

ST. JUDE



inspire

SUMMER 2023

Dear Diary:

My child has cancer

Rinoa's mother
chronicles lifesaving
treatment at St. Jude

Kayla's independence

Cancer didn't temper
St. Jude patient's free spirit

Stella's strides

When support for St. Jude
becomes personal

Game time

Grandmother uses online
gaming to benefit St. Jude



Addie's Inspiration

St. Jude patient Addie Pratt performed her debut single, "The Woman That I Am," at Ryman Auditorium in Nashville earlier this year. The song is an affirmation of her cancer journey at St. Jude and how it made her who she is today.

The performance was at the annual Bobby Bones Million Dollar Show, which has raised \$22 million for St. Jude since 2014. Addie was diagnosed with acute myeloid leukemia in 2016 while a freshman in high school. She graduated from the University of Mississippi and is pursuing a career in country music.



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



Writing is cathartic. It's meditative. For Kary, that meant keeping an online journal when her daughter, Rinoa, was diagnosed with medulloblastoma, a brain tumor.

My poor baby is bruised up and down her arms with some scars from all the pokes, she wrote.

Cycle 2 isn't going well. We didn't get much sleep last night.

And this devastating entry: *What do you tell your child with cancer when they ask, "Am I going to die soon?"*

Sentiments, concerns and fears all too familiar for moms and dads watching over their children in the darkest hours of their lives.

In this issue of St. Jude Inspire, you'll be walked through Rinoa's journey on the stepstones of words many of us may never have to utter.

You'll also get to know Hudson in a moving, first-person account of brain tumor treatment and, ultimately, recovery, penned by his mom, Abbey.

These are stories that couldn't be told – lives that wouldn't have been saved – without our generous donors and volunteers.

As St. Jude researchers and clinicians race to solve the problem of cancers without answers and the multi-year, multi-trillion-dollar problem of childhood cancer around the world, we are so grateful for you and all you do.

Thanks to your support, St. Jude seeks to rewrite the healthcare outcomes for children around the globe, and to help parents like Kary and Abbey answer some of the hardest questions they'll ever have to face.

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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/hope

—a mother's— EMBRACE

St. Jude mom Abbey recounts her son Hudson's journey through cancer treatment at St. Jude.

When I look back on it, I knew something was off. But I never thought it was brain cancer.

It was 2021, my son Hudson was throwing up off and on. We kept him home thinking it was a stomach bug and considered ourselves lucky when the rest of us didn't get sick with it. He was also tired all the time.

Then one Sunday morning as we were getting ready for church, we noticed his eyes were crossed. At first, I thought he was being goofy. Hudson can be silly like that. But when his eyes were still off later that evening, we decided to take him to the doctor the next day.

The doctor said to take him to the nearby children's hospital for a CT scan and MRI. We drove there feeling a little silly, honestly, because at this point we thought our kid probably just needed glasses.

We got the test results several hours later. As the doctors walked us out to

a different room to discuss the scans, my heart just sank.

I heard them tell us, "We found something on his brain," and honestly after that, I don't remember anything. I just feel like I went out of my body. Our world was shaken.

Hudson was admitted that night and had surgery the next morning to get the tumor removed. The tumor itself was 4 centimeters big. The doctors in Michigan determined it was medulloblastoma, the most common cancerous brain tumor in children, and thankfully it hadn't spread to his spine.

They were able to get the entire tumor out. He was in the hospital for about 10 days after that for recovery. It's all a blur, but the next thing after surgery was to consider where to go for radiation and chemotherapy.

My husband, Max, was immediately researching our next steps.

Our doctors in Michigan, who referred us to St. Jude, said the research hospital in Memphis had a proven track record of treating kids with medulloblastoma and finding new and better ways to treat it.

At St. Jude, doctors confirmed Hudson had Group 4 medulloblastoma, which carries intermediate risk. He received six weeks of radiation and four rounds of chemotherapy.

I stayed with Hudson in Memphis while my husband stayed in Michigan with the other two kids, who visited on weekends when they could.

You have these pictures in your head of what you think this huge children's hospital will feel like. And St. Jude just goes above and beyond that. It starts to feel like home.

Hudson got his last chemotherapy treatment in January. The doctors and nurses cheered him on with a party and special song, which was sweet. But Hudson has been sensitive to noise and attention since his surgery and treatment, so he didn't really celebrate. I wrapped him in my arms as tightly as I could to help him feel safe and calm.

As a 5-year-old, he's still having a hard time understanding and processing everything he's been through.



Hudson is re-learning himself. He used to be a naturally athletic kid, riding a two-wheeler bike when he was 3 years old and willing to eat just about anything. Now, he's really picky about food and doesn't eat much.

The surgery and treatment have left him unsteady on his feet, but he's getting stronger every day. He doesn't like change and prefers to stay at home. So now we give him extra time to get comfortable with leaving home and going to the park, for example.

We are on a slow and delicate return to normal, and we have St. Jude to thank for that.



You can help ensure families like Hudson's 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/hope

Kayla is INDEPENDENT and ready to fly

By **Linda A. Moore** - ALSAC

As a toddler, Kayla took off her diaper, handed it to her mother and asked for big girl underwear. She pushed away the bottle, wanting to drink from a cup instead. She wanted to dress herself, even tie her own shoes.

“She was just a really, really fast learner and she wanted to do it herself,” Kayla’s mom, Myestia, said.

At just 4, Kayla visited her godmother, a five-hour drive from her home, and from her anxious mom in Tennessee. Myestia called to check on Kayla, expecting her daughter to be anxious, too.

Instead, “Lady K,” as her godmother called her, was just fine without mom and happily stayed the entire summer without complaint.

Kayla didn’t cry on her first day of school, happily trooping into her classroom. In first grade at her Christian school, Kayla memorized Bible verses and led her classmates in reciting scriptures.

Myestia could imagine the kind of person Kayla would grow up to be. Independent. In charge. Ready to take on the world.

Then, in 2012, at the start of second grade, 7-year-old Kayla began complaining about headaches and stomach pain. Myestia worried what happened next would change who her daughter was meant to be.

After a family outing, Kayla came home, sick with a high fever. Myestia rushed her to the emergency room of their local children’s hospital. An X-ray showed an enlarged spleen and liver. When they drew blood, Kayla wouldn’t stop bleeding.

That was the first time Myestia heard that dreaded word – cancer.

I was like, ‘Oh, my God. They just said my baby was going to die,’” Myestia said.

Kayla was referred to St. Jude Children’s Research Hospital and was on campus by 2:30 the next morning. At St. Jude, Kayla was diagnosed with acute lymphoblastic leukemia, the most common form of childhood cancer.

“I just remember trying not to cry in her presence,” Myestia said.

Showing fear was not an option. Action was.



Myestia educated herself about her daughter’s cancer and worked with the child life specialists at St. Jude to help Kayla understand it. They then helped her young friends understand that Kayla’s cancer was not contagious.

Myestia, a middle school English language arts teacher, learned to clean the central line in Kayla’s chest, while taking care of her 3-year-old and 1-year-old. And she was there for comfort and support when Kayla began to lose her shoulder-length hair during chemotherapy.

With Kayla losing her hair one braid at a time, Myestia decided to just shave her baby’s head.

“I told her it would grow back prettier than ever,” she said. It did.

Even in treatment, Kayla stayed true to herself. She wanted to learn and never stopped asking questions. Kayla explained cancer the best way she could to her 3-year-old sister, showing her the central line in her chest.

Kayla was in treatment until April 2015 and is now cancer-free. For the recent high school graduate, her time at St. Jude helped shape her personality.

“Because without them, honestly, I wouldn’t think I would be as nice as I am and understanding and caring and mature. I really thank them for how I’ve grown up,” said Kayla.

Kayla picked up her independent ways right where she left off. At 13, when her mom wouldn’t pay for an expensive cell phone, Kayla found a way. She bought candy and chips to sell to her school mates.

When she hit her \$1,000 goal, Kayla shut down the candy store and paid cash for the phone.

At 16, Kayla was a trainer at the fast-food restaurant where she works. By 17, she was in management training.

She sees in her future a possible degree in business, an esthetician license, owning her own salon and one or more fast-food outlets.

Even with so much going on, Kayla always finds time in her crowded schedule to celebrate St. Jude.

“Because without (St. Jude), honestly, I wouldn’t think I would be as nice as I am and understanding and caring and mature. I really thank them for how I’ve grown up.”

– Kayla

“I love to speak about St. Jude and tell about my story,” Kayla said. “For me, it’s a second home. I enjoy the fact that I can go there and see people that I’ve grown up with and see their parents and their siblings and understand that this is our community. Our family. This is our safe place.”

Despite her cancer, St. Jude gave her so many once-in-a-lifetime experiences. She has met professional athletes and gospel recording artists and hosted red-carpet gospel awards events.

When she was 9, Kayla met former First Lady Michelle Obama.

“She actually came and sat at the table with us and talked to us and

had a real conversation with us,” Kayla said. “I really enjoyed it.”

For the mother and daughter, their faith in God and the support of their church family got them through those trying times and continue to keep them going.

“She’s really doing well. I’m proud of her and the strides she’s making,” Myestia said.

Her family has moved back to Louisiana. Kayla gets scans now just once a year. Myestia has known for years about St. Jude, its mission and its promise. Families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

Before Kayla’s diagnosis, Myestia oversaw a fundraising drive for St. Jude at her school. Now, after starting their own St. Jude journey, they will be forever grateful to all the donors who made it all possible.

It is inevitable that children grow up and leave the nest. And it would be understandable that a mother who helped her child beat back cancer would want to hold on as long as she could.

But not Myestia.

She is ready to watch Kayla soar.

“I think the whole purpose of parenting is to prepare and then release,” Myestia said. “I’m honored to be able to say I’ve done as much as I can. Fly.”



Kayla hopes to be an entrepreneur one day. You can help other St. Jude patients dream for the future, too. Visit stjude.org/hope to make a gift.

MY CHILD HAS CANCER

Mother's online diary chronicles Rinoa's treatment at St. Jude

By **Linda A. Moore** - ALSAC

What do you tell your child with cancer when they ask, "Am I going to die soon?" Kary wrote in her online journal in August 2022.

The question wasn't new; she'd heard it before. Kary's 10-year-old daughter, Rinoa, had a brain tumor.

August 25, 2022

Today she asked me this again. Probably the third time and I never know what

to say. I just hug her and tell her we're killing the cancer. I hate this so much.

Kary chronicles the ups and downs of the family's cancer journey in regular social media posts. The posts keep friends and family, here and overseas, updated on Rinoa's treatments and progress. For Kary, the posts serve as an online journal that helps her sort her thoughts and express her fears. And on this day, her precious daughter was at St. Jude Children's Research Hospital instead of at home playing with her brother and sister.



“It hit me pretty hard,” Kary recalled. “I tried not to cry. I just told her they were doing everything they can. I know you’re supposed to say ‘no,’ but I told her we’re here (at St. Jude) so that doesn’t happen.”

It’s frank talk for a kid, but real talk. Despite the progress in cancer treatment and advances made at St. Jude, one in five children in the U.S. who are diagnosed with cancer will not survive. Little kids don’t understand what’s going on. A 10-year-old like Rinoa knows.

July 22, 2022

How it began: Rinoa suffered from extreme headaches and vomiting and was referred for an MRI by her physician.

At first, doctors thought she had migraines. After an MRI, Rinoa was rushed to a children’s hospital about four hours away from their tiny North Carolina hometown, population 1,600. Rinoa had a mass in her brain. Over the next 24 hours, she’d have a drain inserted in her brain and undergo surgery.

She was diagnosed there with medulloblastoma, a cancerous brain tumor.

Kary doesn’t really remember getting that heart-wrenching news. “Apparently, I completely shut down. That’s what my sister-in-law told me,” Kary said.

Her husband, Wayan, was standing outside in the rain on the telephone. “I heard from my sister-in-law because my wife couldn’t talk,” Wayan said.

His employer let him join Rinoa and Kary, but the restaurant chef couldn’t stay. He had to work and had two younger children to care for.

After her brain surgery, Rinoa needed proton therapy, and was referred to St. Jude, which is home to the world’s first proton therapy center solely for children.

Oddly enough, just weeks before, Kary had started a St. Jude video

gaming fundraising challenge. She didn’t know anyone who had been treated at St. Jude before Rinoa, but for years she had known about the hospital’s mission to cure childhood cancer. She wanted to help.

“I’ve always donated to St. Jude when I could, even as a teen,” Kary said. “I just thought it was so sad that kids got cancer, too, and wanted to help cure them.”

Her little girl’s referral to St. Jude brought a sense of hope.

“I was happy. That was the only thing that made it all feel a little bit better. Because I knew that St. Jude was the best place she could go,” Kary said. “I was like, ‘Yes, yes, yes, please send her there.’”

July 25, 2022

IV number.... I’ve lost count. My poor baby is bruised up and down her arms with some scars from all the pokes.

Pokes and pain – these are things you can’t do anything about, other than to keep up a brave face.

“Some days, as soon as she was sleeping, I was crying nonstop while she slept. It was just like a roller coaster,” Kary said.

Kary hid her tears, but Rinoa didn’t hide from Kary. Once a port was surgically implanted in her chest, there were far fewer needle pokes. Treatment stole Rinoa’s silky, dark hair and left her tired and nauseous. But there were good days, too, when Rinoa would go outside to blow bubbles or attend classes at the St. Jude Imagine Academy by Chili’s.

By September, with radiation over, Rinoa and her mom were ready to go home to North Carolina for a few weeks before chemotherapy began.

It was good to be back with the family for at least a little while. But they hadn’t left cancer behind.

Chemotherapy started as soon as they returned to St. Jude in October.

November 11, 2022

Cycle 2 isn’t going well. We didn’t get much sleep last night. She was

up puking a lot and now has horrible stomach cramps and diarrhea. Plus she has a headache.

Days after this post, while on a video call with her dad and younger sister, Rinoa burst into tears. With her family so far away, the sound of her young sister’s laughter, which should have cheered her up, instead brought her down.

Tears were a constant for a while, as Kary helped Rinoa through their unpredictable days. One day she’d feel fine, the next there were headaches that made her cry and more nausea. Rinoa might spike a

fever or suddenly have low blood pressure.

She’d feel great one minute and nauseated and debilitated the next.

Oddly enough, sushi, her favorite comfort food, became an acceptable breakfast option for her queasy stomach.

At Christmas, Rinoa and her mother celebrated at St. Jude while her dad, brother and sister celebrated at home. She didn’t ask for anything special and her pile of gifts included squishy stuffed animals, games and a dollhouse.

Rinoa shares a laugh with St. Jude school program teacher, Michaela Shurden.



“I knew that St. Jude was the best place she could go.”

– Kary, Rinoa’s mother



“I’m happy and glad because I don’t have my tumor anymore.”

– Rinoa

Rinoa is quiet, like her mom. She’s a caring kid who wants the best for everyone.

“She’s the sweetest person ever. And is always happy and trying to put a smile on everyone’s face,” Kary said. “She has the best imagination and is super artistic and just an overall great person.”

Her art was one of the first things Rinoa resumed after brain surgery and whenever she’s feeling better. She’s known for the little creatures she draws. One has been reproduced on a T-shirt to raise awareness about childhood cancer.

January 30, 2023
Rinoa has no evidence of active disease. I’ve never felt happier hearing a single sentence in my life....

With those words, “no evidence of active disease,” Rinoa’s months-

long stay at St. Jude was coming to an end.

Grateful goodbyes were followed by a long road trip home. They’ll return for scans later in the year and Kary is hoping the entire family can come with them.

“I’m happy and glad because I don’t have my tumor anymore,” Rinoa said.

Now, the child who for months was so tired that she was asleep by 8 p.m., stays up past midnight to read and play video games. She’s getting stronger, regaining her appetite and is eating more. She’s in fifth grade, but not well enough yet to attend school in person. She’s taking virtual classes.

Rinoa reads her mom’s social media posts now and loves to see the comments of support and encouragement from family and

friends. Kary doesn’t try to hide much from her, just her tears and the sad prognosis for some of the children they’ve met at St. Jude, like those who go into hospice care.

Last fall during their only visit home, Rinoa was too weak to lift her 2-year-old sister. Now, if she struggles, it’s because her baby sister is growing up healthy and strong. And now when she hears her sister laugh, Rinoa laughs, too.



Your gift can help ensure patients like Rinoa get to enjoy more laughs with their families.
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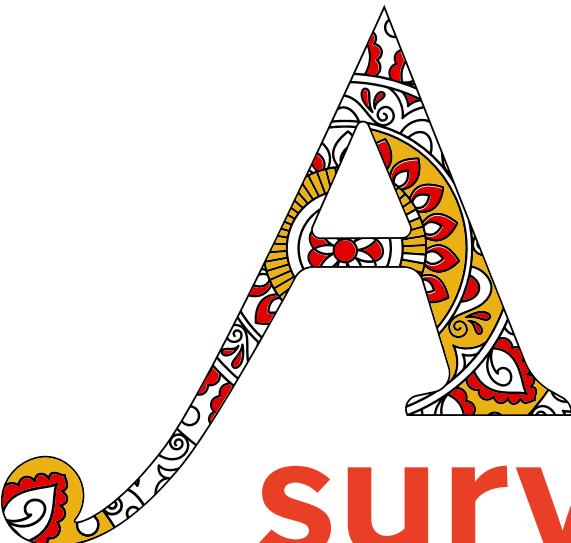
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survivor's mission

Poonam Bagai's charity to 'look after every kid with cancer in India.'

By **Kristina Goetz** - ALSAC

When Poonam Bagai talks about her deal with God, she casts herself as a nautanki, a drama queen of Bollywood films, beseeching the Almighty.

"Dear God, let me survive," she says with considerable flair. "I promise I'll go back to India. I'll figure out a way to reach every child with cancer."

In 2000, Bagai was diagnosed with colon cancer at age 38. She had two boys, 7 and 3.

"I can die, and what do I have to show for my life?" she remembered thinking.

For nine months, she worried every procedure would be the last.

"I pledged that if I could live, if I could survive, then I promise I'll go back to India, and I'll look after every kid with cancer in India," she said. "That way, I could know that I survived for a reason."

Bagai hadn't lived in India for years. She'd been on a five-year leave as a civil service officer from the Indian government, living all over the world — London, Bangkok, Moscow, Warsaw — with her then-husband who worked in international banking. She'd worked as a bureaucrat and a United Nations consultant.

In truth, she had everything, but no idea what poor people whose children had cancer might need. Still, she was undeterred. And once she was cancer-free, Bagai told her husband they were moving back to India — not to Korea for his next assignment. "I promised," she told him. "I have to do this."

Little knowledge, plenty of guts
Bagai started by going to All India Institute of Medical Sciences, in New Delhi, which has comprehensive facilities for teaching, research and medical care. That's where she met Sonal Sharma, a woman whose daughter had cancer about the same time as Bagai.

The pair forged a friendship and co-founded CanKids KidsCan in 2004, whose mission is to enable the best treatment, care and support of children with cancer in India.

The organization is one of the foundations that has recently joined the St. Jude Global Alliance - a global network that brings together institutions and foundations dedicated to the shared vision of increasing access to quality care and improving survival rates for children with cancer and other catastrophic diseases, with a specific focus on low- and middle-income countries.

For the first decade, CanKids provided social support services, home-away-from-homes through a network of hospital partnerships and an overarching support program called YANA — You are Not Alone. Then, they partnered with state governments. And finally, they began to empower patients and families to use their voices in a country where there is centuries-old gender bias, stigma and fear surrounding disease.

Bagai recalled a mother whose daughter had cancer and whose arm already had been amputated.

"Her cancer was not curing, right?" Bagai said. "She wasn't palliative. She wasn't terminally ill, but it was a long haul. And the husband had abandoned his wife. And she would keep asking me, in fact: 'Can you tell the doctor to tell me there's no further treatment so I can

go home? It's too hard. And what will I do with her even if she survives? How will I ever get her married? How will I teach her to be independent? What a hard life I will leave her to have."

Gender inequity is one of the reasons CanKids started the Girl Brigades, to empower female cancer survivors to raise awareness that childhood cancer is curable — and that girls are worth saving.

Sitara Khan, deputy manager at CanKids, is a member of the Girl Brigades. She was 12 when she was diagnosed with rhabdomyosarcoma. People in Khan's community and her own extended family told her parents they shouldn't waste money on her treatment, that it would benefit the family more if Khan didn't survive.

But her parents refused to listen. Khan's father sold his family land to

pay for her treatment until CanKids stepped in to cover the costs.

"It was very heartbreaking," Khan said. "But my parents, especially my father, never gave up on me. He continued my treatment, and here you can see" — she smiled — "I'm here." Khan has a bright future and hopes one day to buy back her father's land. CanKids has given her purpose.

"My aim of my life is I will go to those people who thought cancer was incurable and make them understand that a beautiful life is waiting for their children, whether boy or girl," she said.

A big milestone, but more miles to go
Since those early days, CanKids has grown to partner with 125 hospitals in 53 cities and 22 of the 28 states in India. These days, the gaps CanKids addresses are broad

reaching: diagnostics, drug therapies, nutrition, hygiene and housing support for patient families, and palliative care. CanKids also provides trained manpower for hospitals — for nurses, psychologists, social workers, dieticians, patient navigators and teachers.

But there's so much more work to be done.

"We still have a very long way to go," Bagai said. "We want to reach the WHO Global Initiative on Childhood Cancer target of 60 percent survival by 2030, and that, to us, means 100 percent access to care."

But they're making progress. CanKids is working with ALSAC, the fundraising and awareness organization for St. Jude, on fundraising best practices so the organization can identify and treat more children.

"St. Jude Global changed everything for the whole world when it comes to childhood cancer," she said.

Bagai has reason to take heart.

Though CanKids hasn't yet reached every child with cancer in India, in 2019, the organization did mark a milestone: It helped a child with cancer in every state in India.

"I think I have fulfilled my pledge, but I don't think God thinks so as yet."

It is estimated that more than 400,000 children worldwide develop cancer every year, and nearly half of them are never diagnosed. In many low- and middle-income countries, 4 in 5 children won't survive cancer, due largely to the lack of access to quality care. St. Jude Children's Research Hospital believes children all over the world deserve the same chance at survival and is working with healthcare institutions and foundations across the globe to help make that dream a reality.

Akriti Chauhan (from front to back), Assistant Manager, Poonam Bagai, Chairman and Founder, Sonal Sharma, Co-Founder, and Sitara Khan, Deputy Manager, pose for a photo outside CanKids KidsCan. Chauhan and Khan are both childhood cancer survivors that returned to work for CanKids.



St. Jude gives
kids with cancer
the chance
they deserve



St. Jude patient
Keegan

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PROMISING
RESEARCH



St. Jude mission still
resonates for researcher
after 20 years

Michael Dyer, PhD, is the Chair of the Developmental Neurobiology Department at St. Jude and Co-Leader for the Developmental Biology & Solid Tumor Program. After more than 20 years at St. Jude, he says he is “more excited now than ever” about the prospect of a major breakthrough for pediatric solid tumor patients.

Here’s more about the work he leads in his lab at St. Jude and how it is translating to better outcomes for children with cancer.

Q: How did you get into research and the field of developmental neurobiology?

A: When I was an undergraduate at UCLA, I was actually pre-med. I was planning to go to medical school. I took the MCATs. I was an EMT, but I was also working in a laboratory. And it was during that time that I really fell in love with the laboratory research.

So, I changed my whole career path, and decided to go to graduate school instead. I got a PhD at Harvard University, and then went on and did my postdoctoral fellowship at Harvard Medical School. And during that time, I studied developmental biology, really trying to understand how each organ in the body is formed during development. And then I was recruited to St. Jude because of my expertise in developmental neurobiology.

Q: Why did you decide to work at St. Jude?

A: Three things that really jumped out at me when I first visited (in 2001). The first is the amazing resources. Because of all the donors and all the support we have here, we can really tackle the difficult questions that are hard to do elsewhere.

The second was the collaborative culture. It just really struck me how everybody works together, and since being here now for 20 years, I've come to appreciate that my science is a lot better because of all my colleagues.

And then the final piece is the mission, being able to see our basic research in the laboratory translate into clinical trials. Meeting those patients, the doctors, and seeing that have an impact. That combination of resources, culture and mission really doesn't exist anywhere else.

Q: In your research, what's something you're most proud of in the last 20 years?

A: Seeing the work in developmental biology translate to clinical trials and improving outcomes. Looking back, it's amazing to hear those stories from

the doctors that treat patients about how the laboratory research has helped. I can now say I know a teenager who had Ewing sarcoma and he survived, went home and got to go to college. Those are the stories that really keep you pushing harder and harder every single day to continue to improve outcomes.

Q: Can you describe your field of study and why it's so critical to the treatment of patients?

A: I work in the Department of Developmental Neurobiology. My field of study is really about human development and trying

“The donors really make it possible for us to push the technical and conceptual innovations that allow us to really tackle the hard questions.”

– Michael Dyer, PhD

to understand how each organ in our body forms during development, and childhood cancer is a disease of development gone awry. So, by understanding how it's supposed to work and then understanding what goes wrong in childhood cancer, we can do a better job of finding vulnerabilities in the cancer and exploiting those to kill the tumor cells without damaging the normal tissues.

Q: Why is the support of donors so important to the work you do at St. Jude?

A: The donors really make it possible for us to push the technical and conceptual innovations that allow us to really tackle the hard questions. These are the questions that people thought couldn't be answered before. That funding and that support from the donors make that possible.

Q: After 20 years, you still seem so excited about your work here at St. Jude. What keeps you so motivated?

A: When I first came, my clinical colleagues would tell me, Mike, the thing you need to focus on is recurrent disease in pediatric solid

tumor patients. When a child goes home, sometimes for some of those patients, several months later, the cancer comes back. And they told me that this is so challenging because it's much harder to treat. Survival rates drop below 30 percent for recurrent disease. And we knew almost nothing about it 20 years ago.

We got our first clue 10 years ago from the Pediatric Cancer Genome Project. And through that work, we came to understand that with chemotherapy, 99 percent of the tumor cells will go away. But there's that 1 percent of tumor cells that survive treatment. We knew it was happening. We just didn't know what was special about the 1 percent that allowed them to survive. And now over the past 10 years, we've been able to dig into that question and identify those cells. We grow them in the lab now.

We're now really aggressively trying to find treatments that can kill that 1 percent.

And so my dream going forward, the thing that keeps me coming every morning, first thing is being able to not only kill the 99 percent of cancer cells, but that 1 percent that survives. And so I've never been more optimistic about the chance of doing that and having a major breakthrough for children with solid tumors.

Q: What's something St. Jude has taught you in your time here?

A: I think one of the most valuable lessons to learn from St. Jude is the power of working together, putting self-interest aside for the greater good. These are tough, tough problems, right? There are difficult challenges. We have to work collectively to tackle those.



Your gifts can help researchers like Dr. Dyer continue their lifesaving work. stjude.org/hope

Special bond between

STELLA & BELLA



When Stella became a St. Jude patient, Becki became more than a supporter.

By **Linda A. Moore** - ALSAC

The first time Stella ran in the St. Jude Memphis Marathon® Weekend, she and her grandmother, Becki, joyfully tackled the one-mile St. Jude Kids Marathon.

Stella was 6 and Becki (Bella to her grandkids) was “ecstatic” that her oldest grandchild was running with her. “I just asked her. I thought it would be a great thing to do,” Becki said.

She explained to Stella that the race raised money for St. Jude Children’s Research Hospital.

“I told her about why we ran for St. Jude, that it took care of so many families and saved so many lives because of the work and research they do there,” Becki said. “And it’s the right thing to do.”

Stella was pumped by the energy and the excitement she felt the first time she ran on the hospital campus. Patients and their families were cheering and encouraging the runners, even while they themselves were undergoing treatment.

“It’s so cool running through it. It’s sad that people have to be there during holidays and have to stay overnight there, but it’s also kind



of cool seeing kids and giving kids high-fives,” Stella said.

Two years later, Stella went from St. Jude supporter to St. Jude patient.

‘Weird spot’

Neither Stella’s mom, Scarlett, nor Stella’s dad, Chris, had noticed the “weird spot” on Stella’s upper

thigh. Stella asked her mom about it one night after her bath.

The spot, an indentation about the size of a quarter, wasn’t discolored or bruised. Still, it was worrisome enough to warrant a trip to the doctor.

Their pediatrician sent them to a pediatric surgeon, who

“What (St. Jude) found with me can help someone else.”

- Stella

recommended an out-patient procedure to remove it, Scarlett said. It turned out to be a noncancerous tumor.

But in an examination ahead of the surgery, the anesthesiologist found a lump in Stella’s neck that was about the size of a golf ball, Scarlett said.

“She asked me how long she’d had it. I felt like the worse mom ever,” Scarlett said.

Stella, then 8 years old, was diagnosed with papillary thyroid carcinoma, a cancer of the thyroid gland. She was referred to St. Jude. And that’s when Becki, already a longtime supporter, got a new designation as well, as a St. Jude grandparent.

“When Scarlett called, our worlds just crashed hearing the news,” Becki said, recalling that telephone call from her daughter.

Becki had run the half marathon since 2010 and supported local St. Jude fundraising efforts in her community in Mississippi. But now, it was personal.



St. Jude patient Stella undergoes a scan during one of her regular quarterly check-up appointments in January 2023.

After Stella’s diagnosis, continuing that support “was a no-brainer,” Becki said.

“We’ve had several families in our area where I live who have had children at St. Jude. I’ve always known of St. Jude,” she said. “But it hit home, and I had to do more. I still need to do more.”

Stella’s treatment included multiple surgeries and

chemotherapy. She is still in treatment and is back at St. Jude quarterly for scans and other tests, her mom said.

For now, Stella is living “a very normal, fun, healthy, happy teenage life,” Scarlett said.

And Stella appreciates that whatever doctors learn while treating her will help children into the future and all over the world.

not because they pity the children there with cancer.

“People think like, ‘Oh my gosh, I cannot imagine being in that situation. It would kill me for my child to be in that situation.’ That is the narrative that when I’m talking to people, I try to change. It is difficult. It is hard. I wouldn’t wish this on anyone.

“But St. Jude is a happy place. Donate money to St. Jude, not because you feel sorry for kids with cancer. Donate because the families that get to go there are having the best experience that you could possibly imagine for a family living with a child with cancer. The hospital provides the most loving, warm, hopeful, joyful environment.

“And that’s what I want people to support, ensuring that families after us get to continue having this experience that we get to have there. It’s not doom and gloom, it is hope and joy and warmth.”

and individual donations, Scarlett said.

“It’s not hard to sell St. Jude. People know what it is, who they are, what their mission is. And whether they shell out a dollar or \$100, it all goes to the kids and keeping that research going. It’s not a hard sell at all,” Becki said.

Scarlett wants people to continue to support the work at St. Jude and



You can help ensure kids like Stella keep running.
Donate today at
stjude.org/hope

Supporting the mission

Retired professor's love of St. Jude tied to memory of high school sweetheart.

By **Yolanda Jones** - ALSAC

For nearly 30 years, Marie Conn has given monthly to St. Jude Children's Research Hospital through the Partners in Hope program.

When asked about her steadfast loyalty to the lifesaving mission of St. Jude, she often repeated her go-to response: her love of children.

But it was not until the retired educator was honored for her continuous commitment to St. Jude it triggered a precious and painful memory.

"My high school sweetheart, Jimmy, died of brain cancer. It was February 1961 of our senior year," Conn recalled. "We didn't even get to go to the prom, and I have carried this with me – all these years."

She said she didn't connect this memory of her high school boyfriend with her giving as a Partner in Hope until she was asked at that St. Jude awards event about the reason behind her giving.

"I think about Jimmy over the years, but as I got older and learned about St. Jude, I began to think about what he and his family faced," she recalled. "I think this played a big part in my decision to become a Partner in Hope."

The monthly giving option appealed to Conn because it was simple to plan through her budget and it also kept her connected to the St. Jude mission.

Like many other Partners in Hope, Conn loves to know how her support helps ensure families never receive

a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

"St. Jude is a place of generosity and progress," she said. "It is such a pleasure for me to visit St. Jude and see the many great and wonderful things there to help families. St. Jude doesn't miss a trick to make the families comfortable."

She saw this firsthand when, during a tour, she noticed the unique design of the registration area where young patients and families check in.

"The size of the furniture was at just the right height for children, so the child feels part of the conversation," she said. "St. Jude is set up for the entire family from the furniture to the painted walls. They have thought of everything, and that is why I love St. Jude."

A retired religious studies professor from Chestnut Hill College in Philadelphia, Conn spends her days doing The New York Times' crossword puzzle and watching documentaries and murder mysteries on PBS.

Conn is nationally certified in bereavement counseling and education. Since the pandemic, she has been able to work with people dealing with grief through online counseling sessions.

“

St. Jude is a place of generosity and progress.

– Marie Conn



Conn marveled at the progress she had noticed since her previous visit, and was grateful to know the impact supporters like her have helped make possible.

"Where there was a hole in the ground, now that is where the proton therapy center is installed," Conn said. "I have seen the building of things and the extension of campus. I feel so lucky to have seen all of this over the years."

That is why, in addition to her Partners in Hope support, Conn also has left St. Jude in her estate plans. She wants to ensure her legacy can continue to help children and families relying on St. Jude for hope and healing.

Conn still thinks of Jimmy, after all these years. And she is grateful to be a part of a mission that has helped raise the overall childhood cancer survival rate in the U.S. from 20 percent in 1962 to more than 80 percent today.

"Jimmy died in February 1961 and St. Jude opened in February 1962," she said. "He didn't get a chance to come to St. Jude, but my hope is that they reach Danny Thomas' goal that no child dies of cancer, not just here in this country, but universally. That is my hope."



You can join Marie Conn in supporting the St. Jude mission. stjude.org/hope

STREAMING for St. Jude

TacticalGramma's video game antics inspire others to help, too.

By **Betsy Taylor and Larry Morales** - ALSAC

One by one, Michelle Statham, who is known in the video gaming world as TacticalGramma, greets the guests who join her Facebook livestream.

"Good morning! I made cupcakes for later," she greets her online followers.

"Good morning, James!"

"Whaddup, Edgar?"

She reads aloud through their comments, which vary from thoughts on the cool T-shirt she's wearing to how they're recovering from a yucky cold to the weather on the East Coast right now.

Statham begins playing a combat game and the easygoing conversation continues — even as she's blasting things onscreen into oblivion.

Sometimes she coos a word of sympathy, sometimes she cracks a joke, but she's always comforting, like a warm cup of cocoa.

The grandmother of two from Bellingham, Washington, began streaming in 2019, but it wasn't until the pandemic in 2020 that her popularity exploded. Maybe because at a time when Statham's audience of primarily 18-to-32-year-old males was keeping a safe space from their own

grandparents, she offered a warm, nurturing place to hang out for a while.

"I think what drew people to my stream is I tried to create a community that was inviting to everyone, that was safe, that everyone felt welcome," said Statham.

Now she's using her platform — which includes 1.4 million followers on TikTok and 274,000 followers on Facebook — to support St. Jude Children's Research Hospital.

She hosted her first livestream on Oct. 1, 2019, and following the lead of other gamers she admired, such as DrLupo, threw her first St. Jude PLAY LIVE fundraiser soon after.

"I think we raised 100 bucks the first time, but Facebook matched it, so I'm like, 'That's 200 bucks.' So, it's 200 bucks that's going to help the families and the kids at St. Jude."

Today she's raising thousands for the kids of St. Jude, and nothing can stop her.

'Another chance at life'

Statham tries to keep a straight face, but the inflatable puppy costume she wears for her St. Jude

PLAY LIVE fundraiser flops into her field of vision. Its bulkiness makes it hard for her to reach the video game controls.

She giggles and focuses on her combat game. She takes aim and makes a hit.

"Ha ha, I'm better than you," says Statham, who excels not only at virtual marksmanship, but also at good-natured trash talk.

She dances a victory dance, and the costume jiggles. She can't stop laughing.

The comments from her followers flood in, and so do the St. Jude donations.

"OMG that laugh!! And that little dance at the end!" writes one.

"I love you grandma You're amazing for doing this!" writes another.

She says her St. Jude PLAY LIVE fundraisers are marathon fun sessions. The challenge of keeping her audience entertained for hours reminds her of the old TV telethons that St. Jude founder and entertainer Danny Thomas hosted decades ago.

For a donation to St. Jude, she's eaten jellybeans that taste like dishwater. She's played blindfolded. Silly things to do, but with a serious



purpose: She wants to help save every child.

Sometimes she hears from pediatric cancer survivors. A follower who goes by the name “Average_Taco” made a \$50 donation and posted to her PLAY LIVE fundraising page:

“I’m alive today because people like you and others donated and helped give me another chance at life. Thank you for helping me and other children out. I am here 20 years later to write this message.”

‘An important thing’

Statham’s grandkids often climb into her lap between gaming sessions, reach for the keypad with their little sticky fingers and nestle into her arms.

She’s not tactical to them. She’s just Gramma.

Their simple, trusting presence inspires her to act heroically on behalf of every child.

Before her later-in-life success as a gamer, she’d worked as a fast-food restaurant manager, a school bus driver and a stay-at-home mom. She understands the value of a dollar and the hardship families can feel when the unexpected happens.

Good health is something she believes all children deserve from the day they come into this world.

“It’s such an important thing,” said Statham, and that’s when this grandma and video game streaming sensation who loves to keep it light chokes up.

‘I could do that, too’

Statham didn’t have many role models three-and-a-half years ago when she began all this. There aren’t many grandmothers in the streaming

“

I also would like people to maybe look at me and say, ‘Hey, she went out there, she raised money for St. Jude. I could do that, too.’

– Michelle Statham, aka *TacticalGramma*

world. Still fewer playing combat games. But lately she’s noticed an uptick in older women visiting her stream.

“It’s been fun to be able to inspire females – women – to pick up the game because we kind of grew up in an age when it was kind of weird if females played video games. ...So now they’re trying, and it’s pretty awesome.”

She’s compassionate, determined to bring others along with her in her success, and determined to make a difference in the world from the platform she’s built for herself – especially when it comes to St. Jude.

“What I hope people take away from watching me: One, is you’re never too old to chase your dreams. And I also would like people to maybe look at me and say, ‘Hey, she

went out there, she raised money for St. Jude. She raised awareness. I could do that, too.’ And the third thing would be just to be a kind human being, right?”

“Because a few of us start doing that and it spreads out and we could make this world better if we just decide to treat people with kindness.”



You can join Michelle Statham in supporting the St. Jude mission. stjude.org/hope

New York volunteer gives 100% to St. Jude

Regina Allen-Maxwell: ‘You don’t have to have a child with cancer to be involved.’

By **Linda A. Moore** - ALSAC

When Regina Allen-Maxwell was recruited to volunteer on behalf of St. Jude Children’s Research Hospital, she knew she needed to learn more about St. Jude and its mission.

The New York retiree was familiar with the work being done at St. Jude to save the lives of children. But as she learned more about the research hospital’s history, including its founder, Danny Thomas, and his commitment to treat children of all races with compassion, her passion for St. Jude took root and blossomed.

Now, four years later, she’s taken on a new leadership role as a St. Jude Volunteer Crew Captain. Allen-Maxwell will recruit and coordinate the work of St. Jude Volunteer Crew members, who commit to work at least 24 hours a year at fundraising programs and events.

In keeping with Danny’s ideals, Allen-Maxwell has a personal goal to seek out and grow a diverse pool of new volunteers. When St. Jude opened in 1962 in Memphis, it was the only pediatric hospital in the segregated South that treated patients regardless of race, religion or ability to pay.

The original hospital building was designed by Paul Williams, an African-American architect. After the hospital opened, doctors, researchers and other staff members represented many races and nationalities.

St. Jude hasn’t wavered in its commitment to diversity, and neither will Allen-Maxwell. Today, in her multicultural Bronx neighborhood, she says St. Jude isn’t very well known. She plans to change that.

“Diversity is very important. It’s like anything else, we need to see people like us volunteering,” Allen-Maxwell said. “One of the things I’m seeking to do is to bring St. Jude into the Bronx.”

Allen-Maxwell has her elevator pitch at the ready. She simply references the St. Jude patients and their families featured in the fundraising campaigns.

“You see the kids on TV? It breaks your heart. Wouldn’t you like to be a part of that? Wouldn’t you like to know that you had a hand in helping a child?” Allen-Maxwell asks potential volunteers. “It works.”

Like so many volunteers and donors, Allen-Maxwell has no direct connection to St. Jude. She’s grateful her two adult children and her grown grandson were never diagnosed with a childhood cancer or any of the other life-threatening diseases St. Jude researchers work to cure.

“You don’t have to have a child with cancer to be involved. You don’t have to know a child with cancer to be involved,” she said.

Allen-Maxwell recently visited the St. Jude campus. That first visit reaffirmed her dedication to the cause.

Walking through the doors for the first time was uplifting, she said, knowing the dollars she helped raise in New York contributed to the ever-expanding research efforts to cure childhood cancer and other devastating diseases, like sickle cell disease, around the world. The first research grant ever received by St. Jude was for the study of sickle cell disease, which disproportionately impacts the African American community.

“All you need is the passion to do it,” Allen-Maxwell said.

It’s volunteer work that anyone can do.



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. stjude.org/hope

Global CONNECTIONS

From Miami to Memphis: Rosie Cruz-Sotero is excited by the growing global goals of St. Jude.

By **Linda A. Moore** - ALSAC

Rosie Cruz-Sotero's first involvement with St. Jude Children's Research Hospital was in 2000. She was working at a Spanish-language radio station in Miami which was hosting a St. Jude radiothon fundraising event.

Cruz-Sotero recalled how she snuck into the DJ booth to hear the stories of hope that patients and their families shared with listeners. About a year later she was asked by a representative from the ALSAC office in Miami to help organize a new fundraising event. ALSAC is the fundraising and awareness organization for St. Jude.

Still moved by the strength and resilience of the St. Jude families, it was impossible for Cruz-Sotero to say no. That event was the first FedEx/St. Jude Angels & Stars Gala in Miami which has, since its inception, raised more than \$7.5 million for the lifesaving work of the research hospital.

For the next two decades, Cruz-Sotero solidified her place as a valued St. Jude

volunteer. She knows volunteers for St. Jude share her desire to make a difference and do their part to help St. Jude improve survival rates for childhood cancers and other catastrophic diseases in the United States and around the globe.

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

"We've learned through the years that we have made great strides in the U.S. with survival rates of cancer. But we know definitely the numbers are not where they need to be globally," Cruz-Sotero said.

When St. Jude opened in 1962, childhood cancer was considered incurable. Since then, St. Jude has helped push the overall survival rate in the United States from less than 20 percent to more than 80 percent.

Conversely, each year, 400,000 children around the world develop cancer, and half



"I have been really wowed by the global scalability that we're trying to accomplish together."

– Rosie Cruz-Sotero

of them are never diagnosed. Without access to quality care, four in five children in low-and middle-income countries will die.

Last year, after Russian troops invaded Ukraine, St. Jude Global, as part of the SAFER Ukraine humanitarian effort, helped evacuate and provide for the continuous treatment of more than 900 Ukrainian children with cancer. Those kids were taken to institutions across Europe, Canada and to St. Jude.

Cruz-Sotero is now a real estate agent. Her 16-year-old daughter has been a regular attendee at volunteer planning and fundraising events since she was a young child. Cruz-Sotero has visited the St. Jude campus many times and takes pride in knowing that her hard work in Miami provides the resources that allow the campus to continue to grow.

This growth, coupled with the global commitment of St. Jude, has energized her even more.

"I have been really wowed by the global scalability that we're trying to accomplish together," she said. "Opening our eyes to the global community has been really important and knowing that St. Jude is leading and pioneering that is really inspiring."

Cruz-Sotero intends to continue to do her part toward the fulfillment of this ambitious plan.

"There's more work that I can definitely be a part of, and I am definitely looking forward to and excited for that," she said.



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.
stjude.org/hope



Craig now appreciates every day

He and other patients share their stories on St. Jude Storied Lives podcast

Without soccer, Craig might not have come to St. Jude. One day in high school, he got injured at practice. A trip to the doctor in 2008 led to a diagnosis of a hernia and a torn spleen. And a blood test showed something more: leukemia. He was 15.

St. Jude saves lives, and patients like Craig go out into the world and get to live their lives. But their cancer story is just a part of their whole story.

"It really taught me how to slow down and appreciate, you know, the things that are going on around you," Craig said. "But also, don't be ashamed to tell somebody you love them because you never know when those

moments can be taken away because it can happen in a snap."

The experience as a high school student also taught him about love and loyalty and friendship.

"One of the biggest things I learned with my cancer journey is who truly loves you," Craig said. "Who's authentic in their relationships, and who's not going to be weird, you know, no matter what.

"And so, like a great group of my friends from back then are still a great group of my friends right now. And so especially during those, you know, collegiate years and during those high school years when I was still under treatment, they treated me like normal. They still crack jokes."

To hear the rest of Craig's story and other stories from patients and families at St. Jude Children's Research Hospital, tune in to the St. Jude Storied Lives podcast, hosted by St. Jude cancer survivor Joel Alsop.



Listen on Apple Podcasts, Google Podcasts, Spotify, Amazon Music and at stjude.org/inspire.

A GIRL'S BEST FRIEND

Service dog is constant companion to St. Jude patient

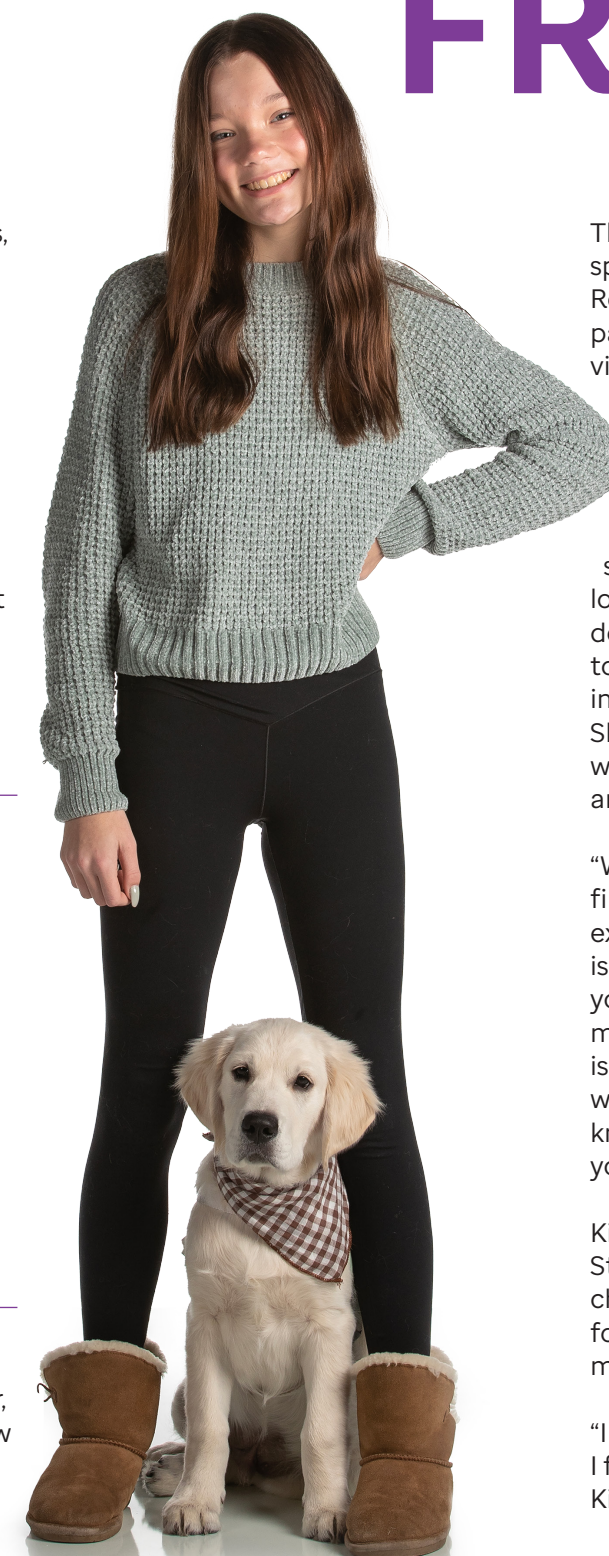
Everywhere Keatan, "Kiki," goes, her four-legged friend, Asher Lux, is sure to follow.

Asher Lux is Kiki's service dog who is trained to detect changes in her heart rate and notify her when she is about to have a headache or seizure. The English Cream Golden Retriever is still fine-tuning his skills but already has been an immense help to his charge as she goes about her routines, which include medical appointments, home school and dance class.

"From the start, his focus was on her, and we truly believe he already knew he was meant for her and what his job was."

— Jenna, Kiki's mom

"From the start, his focus was on her, and we truly believe he already knew he was meant for her and what his job was," said Kiki's mom, Jenna.



The idea for a service dog was sparked at St. Jude Children's Research Hospital where Kiki is a patient and where she has been visited by therapy dogs.

At 10 years old, Kiki was diagnosed with brain stem glioma after struggling with severe headaches and suffering a seizure where she lost consciousness. Soon after, she developed hydrocephalus and had to undergo emergency brain surgery in her home state of North Carolina. She was then referred to St. Jude where she received chemotherapy and proton radiation therapy.

"Walking through those doors the first time is a feeling that is so hard to explain. You are terrified, your heart is breaking in pieces as you hold your child's hand, and yet in those moments and all that come after, it is like someone is reaching out and wrapping you into a hug. Letting you know it will all be OK. They've got you," Jenna said of St. Jude.

Kiki is home now but returns to St. Jude every few months for checkups and continued treatment for seizures and headaches, her mom said.

"I am forever thankful for St. Jude. I feel safe and understood there," Kiki said.



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Kaleb's story

At just a few months old, red dots began to appear all over Kaleb's body. One day when Kaleb was 10 months old, he turned pale, would not take the bottle and was unresponsive. His parents took him back to the hospital where he was diagnosed with immune thrombocytopenia, or ITP, an autoimmune disorder which causes low numbers of platelets. Platelets are blood cells that help stop bleeding.

Doctors referred Kaleb to St. Jude Children's Research Hospital® where he was treated to slow the destruction of platelets. He also receives weekly injections to help the body make more platelets. "St. Jude and its staff take care of the children like they are their own children," said his mother, Jerhonda.

Earlier this year, Kaleb celebrated his 2nd birthday. He loves to run, play basketball, cuddle with his mother and hum along to songs.



You bring hope and healing to patients like Kaleb 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? To help us get closer to that day, please consider giving an additional, one-time gift by scanning the QR code or go online to stjude.org/hope.

