans. She was reunited with her three older siblings.

More than a hundred vehicles, including police cars and fire trucks, filed by Madelyn's house to celebrate her homecoming.

School of life

Madelyn and her mom enter the high school gymnasium and climb the back stairs to the coaches' office. They're allowed to be here, but they still call it "sneaking in" because the aim is to avoid encountering anyone. They make a game of it.

A window overlooks the gym floor. They open it.

There's her 16-year-old sister, Annalise, down below with her cheerleading squad.

Madelyn's treatment has ended, but she's still in what her parents call a bubble of safety for a little while longer because of her compromised immunity.

She loves her sister's pep rallies, so they watch from a distance.

Madelyn, now 7, is being homeschooled this year, following along with the local elementary school's first grade curriculum so when the time comes to go back to school she'll be ready.

Madelyn messages regularly with the athletes of the University of Alabama women's softball team who've become her good friends.

Other than that, said Madelyn's mom, Alison, "We do a lot of baking," including creating cakes themed after Taylor Swift albums.

Madelyn dances around the house to Swift's music, singing along to every word.

"She's got pretty good energy," said Alison. "I mean, she's amazing."



Your donation helps ensure patients like Madelyn get to keep celebrating victories. Please consider giving an additional gift at stjude.org/ImpactGiving.

About the artist

Lilly formed an interest in art during a very difficult time, when her life was really just beginning.

She was diagnosed with acute myeloid leukemia at 4 years old. Worse still, hers was a rare subtype of this blood cancer that was more aggressive, more resistant to treatment and more likely to relapse. Undergoing high-dose chemotherapy at St. Jude, Lilly found that art helped fill the downtime. It became “kind of a coping mechanism,” she said. “However I was feeling I could put into my art.”

It was an outlet she would turn to again.

Lilly’s cancer came back in 2016. She returned to St. Jude, where she received chemotherapy, radiation therapy and a haploidentical (or half-matched) bone marrow transplant, a procedure St. Jude helped pioneer. She was able to return home cancer-free right before Christmas of that year. Now she visits St. Jude for regular checkups. Life has changed as cancer has receded into the background. But art has remained.

Lilly, who is now 14, believes the experience of living through childhood cancer twice has made her more able to focus on the positive. The ability to distill and interpret a complex or powerful moment or emotion or experience is, arguably, the essence of an artist.



“This is not a portrait of a specific person. It’s inspired by seeing beyond the normal and finding the unusual in the everyday.”



“My intent with this painting was to stretch my imagination even further.”



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St. Jude cancer survivor, **Mabry**, pictured above with her mom and brother
Art inspired by St. Jude cancer survivor **Tayde**



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Help for Chance

In 2021, Chance was constantly sick to his stomach. When he was rushed to the emergency room early one morning, scans revealed a large brain tumor.

He was diagnosed with metastatic medulloblastoma. Following surgery, he was referred to St. Jude Children's Research Hospital®, where he has received chemotherapy and proton therapy treatment.

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

“It’s like this marvelous gift, and I don’t know how you explain that to people,” his mom said. “I know people know you don’t get a medical bill, but there’s so much more. When you get this diagnosis and the love of your life has such impossible odds, the greatest gift anyone can give you is hope. And that’s what St. Jude has given us.”

You help bring hope and healing to patients like Chance 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