

ST. JUDE inspire



SPRING 2020



ALL for **ONE**

Coping with childhood cancer
the best way possible – together

By Design

the impact of
Paul Williams

Social Distance

a safe 'no more
chemo' celebration

Honoring Suzy

couple gives
back after loss

Digging In

studying survival
through data



Patients at St. Jude are treated to an inspiring sight when they gaze out the windows to the area between Chili's Care Center and the Kay Research and Care Center. An astounding 1.2 million sequins shimmer in the breeze as part of an installation that transforms a drab interior courtyard into a glittering work of art. Artists are submitting the 12,000-square-foot mosaic mural to Guinness World Records.





As you read this issue, I hope you and your families are safe and managing as best you can as we all navigate the health, economic and community impacts of the COVID-19 pandemic. Though it's a situation that changes daily I can assure you every precaution is being taken to protect the children under the care of St. Jude Children's Research Hospital.

Access to patient care areas is strictly regulated. Those working closest with patients are regularly screened for symptoms of the virus and tested by a test we rapidly developed and scaled at St. Jude.

Nearly all of ALSAC's employees, me included, and those not on the frontlines of patient care or conducting vital research at St. Jude have been restricted to home offices and kitchen tables for several weeks. We're not hosting visitors or supporters on campus. And we've cancelled or postponed fundraising events that require people to gather in close proximity, and moved many to virtual events. Fundraising is the lifeblood of our mission, and though it's been severely disrupted, we are thankful for all who are able to continue giving.

Through our forced separation it's become increasingly apparent we are forever deeply connected by what Danny Thomas started in Memphis decades ago. Connected by a common goal to end childhood cancer. Connected by a promise no family ever receives a bill for treatment, travel, housing or food because, even today while the world faces this unprecedented health threat, one truth remains – we believe all a family should worry about is helping their child live.

So, separately, we've come together. In patient rooms and clinics where our heroic care teams haven't wavered in their commitment to providing the best care anywhere while worrying about their own families. In the labs where important research continues. And, at ALSAC where we won't forget our financial promise to the kids and parents who need us now more than ever.

In these uncertain times, there is still St. Jude – thanks to you.

Richard C. Shadyac Jr.
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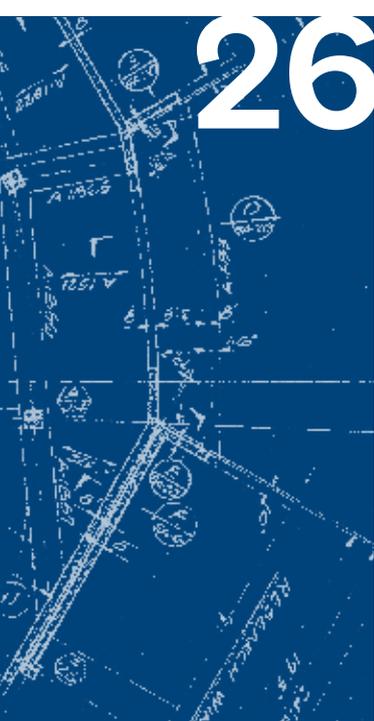
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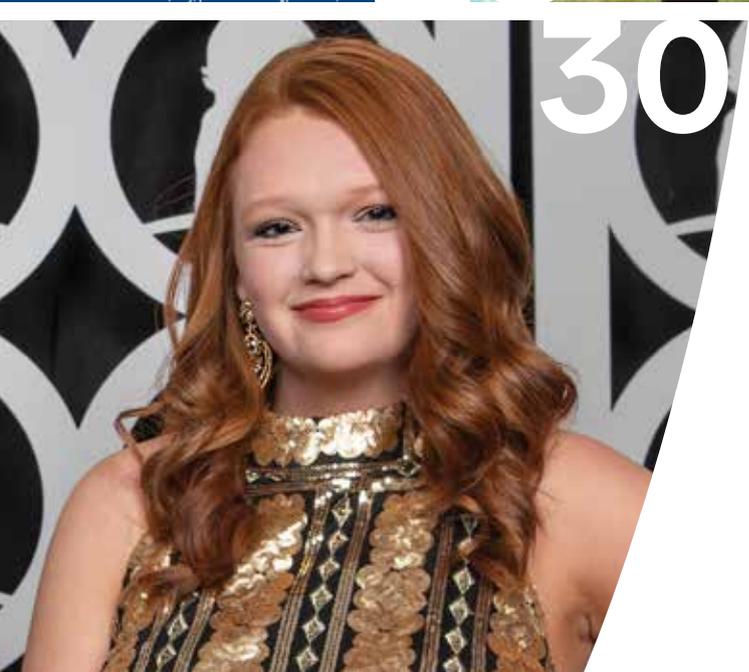
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Even in these challenging times, there is still St. Jude – thanks to you. You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate





family Strong

By David Williams and Kelly Cox • ALSAC

Moms and dads. Sons and daughters. Brothers and sisters. Step-siblings, too. Their powerful bonds are a crucial part of the healing process at St. Jude.

Javon can tell you about his years and years of treatment for acute lymphoblastic leukemia (ALL). He can tell you about his two relapses – including one that was discovered on the very day he was to finish chemotherapy.

He can tell you about his bone marrow transplant, after which he slept for days then woke up temporarily without his memory – asking his mom, as she hugged him, “Who are you?”

He can tell you about friends made and friends lost among his fellow patients, and the time he started

hiding his medicine because he was “sad and depressed,” but also because “those were some big ol’ pills.”

“But perhaps the most telling moment of this 19-year-old college student and St. Jude Children’s Research Hospital cancer survivor’s tale comes when he says, “Two years ago, I literally learned how to ride a bike.”

People laugh when he tells them. They naturally wonder: *How are you a teenager and just learned to ride a bike?*

That’s when he tells them about his childhood, the one he really didn’t have. The one cancer stole.

Imagine if nearly
all of your childhood
memories took place
in a hospital.

Imagine if your best
friends all had cancer.



That's when he tells them about his family, a source of love, strength and hope that carried him through – that carried them all through.

Little Sister

Jakayla, 13, can relate. She was a familiar sight in the halls of St. Jude as a patient sibling – Javon's little sister – before she, too, was diagnosed with ALL.

She can also tell you what it's like to relapse. She can tell you about her own bone marrow transplant. And she, like Javon, can tell you about the difficulty relating to schoolmates and others whose childhoods weren't marred by a catastrophic disease.

"I couldn't really tell people how I feel about having cancer," she says. "It's hard for people."

This is a girl, after all, who attended her St. Jude kindergarten graduation via Skype from the bone marrow transplant floor.

It helps, then, to have somebody close who really understands. Somebody who's been there, like a big brother.

Or a mother. Yes – her, too.

Mom and Her Babies

Some 25 years before Lisa was a mom with two children simultaneously undergoing chemotherapy for ALL, she was a St. Jude patient with the same disease.

She relapsed, too. She made dear friends only to lose them. And she remembers seeing other patients who had lost limbs, and asking her own mom, "Am I going to get my leg cut off, or my arm?"

She can tell you all that, and also how she coped, post-cancer:

"I just put it in the closet and never thought about it."

The strategy worked until it didn't. Until, she says, "my baby" was diagnosed.

That was Javon, in 2003, at age 2.

Five years later, 2-year-old Jakayla was diagnosed.

Mother. Son. Daughter.

In fact, the family's connection with ALL – and with St. Jude – is deeper still. Lisa had a relative who was successfully treated at St. Jude for ALL in the late



1990s, and another relative was an early 1960s ALL patient who did not survive.

The family's history spans nearly the history of St. Jude, from those early days when the survival rate for ALL was 4 percent. Today, it's 94 percent.

The Day Michelle Obama Visited St. Jude

What are your most vivid childhood memories? Ballgames and dance recitals? School days and beach vacations? Secrets shared with best friends?

Imagine if nearly all of your childhood memories took place in a hospital. Imagine if your best friends all had cancer.

That's especially the case for Javon, whose treatment was the longest and most fraught of the family. He didn't attend a traditional school until sixth grade; before that, he was educated at St. Jude, which has a K-12 school program.

"I made so many friends I lost count," Javon says of his St. Jude childhood. "We'd pretty much talk about everything" – from their low ANCs (absolute neutrophil count, a reflection of the body's ability to fight infections) to their next chemo treatments to why they had to wear face masks. "We'd pretty much talk about medical stuff at a very young age.

"But, at the same time, we were goofing around. Have you seen Power Rangers?

"We had a lot of fun."



“At one point, he stops himself. “Wow ... Now that I think about it, I’ve been through a lot as a child.”

Javon smiles – an unmistakable after-effect of all his years at St. Jude. So it is for the rest of the family. “We’ll laugh about it,” Lisa says. “We’ll basically talk about the good times we had.”

That’s by design at a research hospital where treatment allows kids to be kids, where laughter is medicine, too. St. Jude is doctors and nurses and therapists, but some of the latter play guitar and sing. St. Jude is transplants and proton therapy and clinical trials, but also school and teen formal and hanging out with celebrities.

“Oh, celebrities,” Lisa says – and there’s that family smile again.

The best was then-First Lady Michelle Obama, who visited St. Jude in 2014.

“She gave me some candy and cookies,” says Jakayla.

“My favorite, hands down,” Javon says. “She was so welcoming and nice. Oh, she was the best.”

For mom, it almost made up for her greatest missed opportunity – sleeping through a visit by St. Jude founder Danny Thomas during her own patient days in the mid-1980s.

“The Benadryl had knocked me out,” she says. “My mom even said he stood over me. And I’m like, ‘Wow. And why didn’t you wake me up?’”

They have the other kind of stories, too, of course. A happy hospital is still a hospital. When asked if he ever worried he might not survive, Javon tells this story:

“That moment was when I had my transplant. It was like a horror story, slash, a good story. I’ll never forget this night. It was thunder-storming so bad that the lights went out.

Then all the transplant patients like me were moved to the hallway. They had to almost postpone my transplant because the lights went out so bad.

“After the lights came back on, I had to go to my transplant. They had to put the cells into my Hickman line. The lights almost went right back off. I was panicking. My heart rate was going high. Everybody thought I was going into shock, and I was panicking so bad.”

After the transplant, Javon says he blacked out. In his admittedly exaggerated version of events, he was asleep for probably two weeks. “Completely normal sleep,” he says, “for two weeks.”

When he awoke, he didn’t recognize his mom, didn’t know where he was, and seemed to have forgotten he had cancer. He began to unhook and unscrew everything connected to him.

“I almost yanked on my Hickman line – almost,” he says of the tube through which patients receive chemotherapy and other drugs.

Javon says it was another week before “I caught up with my memory.”

There’s amazement in his voice as he speaks. He seems to marvel at his own stories, as if they must have happened to someone else entirely, or maybe to a character in a movie.

At one point, he stops himself. “Wow. I’ve been through hell and back. Now that I think about it, I’ve been through a lot as a child.”

Surviving Together, Thriving Together

Javon is a college freshman. He plays trombone in the marching band. Life is “awesome.”

Jakayla is an eighth-grader. She’s soft-spoken, but maybe she’d just rather sing than talk. “I’m in the school choir,” she says.

Lisa is a proud mom, though she makes no claim on the music her kids are putting out into the world. “I don’t know where they get it from,” she says. “They didn’t get it from me.”

They did get her strength and perseverance, it seems, and a sense of family that does not quit. They’re tight. You can tell by the way they interact, the way they talk about each other. Javon describes Jakayla as “a fun spirit, and she’s like a little diva.”



Javon, 11 years old and Jakayla, 6 years old in 2012

Lisa says of her daughter: “She’s more open now than she was. She’s more energetic now. The choir thing I never thought she’d be doing. She’s been in competition. We went to Florida, she sang in front of all those people. I never thought she would have done that. She’s started coming out more. She was very shy.”

Then there’s Javon’s bond with his mom. He calls her every day, though campus is just 20 miles from home. And so many of his stories involve her, like the one about relapsing just as chemotherapy was ending:

“Younger me thought I was going to go back to being a normal little boy,” Javon says. “I noticed my mom was crying, but I thought she was crying for joy. But she was trying to explain to me that I had relapsed.”

“Younger me was like, ‘I don’t care, Mama, I’m here with you.’ That’s what I remember saying – ‘I don’t care, Mama, I’m here with you.’”

They’re still here, all of them.

Lisa. Javon. Jakayla.

Mother. Son. Daughter.

A St. Jude success story, times three.

Even in these challenging times, there is still St. Jude – thanks to you. You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate





For the Love of Olivia

They were in the car, getting ready to leave. But first, they were doing what cancer families do – running through a checklist of medications, making sure they hadn't forgotten one. And from the backseat, Olivia, 3 at the time, said: "I didn't take my gabapentin."

"We didn't even know she knew that word," said Kacie, mom to Olivia and her twin brother Owen. Kacie

and her husband, Peter, laughed. It helps to laugh, even if the reason your little girl knows the name of gabapentin, a pain medication, is because she's being treated for acute lymphoblastic leukemia at St. Jude Children's Research Hospital. This is life after your child has been diagnosed. You're a cancer family, and each family member is uniquely affected.

Olivia

The once-shy girl has bonded with caregivers and blossomed into "this little, independent person," Kacie said.

Peter gave her age as "going on 30."

Olivia, now 4, is not just a model patient, she's a nurse in training.

"At St. Jude, they give you a port doll," Kacie said. "It's just this stuffed doll that has a pretend port in it to normalize the ports that the kids get. And they give you this kit that has a line in it and some basic stuff."

"Well, Olivia has taken that to the extreme. ... She has decided that she wants to be a line nurse already."

Owen

Owen had one speed: 90 miles per hour.

"Never met a stranger, into a lot. Very inquisitive and moving," Kacie said.

the Stepsisters' Story

Yet Olivia's St. Jude experience has changed Owen. He's learned to change gears and slow down, especially when it comes to his twin sister.

"He's definitely softer, more gentle," Kacie said. "And when we tell him, 'You can't do that,' he knows."

Peter

He's heart-on-the-sleeve emotional, hates hospitals, and said, "I just don't handle crisis well."

So imagine how Peter took the news of his daughter's leukemia.

A year later, though, Peter has proven to be stronger than he knew. He's embraced the positives, and said of St. Jude, "I don't even think of it as a hospital anymore."

Kacie

As a therapist, Kacie considers listening to other people's problems "a good escape."

Even so, she said Olivia's diagnosis was "absolutely terrifying," because "everything, our normal, had just been totally rocked."

Our normal.

That's the reality for a family whose child has cancer. But this family has a secret weapon. It's Olivia, who lives in the now and doesn't dwell on the difficult months ahead – but knows when treatment ends, there will be a big family trip to celebrate.

"She deserves it," Peter said.

They all do.

Watch and read more of Olivia's story at stjude.org/olivia

No one knowing that nearly a decade later, their easy bond would be deepened by circumstances not only unpredictable, but unthinkable. Unbelievable. At 13, these stepsisters would be diagnosed with cancer: the same type, in the same leg, just weeks apart.

An Ominous Dream

Olivia was at the splash pad with her father, Chad. Chad, divorced from Olivia's mom, Bobbie, had Olivia every other weekend and was dating Stacy, a single mother to Natalie and Noah. If it sounds confusing, it felt straightforward. "We immediately became a family of five," said Stacy.

Natalie and Olivia, relating it separately, recall their first meeting the same way.

"We met at a splash pad," said Olivia.

"She just came up to me and hugged me, and we started playing," said Natalie.

A pair of 4-year-old girls with long, brown hair, making instant friends at the park. Not yet knowing they would soon be stepsisters.



Stepsisters Olivia, left, with Natalie, right.

Chad and Stacy were married in October 2011, when the girls were 5, and although Olivia did not live with them full-time, the family dynamic was very blended. Even after Olivia moved away in the fifth grade, the girls still saw each other on alternate weekends, every other Thanksgiving, on Christmas Eve and for a few weeks each summer.

The summer of 2018 began the turning point for both families. From the very onset of Olivia's leg pain, Bobbie had doubts. The pediatrician favored a meniscal tear, but come the day of the MRI, said Bobbie, "I had already been preparing myself for this to not be just a meniscal tear because I'm a nurse, and I knew that she did not present with the symptoms of just having a meniscal tear."

And she wasn't the only one with concerns. On the way into the scan, Olivia looked at her and confessed, "Mom,

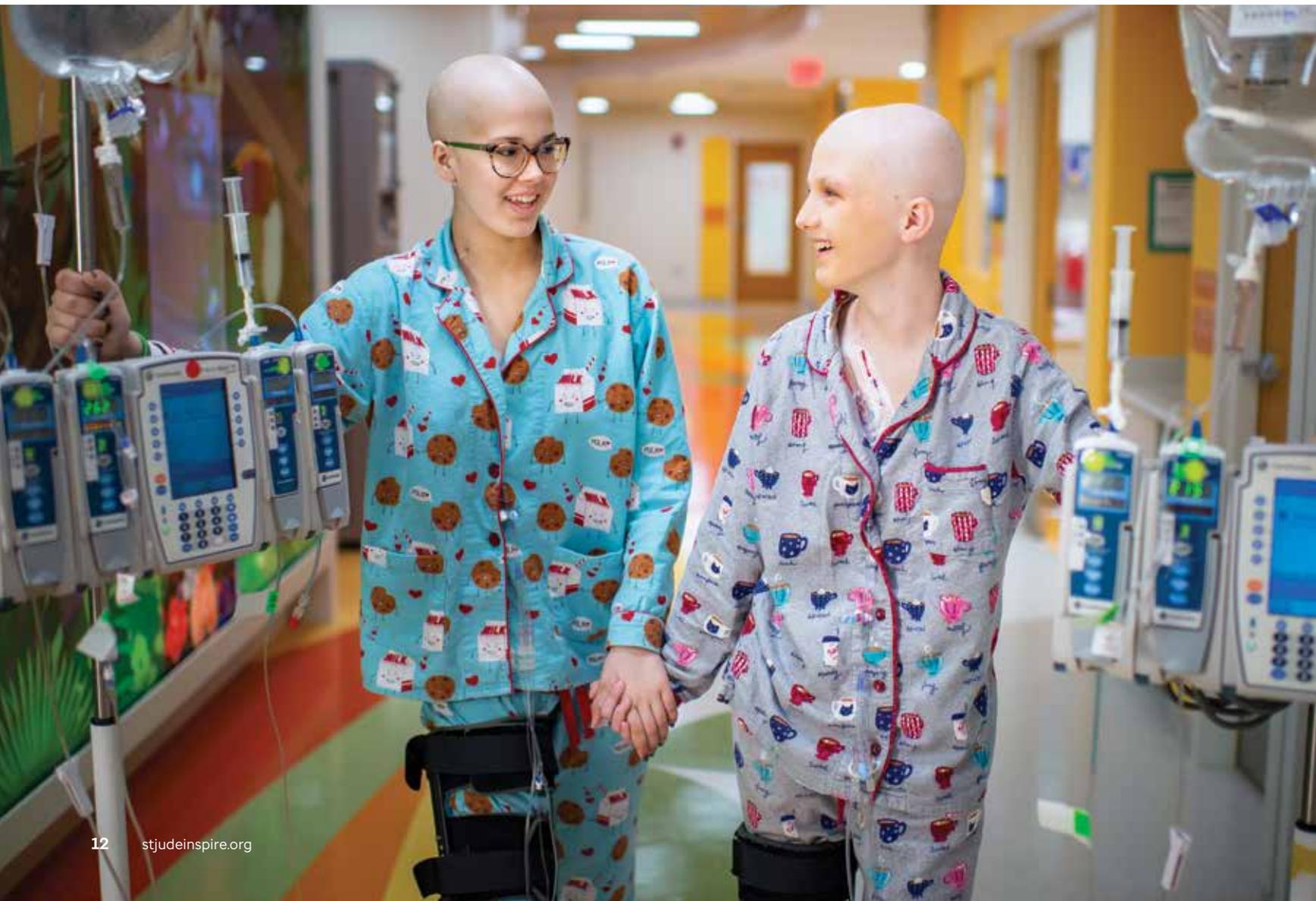
I dreamed last night that I had to have my leg cut off because this is cancer." Bobbie calmed her sobbing daughter, but it was a little like the cards had been tipped to show the hand. The look on the tech's face just sealed it. Their eerie feeling remained an unspoken fear until the phone call.

Olivia was immediately referred to St. Jude Children's Research Hospital and arrived the day after her scan, to an official diagnosis of osteosarcoma – bone cancer – and the first of many weeks of chemotherapy.

Taking No Chances

"Whenever I tell the story," said Bobbie, "it's hard for people to know how to react because they just can't believe it."

After about a month, Stacy and Chad arrived at St. Jude to relieve Bobbie, so she could travel home to see her



husband and three other children. And Stacy mentioned that her mom was taking Natalie for an MRI due to a knee injury at cheerleading. “With Olivia’s stuff going on, I didn’t want to take any chances,” she said.

Natalie’s MRI did not show the obvious malignancy of Olivia’s. It could possibly have been a bone infection. But the biopsy proved Natalie had osteosarcoma – same as Olivia – in her right tibia.

Back when Stacy got the call about Olivia, she’d thought, “This can’t be real.” Now, as she learned about Natalie, she thought, “How is this even possible? God would not do this to me, both of my girls.”

When Bobbie learned the news, she was determined that Natalie needed to be at St. Jude, too.

In a matter of days, she was.

Being There for Each Other

Natalie suffered more severe side effects than Olivia. Olivia was able to recover from chemo as an outpatient in St. Jude housing, but neutropenic fever landed Natalie inpatient again and again and again.

But, when both were outpatient, they came together as a different kind of blended family. Just the mothers and daughters, visiting one another’s St. Jude apartments for meals, movies, moral support. Moral support that involved very little discussion of cancer, actually. Whereas the girls were finding that friends back home were unsure how to interact with them, they knew they simply wanted to be treated normally.



“A lot of people at home almost consider me as a different person, but I’m the same person,” Natalie said.

Said Olivia, “It’s almost like they think you’re fragile, like glass, and if they say something the wrong way, it’s the end of the world.”

So, their time together during treatment was normalizing teen time. Thirteen-year-old girl time. Time to talk about make-up and Netflix.

For their part, Stacy and Bobbie had always had an amicable and collaborative relationship. Yet, when marriages dissolve, new spouses appear, and former spouses stay close – it would be most people’s definition of natural for there to be a certain distance, maybe a self-protective guard up.

I want to live a long life and a healthy life. I didn’t want to be sick, but I was sick, so I had to learn to live with it and learn to be happy with it. It took a while.

- Olivia

“That all just went out the window,” said Stacy. “Now, she’s probably one of my best friends.”

Said Bobbie, “You can’t pick who your exes marry, but I couldn’t have asked for somebody better for Olivia to have for a step-mom.”

Closer than Ever

The stepsisters have successfully finished treatment and have gone home cancer-free. And as much as the girls are the same people they were before, the fact is they were plucked from their regular lives and set on a new path.

Can it be surprising, then, that Olivia now gets excited about going to school? After being so sick for so long, the simple ability to do a thing makes doing it enjoyable. Natalie recently made meatloaf for her family’s dinner, something that had never crossed her mind to do before. She said, “I could do it, and I wanted to because I knew that I could.”

“I think Olivia appreciates everything a lot more now,” said Bobbie. “The way the sky looks, her little brother’s laugh, the way food tastes.”

These families hope their story, while jaw-dropping, will also be eye-opening. “People always say, ‘This is so weird,’” said Bobbie. “I’m, like, ‘Yeah. But you know, there’s more childhood cancer than anybody realizes.’”

Olivia’s family already had another move planned before any of this happened – a move that puts them just 30 minutes from Natalie’s house. Closer than ever, in more ways than the map can show.

Read more about stepsisters, Natalie and Olivia, at stjude.org/stepsisters

Second Chances

Walking hand-in-hand through St. Jude Children’s Research Hospital, Heather and her nephew Pepe forged a special bond – not just as family members, but as cancer patients.

“We’ll go to appointments together. We’ll support each other and walk down the hall,” said Heather.

She was diagnosed with a rare form of leukemia at 17, a time when her focus was on college entrance exams and other teenagers’ concerns. Pepe began treatment for neuroblastoma when he was just 6 months old. He practically grew up in St. Jude, where the hallways were his playground.

Both are cancer-free now, and their family, far from being bitter after dealing with two rare childhood diseases, considers St. Jude not just a blessing, but a second home.

“For me, St. Jude – my heart is there,” said Heather’s mom and Pepe’s grandmother, Sonia. “The truth is, if St. Jude didn’t exist, I don’t know what would have become of my family.”

Watch the four-part video series of how a family – after facing cancer twice – found a second home at St. Jude. stjude.org/pepe

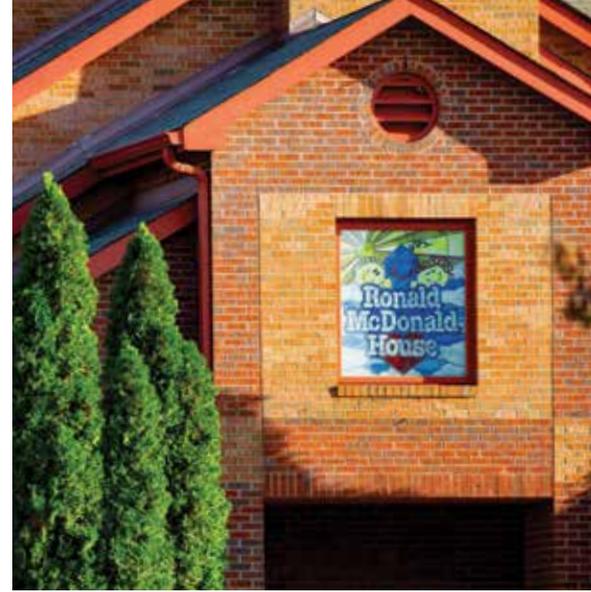


ST. JUDE
PARENTS
HONOR THEIR
DAUGHTER
THROUGH
WORK WITH
ST. JUDE

A HOUSE FULL OF HOPE

BY THOMAS CHARLIER · ALSAC

PLAYFUL VOICES OF CHILDREN ECHO IN THE BACKGROUND AS BARBARA AND JACK PAVLAT GUIDE A VISITOR THROUGH THE RONALD MCDONALD HOUSE IN MEMPHIS, A PLACE WHERE THE COUPLE'S INFLUENCE IS EVIDENT ALL THE WAY DOWN TO THE SLIM STRIPS OF PLASTIC PROTECTING WALL CORNERS.



"All these plastic corner pieces, I put all those up," said Jack, referring to one of his first projects at the facility that provides free lodging for patients and families at St. Jude Children's Research Hospital.

The Pavlats live in Virginia Beach, Virginia, but it's fair to say their home is just about any place connected to St. Jude. Places like the Ronald McDonald House. Year after year, they make the 14-and-a-half-hour drive to Memphis to manage the facility during the Christmas holidays, giving staff time to spend with their own families.

Then there are the events the Pavlats support. They have worked on St. Jude Dream Home® Giveaway campaigns from Virginia to Idaho and have often spoken to donor groups. They have served on the St. Jude Family Advisory Council and helped coordinate benefit events ranging from golf tournaments to motorcycle rallies to regattas. They have raised nearly \$100,000 through a team in the St. Jude Memphis Marathon.

So numerous are their support activities, in fact, that the Pavlats have trouble recalling them all.

"My wife and I were laughing about that this morning," Jack said. "We were trying to think of something we haven't done for St. Jude."

It all began with a burning need to keep busy.

"Working here (at the Ronald McDonald House) helped me keep my sanity while we were going through a hard time," Jack recalled.

He's referring to the long, wrenching period when his and Barbara's only child, Suzanne, or Suzy, as they sometimes called her, was undergoing treatment for a type of cancer known as neuroblastoma. She had been diagnosed at age 3 during the same week in 1993 that Jack underwent surgery for colon cancer and Barbara learned she had breast cancer.

Mom and dad were cured of their cancers, but Suzy was still battling hers in December 1999 when the family first stayed at the Ronald McDonald House during her treatment at St. Jude. The Pavlats later moved to Target House, which accommodates patient families for long-term stays at St. Jude.

At each place, the couple took turns staying with Suzy. While Barbara watched her during the day, Jack volunteered to perform chores and do odd jobs around the Ronald McDonald House, which at the time was undergoing expansion and renovation. "You can sit around in your room just watching your child

as they're sick," he said, "or you can get out and do something."

"When Suzanne had good days," Barbara added, "we would take her out to town to do something, thinking we were making memories for her. But really they were for us."

Suzy passed away in 2001 at age 11. But in the nearly two decades since, the Pavlats' work on behalf of St. Jude hasn't faltered. If anything, it's intensified.

That may seem surprising, since they're both 71 and Barbara is mostly confined to a wheelchair as a result of a long-ago surgery. The Pavlats trace their persistence, in part, to a promise made to their daughter.

"We were sitting at our kitchen table at Target House," Jack recalled. "She said, 'Daddy, if I die, will people remember me?' I said, 'Well, that'll be my job, won't it?' And she never asked me about death again."

Jack said he feels his daughter's presence every time he speaks to groups about St. Jude. "I know Suzy's there behind me, helping me."

So the couple will tell you that, yes, they're keeping the promise to their daughter. But there's a more urgent motivation for their St. Jude work.

"We want to see a cure," Jack said. "I don't want to see other parents

go through what my wife and I have gone through.”

He knows St. Jude needs resources to find cures. “It takes time, it takes doctors, it takes money,” Jack said. “Well, time and doctors they’ve got. They need the money, so I’m willing to work to raise money so that they find a cure, they make it so other parents don’t lose their children.”

The Pavlats also admire the guiding philosophy of St. Jude. “I like the idea that they provide the best medical care, and it’s not dictated by an insurance company what can and can’t happen. It’s dictated by the doctor,” Jack said.



WELL, TIME AND DOCTORS THEY’VE GOT. THEY NEED THE MONEY, SO I’M WILLING TO WORK TO RAISE MONEY SO THAT THEY FIND A CURE, THEY MAKE IT SO OTHER PARENTS DON’T LOSE THEIR CHILDREN.

The couple’s unflagging devotion has earned them honors from ALSAC, the fundraising and awareness organization for St. Jude, and the Ronald McDonald House, where they were the first parents to win the volunteer of the year award.

But they will tell you the work they do for St. Jude is anything but burdensome. At the Ronald McDonald House, for instance, the holidays seem festive for the Pavlats even though they’re working.

“Our house is empty. This house is full,” said Jack, while sitting with Barbara in the lobby. “We could sit in an empty house, or we could be in a full house. This house is full of children and things to do.”

To be sure, they stay busy. Jack handles chores that include fixing clogged sinks and toilets, while Barbara picks up misplaced items and helps her husband “put out fires,” she said. The couple also spend time answering questions and helping guests who have locked themselves out of their rooms.

Occasionally, the Pavlats have to shift into crisis-management mode, such as the time an overflowing washing machine caused a flood that collapsed the ceiling over the director’s office. Another year, they had to deal with a six-hour power outage.

A plaque on the door to the room across the hall from theirs offers a poignant reminder of why the Pavlats started working at the house. It pays homage to a former St. Jude patient who stayed there. A bright-eyed girl named Suzy.

Together, nothing is impossible. Find out how you can help at stjude.org/volunteer







Call it love and a little ingenuity in the time of COVID-19. Plans to celebrate 4-year-old Isabella's final chemotherapy treatment had to be halted, so family friends brought the party to Isabella and family. Parents and kids stood outside the St. Jude campus, in front of their decorated cars, and cheered from a safe distance as Isabella exclaimed, "It's all my friends!"

Read more about Isabella and other acts of kindness at stjude.org/isabella



St. Jude Children's Research Hospital, Memphis, Tennessee:

Treated in 1990-91 and 1999 for juvenile pilocytic astrocytoma, a non-cancerous brain tumor.

El Salvador:

(2007) Studied here during college, focusing on Spanish and cultural studies.

Dominican Republic:

(2008) Studied Spanish and culture while still in college.

FROM ST. JUDE TO THE WORLD

Sean Kenney was treated twice at St. Jude for a non-cancerous brain tumor, first in 1990 and again in 1999. Surgery to treat his tumor caused long-lasting side effects, and he had to learn to speak and even swallow again. He still suffers partial hearing loss and double vision, but he is a veteran world traveler and aid worker who has learned four languages.

Those close to him say they can trace the origins of Sean's current path to his St. Jude journey: how he drew from his own experiences to help others facing hardships, how the compassion shown to him during treatment magnified his own innate kindness, how his love of speaking foreign languages harkens to a time he struggled to speak at all.

"I get a lot of encouragement and energy from working with other people. It helps me put into perspective the struggles I have."

Read more about Sean's journey, from St. Jude patient to world traveler at stjude.org/seankenney

Gaza:

(2015) Fellowship training with the Catholic Relief Services to work on improving civic, economic and environmental conditions.

Jerusalem:

(2016) Further training with CRS to become a program manager working with local partners dealing with humanitarian crises.

Lebanon, Jordan, Cyprus:

(2016-2019) Managed a program that helped refugees from the Syrian civil war.

South Sudan:

(2019-present): Provides educational and psychosocial help to refugees fleeing unrest in neighboring Sudan, and South Sudanese residents displaced by civil war.

Tanzania:

(2010-2012) Worked with the Jesuit Volunteer Corps. He learned Kiswahili and tutored kids in mountain villages, then taught at a high school that he helped establish.



ST. JUDE LAUNCHES INFORMATION HUB ON KIDS WITH CANCER AND COVID-19

BY THOMAS CHARLIER · ALSAC

Recognizing the twofold threat the COVID-19 pandemic presents to kids with cancer, St. Jude Children's Research Hospital helped develop an online network enabling doctors around the world to track pediatric cancer patients who have been infected with the virus and share information on how to treat them.

The Global COVID-19 Observatory and Resource Center for Childhood Cancer, established in partnership between St. Jude and the International Society of Paediatric Oncology (SIOP), has three components: a registry for gathering data on infected cancer patients worldwide, educational resources and a community space for news, the sharing of experiences and information and discussion.

In discussing the need for the observatory, organizers said the pandemic poses a dual threat to childhood cancer patients. First, chemotherapy and other treatments can ravage kids' immune systems, leaving them especially vulnerable to infection. Secondly, measures to contain and minimize the spread of the virus can disrupt healthcare systems and limit access to care and the very therapies needed to overcome cancer.

"We are facing a global challenge like never before, and we need to articulate a response that brings together multiple organizations around the world," said Carlos Rodriguez-Galindo, M.D., director of St. Jude Global.

"Not only is this virus placing the lives of children with cancer at risk, but it is also disrupting the entire continuum of care. Access to care around the world is limited, and our international partners, like us, are focusing substantial hospital resources on fighting COVID-19."

The registry will be based on a reporting system using a secure, cloud-based platform to collect and store real-time data and analytics on infected pediatric cancer patients from institutions around the world. The patients will be "de-identified," or made anonymous,



The Global **COVID-19**
Observatory and Resource Center
for Childhood Cancer

to comply with the Health Insurance Portability and Accountability Act.

The success of the registry, organizers said, ultimately will depend on robust participation from health care providers globally. Professionals in the pediatric hematology and oncology community not only will have access to the data, but will receive regularly updated summary information about reported cases broken down by country and by method of treatment.

"We want to be able to capture all the cases of children with cancer affected by COVID-19 and let that inform our decision-making," said Professor Kathy Pritchard-Jones, SIOP president. "The registry is a high-level, first-pass effort to get the information quickly, because what we find out now can guide future interventions. With the data generated by the registry, we will be able to create an observatory to monitor the impact of COVID-19 on childhood cancer care and control."

The establishment of the registry and resource center comes two years after St. Jude launched a \$100 million initiative to improve and expand pediatric cancer care globally, especially in low- and medium-income countries where survival rates lag far behind those in affluent nations.

"Through St. Jude Global, we have started a new effort to coordinate knowledge-sharing for treating pediatric cancer patients who have COVID-19," said St. Jude President and CEO James R. Downing, M.D. "Development of COVID-19 is particularly worrisome because these patients have suppressed immune systems from cancer treatments. Our physicians organized this platform for collecting data, sharing clinical experiences, developing online seminars and workshops, and outlining best practices for treating children with cancer and COVID-19."

In addition to the registry, the observatory offers educational content for clinicians and forums on which they can discuss COVID-19 insights and treatments.

"There are lessons learned from countries where the pandemic peaked ahead of us," Rodriguez-Galindo said. "We've already held educational sessions with physicians and infectious diseases experts from Singapore, Japan, China and Russia."

Read more about this resource at
[covid19childhoodcancer.org](https://www.covid19childhoodcancer.org)

HOW DO YOU TACKLE A RARE CANCER?

By Alberto Pappo, M.D.

Director of the St. Jude Solid Tumor Division and co-leader of the Developmental Biology & Solid Tumor Program

All pediatric cancers are rare diseases as defined by the Rare Diseases Act of 2002. This law defined a rare disease as one that affects fewer than 200,000 people in the United States. However, among pediatric cancers, 11 percent qualify as the rarest of the rare. Some of these diseases are: thyroid cancer, testicular cancer, melanoma (skin cancer) and carcinomas like adrenocortical carcinoma or nasopharyngeal carcinoma.

Research on rare diseases is especially needed because these disorders are often poorly understood, there are few clinical trials and little incentive for companies to develop drugs for these diagnoses.

One of the most successful examples for the study of rare pediatric cancers has been the creation of the International Pediatric Adrenocortical Tumor Registry (IPACTR). This project is spearheaded by Raul Ribeiro, M.D., of St. Jude Oncology. With colleagues in Brazil, IPACTR facilitated research that identified various inherited mutations in the tumor suppressor gene *p53*. These findings led to the recommendation that young patients with adrenocortical carcinomas be screened for Li Fraumeni Syndrome. The hallmark of this inherited cancer predisposition disorder is a mutation in *p53*.

Another way to tackle rare pediatric cancers is by creating dedicated referral clinics. At St. Jude, I help lead our Melanoma Referral Clinic. While it is rare, melanomas make up 6 percent of all cancers that occur in adolescents 15-19 years old. Creating a dedicated clinic allowed us to offer more comprehensive multidisciplinary care, but it also allowed us to create a registry and tissue bank for research.

Melanoma in children can occur in three forms: conventional, congenital and spitzoid. Researchers have made great strides toward better understanding of spitzoid melanoma. This subtype is the most common form of pediatric melanoma.

Research at St. Jude has shown that *MAP3K8* mutations account for about one-third of this group – a finding that could only be made through the routine use of comprehensive sequencing, including whole genome sequencing since this gene is not found in current Food and Drug Administration approved genetic tests. Genetic analysis also helped our team determine that *TERT* promoter mutations can be used to predict a poor outcome in spitzoid melanomas. This test has now been incorporated in some centers as part of routine diagnostic evaluation.

Through research and clinical care it has become increasingly apparent that the same disease in adults can run an incredibly different course in pediatrics. In adults, gastrointestinal stromal tumor (GIST), is almost exclusively driven by mutations in *KIT/PDGFR*. A targeted therapy for these mutations, imatinib, has been approved for many years. In younger patients, imatinib is usually ineffective. Collaborative research has found that tumors in these patients are driven by defects in succinate dehydrogenase (SDH) an enzyme complex involved in metabolism. These tumors are now classified as SDH deficient.

Understanding the biology of rare pediatric cancers is the first step toward determining the best way to treat them. We have moved the needle against some rare pediatric cancers, but many are left to tackle. With the support of registries, tissue banks and dedicated clinics we can continue to make progress against these diseases.

This article originally published on the St. Jude Progress blog.

SURVIVORSHIP STUDIES

DIG IN ON DATA

By Kirsten Ness, PT, Ph.D., FAPTA

Epidemiology and Cancer Control,
St. Jude Children's Research Hospital

Childhood cancer may strike early in a person's life, but the effects of both the disease and its treatment can have an enduring influence. Although doctors have seen these effects in the clinic for many years, to really understand the challenges childhood cancer survivors face we need to conduct scientific research – we need data.

That is where the St. Jude Lifetime Cohort Study (St. Jude LIFE) and the Childhood Cancer Survivor Study (CCSS) come in. Both efforts have created resources for research by systematically collecting data on the health of childhood cancer survivors.

Through St. Jude LIFE, long-term childhood cancer survivors come back to St. Jude Children's Research Hospital for regular health screenings throughout their adult lives. To date, more than 5,000 participants and 580 control subjects have undergone comprehensive health evaluations through St. Jude LIFE. The study tracks a wide range of health outcomes, using measures of cardiac, reproductive, neuromuscular, neurocognitive and psychosocial function, among others.

The CCSS is a retrospective cohort of nearly 36,000 childhood cancer survivors and 5,000 siblings of survivors. The CCSS comprises 35 participating centers

in the U.S. and Canada. It is coordinated through St. Jude and supported by the National Cancer Institute and National Institutes of Health.

With these resources, my colleagues and I are able to follow the data to learn more about the health of childhood cancer survivors. Our recent published work shows that with increased understanding we can continue to optimize treatments and improve care throughout the lives of survivors.

CAN WHERE A SURVIVOR LIVES INFLUENCE OBESITY?

Where you live matters when it comes to health. This is called the neighborhood effect, and it reflects the characteristics of the neighborhood where someone lives and how that influences their health. Our team recently used data from St. Jude LIFE to look at the neighborhood effect on obesity in childhood cancer survivors. This included socioeconomic status, access to healthy food and availability of safe places to exercise.

The results are striking and indicate that where a survivor lives is associated with obesity. Thus, interventions for obesity in survivors should include strategies that take into account where they get their groceries and whether or not they have safe places to exercise.

“A better understanding of how neighborhood influences obesity in childhood cancer survivors can help us guide future obesity interventions,” said first author Carrie Howell, Ph.D., Epidemiology and Cancer Control.

A paper detailing this work was published in the *International Journal of Cancer*.

EXERCISE INTOLERANCE LINKED TO HEART FAILURE AND MORTALITY

While many children with cancer can be cured with modern therapies, treatment can affect heart health. Using data from St. Jude LIFE, we studied the relationship between treatments that impact the heart and exercise intolerance (inability or decreased ability to perform physical exercise) in childhood cancer survivors.

“Our results showed that survivors in their 30s had exercise intolerance at rates similar to rates in the general population of individuals in their 60s and 70s,” said senior author Greg Armstrong, M.D., of Epidemiology and Cancer Control.

The reduced exercise tolerance was associated with increased risk for mortality. Understanding how exercise is affected by cancer treatments is important for guiding the care of survivors.

Fortunately, exercise intolerance can be improved with exercise, even in persons with chronic disease.

This work was published in the *Journal of Clinical Oncology*.

FRAILTY AMONG CHILDHOOD CANCER SURVIVORS COMPARED TO THEIR SIBLINGS

Low energy expenditure, exhaustion, walking limitations, weakness and low lean muscle mass are what constitute frailty in older adults. Using data from the CCSS we looked at the prevalence

THE DATA HIGHLIGHTS



The number of centers in the U.S. and Canada that are participating in the CCSS



Socioeconomic status, access to healthy food and availability of safe places to exercise are important factors in determining obesity



Childhood cancer survivors are three times more likely than siblings to have frailty



Improving survivors' physical fitness may boost their thinking and learning skills

and predictors of frailty among childhood cancer survivors of at least five years, compared with siblings who did not have cancer.

We found that childhood cancer survivors are three times more likely than siblings to have frailty. Survivors in their 30s had frailty rates similar to older adults. In particular, survivors exposed to certain types of radiation and lung surgery treatments had an increased risk of developing frailty.

“Interventions to prevent, delay, or address chronic disease and promote healthy lifestyles are needed to decrease the prevalence of frailty and preserve function among childhood cancer survivors,” said first author Samah Hayek, Ph.D., of Epidemiology and Cancer Control.

The Journal of Clinical Oncology published a report on this work.

EXERCISE MAY GIVE THE BRAIN A BOOST

Childhood cancer survivors are more likely to have limited ability to exercise. Yet, physical activity can have a positive effect on cognitive ability.

We led a study to better understand the relationship between exercise and cognitive ability using data gathered through St. Jude LIFE. We tested 341 childhood leukemia survivors and 288 control subjects and found that improving cancer survivors' physical fitness may boost their thinking and learning skills.

“Even minor changes like going from sitting to walking for 30 minutes can have an effect,” explained first author Nicholas Phillips, M.D., Ph.D., of Epidemiology and Cancer Control.

This work appeared in the journal *Cancer*.

This article originally published on the St. Jude Progress blog.

Paul Williams, a friend of Danny Thomas who made his name designing homes for celebrities, donated the star-shaped design for St. Jude Children's Research Hospital.

Architect of the Star

BY THOMAS CHARLIER · ALSAC



He styled a Mid-Century Modern bachelor's abode for Frank Sinatra that enthralled a national audience during a televised tour. For Lucille Ball and Desi Arnaz, he designed a Palm Springs weekend home that epitomized sleek, glass-walled elegance.

But Paul Revere Williams had something simpler, more functional in mind when he drew plans for the original St. Jude Children's Research Hospital.

For this project, the so-called architect to the stars sketched a star.

With five wings radiating like spokes from a central hub, the first St. Jude building served thousands of patients during the research hospital's formative period. It accommodated

groundbreaking research that produced the first major advances in treating leukemia and other previously incurable childhood diseases.

That star-shaped building, to be sure, lacked the grandeur and renown of other designs by the architect. However, noting the vital, lifesaving work conducted within the walls of St. Jude, Williams would later call the project the most satisfying of his highly acclaimed career.

The satisfaction was nothing if not reciprocal. Among all the contributions that transformed St. Jude from a quixotic dream into concrete-and-steel reality, few were as significant as the one made by the brilliant, yet humble African-American architect who donated his services to help his friend and St. Jude founder Danny Thomas get the research hospital built.

He was born in California in 1894 and devoted most of his career to projects along the West Coast, but Williams' ties to Memphis ran deep. His parents hailed from the city, where his father served as a waiter at the old Peabody Hotel.

Orphaned by age 4, Williams studied architecture in art schools and college, eventually opening his own office and becoming the first African-American member of the American Institute of Architects.

The architect was able to transcend racial barriers that forced him to accept lower fees than his white counterparts and then build an unusually successful and long-lived practice.

Williams might not have come to Memphis were it not for Thomas, one of his famous Hollywood clients.

A March 1954 article in *Jet* magazine reported that Williams would donate his services in designing St. Jude, which would be open to people of all races and creeds. The architect submitted several renderings for use in fundraising, including one in the shape of a star that, to Thomas, evoked the symbol of St. Jude Thaddeus, the patron saint of hopeless causes and the inspiration for the hospital.

Thomas was delighted. "Some people call this a nice coincidence," he said at the time. "I call it the hand of God pushing Williams' pencil."

A hub-and-spoke design especially made sense for a children's hospital, given that the traditional methods of treating sick kids involved sunlight and fresh air.



The final blueprints showed the hub housing the outpatient department, staff offices, record rooms, blood bank, admitting office, medical library, assembly rooms for meetings, schoolrooms for kids in treatment, and administrative offices. The various wings contained inpatient rooms for 38 children, dining and kitchen facilities, as well as X-ray equipment, clinical labs and research offices.

The research hospital that Williams designed opened February 4, 1962, having cost about \$3.5 million to construct and \$2.5 million to equip. During dedication ceremonies that day, Thomas mentioned Williams' involvement as an example of the race-blind, multicultural mission of St. Jude.

Williams retired in 1973 and died in 1980 at age 85. Thomas – the longtime friend with whom Williams shared a dream to help children – delivered a eulogy at his funeral.

Nearly four decades after Williams' death, the AIA named him the first African-American recipient of its Gold Medal.

The original hospital building stood for 30 years, falling to demolition crews in 1992 to make way for the new Patient Care Center. A plaque in the research hospital pays homage to the original St. Jude designer, "This building is dedicated to the Glory of God in memory of architect Paul Williams."

Read more stories
about the history and
legacy of St. Jude at
stjude.org/legacystories





“ST. JUDE IS A HOSPITAL WHERE THEY SAY, ‘WE BELIEVE YOU AS PARENTS.’”

COMPASSION CRUSADER



How one St. Jude mom is helping nurses and doctors deal with burnout

By Betsy Taylor · ALSAC

Transformed by her experience as a St. Jude mom, Jessica is on a mission to educate others in healthcare about what it's like to have a family member with a life-threatening illness.

When Jessica's daughter Zoe underwent surgery at her local children's hospital to remove a brain tumor, the Wisconsin mom and life-long nurse found herself unprepared for life after treatment.

"I think they assumed because I'm a nurse and my partner is a physician that I would be prepared and know a lot more. But things change when you're the parent. Her tumor comes with life-long complications and side effects. We weren't ready."

The medical care Zoe received was sound, but Jessica perceived something was lacking. There were too many times Jessica had to ask a question before she got an answer that would have been important to know. And too many times she felt her words were disregarded by medical professionals who seemed a little preoccupied, no doubt because of their heavy patient load.

Jessica recognized herself in these nurses – because she had experienced compassion fatigue in her own career.

The experience lit a fire under Jessica, who went back to nursing school for her Ph.D. Drawing from her own family's experiences, she began giving presentations to other healthcare professionals about empathy and compassion fatigue.



Far left: When Zoe was diagnosed with a brain tumor in 2014, her mom, Jessica, knew she needed to explain things in a way her younger daughter, Olivia, could comprehend. She invented a story of a ladybug who had taken up residence in Zoe's brain and needed to come out. The story demystified something scary and helped Olivia, who was 3 at the time, understand her sister's treatment.

Far right: Zoe and her family work on a craft project together. Craft sessions like these act as mini-therapy sessions for Zoe, helping to retrain her brain and form new connections.

When Zoe's tumor came back in 2018, Jessica sought a referral to St. Jude Children's Research Hospital. As Zoe underwent proton beam radiation therapy at St. Jude, Jessica witnessed an approach to patient care that seemed centered on the sentence: "How are you?"

"St. Jude is a hospital where they say, 'We believe you as parents,'" Jessica said. "Her doctor, the nurse practitioner, Child Life, the social worker – everyone stops in when you're there in clinic. Everybody asks, 'How are you doing? Are you okay? Do you need anything? Do you have any questions?'"

The inquisitiveness wasn't just a form of kindness, Jessica realized, but a way of ensuring no aspect of Zoe's care got neglected. "Everyone does this little mini assessment, no matter what their discipline is,

just to make sure that you're not in need or something is missing."

It was a Eureka moment. "As a nurse, that really resonated with me," Jessica said. "I thought, 'That's what I see that's missing from healthcare, that leads to these gaps in care.'" And she realized she needed to update her presentations for her fellow healthcare professionals.

Today, Jessica has a new career as the director of compassionate care at one of the largest managed healthcare companies in the U.S. She's a compassion crusader, thanks to St. Jude.

Read more from St. Jude parents at stjude.org/perspectives

Singing with country superstar Brad Paisley has put St. Jude survivor Addie Pratt on a national stage. She's using it as a platform to help others.

ALIVE & SINGING

BY DAVID WILLIAMS · ALSAC

REHEARSALS FOR THE NETWORK TV SPECIAL

had ended, but Addie Pratt lingered on the stage to let it all sink in.

"I just sang with Brad Paisley," she said.

For a Mississippi college freshman just three years removed from treatment for acute myeloid leukemia (AML) at St. Jude Children's Research Hospital, it was a moment to marvel over. She was performing with one of country music's biggest acts, on a bill with the likes of Carrie Underwood, Kelsea Ballerini, Hootie & The Blowfish, the Jonas Brothers and Peyton Manning.

But Brad, so taken with Addie's voice and spirit that he'd invite her into the studio to sing on his St. Jude-inspired single "Alive Right Now," was marveling, too.

"Better," he said, "than Brad Paisley."

'I WANT TO SING'

On stage with a country superstar, in a TV performance seen by 6.3 million people – Addie sure was a long way from the Haute Pig.

(continued on page 32)







RAISING VOICES, LIFTING HEARTS

When the members of Lady Antebellum were about to visit St. Jude Children's Research Hospital for the first time, more than a decade ago, Hillary Scott remembers having "some nerves."

"I remember I picked out this bright pink shirt that I wanted to wear," she said. "Bright pink, because I was like, 'I want to go in happy.'"

"And what I didn't realize is that the happy came from everybody I met. All the patients and just the staff and the incredible people who were there, and the joy that fills that place."

If that first visit was a learning experience for the superstar country trio, the years since have shown this to be a band with a deep sense of purpose for a cause they hold dear. Scott and Lady A bandmates Dave Haywood and Charles Kelley were honored with the Randy Owen Angels Among Us Award, recognizing a decade-plus of devotion to St. Jude at the annual Country Cares Seminar.

That's the Mississippi barbecue joint where she made her public singing debut as a very persistent 3-year-old. The family was there having dinner. Two guys with guitars, the hired entertainment, were performing. And little Addie decided she wanted to sing.

"She just kept on – 'I want to sing, I want to sing,'" said Kim, Addie's mom. "So she did. She got up with her little red curly hair, marched herself over there, told them she wanted to sing, in the microphone. And she sang 'You Are My Sunshine.'"

Addie's been singing ever since – from her car seat in her dad's truck, a 4-year-old belting out Toby Keith's "I Love This Bar" on the way to daycare, to the privacy of a schoolroom closet at St. Jude, a 15-year-old cancer patient asking her teacher, "You want to hear a song I wrote?"

Addie doesn't usually get nervous before she sings – she's usually having too much fun, doing something that's as natural to her as breathing. But that day at St. Jude was different. The song was one she'd written during treatment. It's a song about faith, hope and perseverance; it's the sound of a girl who has "come too far to end up letting go."

So she and her teacher huddled in a closet, and Addie sang "I Hold On" – the first time she'd performed it for anyone.

Three years later, she was singing on stage, and in the studio, with Brad Paisley, one of St. Jude's biggest supporters in a country music community that's raised more than \$850 million through the *Country Cares for St. Jude Kids*® program.

He sings the bridge:

***I've met angels and survivors
That twenty years ago there'd
be nothing they could do
But thanks to places like St. Jude***

And then Addie joins him on the chorus:

***It's great to be alive right now
By the grace of God somehow
No one knows how long a time
But guess what? You're alive
right now***

"You hear it and you think, 'Oh, what artist is that? What major-label artist is singing with him on that?'" said Paisley, who was joined by Addie for a surprise reprise of "Alive Right Now" at the St. Jude *Country Cares Seminar*, an annual gathering of artists and representatives of hundreds of country radio stations.

"When I sing the words 'It's great to be alive right now,' that's one thing. But hearing them from you?" he said, turning to Addie in a pre-show interview. "She said it in a way that I can't say it."

As Paisley introduced the song on stage, he said, "There's a lot of great things about being on this planet right now. Don't lose sight of that. The greatest example, I think, of what humankind is capable of is this hospital."

"And when you're going to sing about being happy to be alive in these times, who better to do that than someone who has been through St. Jude and back again."

When Addie joined Paisley on stage, and in song, the crowd in the packed ballroom erupted. She rose to the moment again, her voice soaring above the ovations.

Read more of
Addie's story at
stjude.org/addie



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St. Jude patient **Brianna**
rhabdomyosarcoma
pictured with her mom

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Life Lessons in a Texas Garage

What does a garage in Texas – and the lessons learned there – have to do with cancer treatment more than 10 years ago? Everything, it seems.

Cole's father, Nathan, says his son's treatment experience turned him into a "better dad." Cole learned from his dad there's no such thing as a lost cause. With hard work and dedication, maybe a little faith, you can return a thing you love to its former glory, and then some.

So who's teaching whom?

Watch and read more about Cole, his father and the pickup truck that binds the two together today.

stjude.org/cole



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