ST.JUDE

SPRING 2023

Celebrating Through groundbreakin research and treatment at St. Jude, Allie's

Through groundbreaking

70+ candles

This grandmother celebrates family, long life after treatment at St. Jude in 1972

Luna's lifeline

Named for the moon, a little girl from Guatemala is the light on darkest days

A mother's heart

A CONTRACTOR OF CONTRACTOR

After leukemia treatment at St. Jude, Kamryn's love and life continue to uplift

Child's play

St. Jude patient Nash and his dad take a break in the new, one-of-a-kind Family Commons area at St. Jude. The kid-friendly haven offers families much needed respite in between appointments, thanks to a generous and historic \$50 million gift from AbbVie.

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



n the midst of the holiday festivities a few months ago, I was blessed to celebrate life and love in the most meaningful way. Allie, a St. Jude cancer survivor, was married in a beautiful ceremony surrounded by family and friends.

Surrounded by love.

Though the millions of St. Jude supporters couldn't have fit in the intimate space of the chapel, you were all there, too, uplifting the bride on her special day.

Milestones like graduations, proms and weddings are never guaranteed for the 400,000 children who will get cancer around the world each year. Yet more and more will celebrate those occasions as research at St. Jude advances and developments are shared around the world.

And though you might not be there for those events in person, I assure you these patients carry you all in their hearts.

This issue of St. Jude Inspire magazine comes to you, as always, with gratitude.

In these pages you'll read about St. Jude patient Luna and her dad. You'll be taken on a 70.3-mile journey of friendship, heartbreak and comfort with three St. Jude dads as they tackle an IRONMAN race together. And you'll learn what inspires other generous supporters just like you.

Thank you for celebrating with us. Thank you for keeping our kids in your thoughts and in your hearts and please know that only through your support are we able to give more kids like Allie their special day in the spotlight.

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



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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. **stjude.org/ImpactGiving**

NEWFOUND HOPE FOR KANRYN

By Ruma Kumar - ALSAC

The kindergartner is thriving thanks to advances in research and treatment pioneered at St. Jude.

elissa always dreamed of having a son. They love their mamas best, she'd heard. And like a gift, Kamryn was born to her on Valentine's Day.

When his hands were large enough, Kamryn held his mother's face in them and pulled her close so she could properly hear him when he told her he loved her.

"Kamryn is so happy, so loving; he just lifts me up," Melissa said.

"Can you imagine life without that?"

That fear hit her three years ago when Kamryn was diagnosed with acute lymphoblastic leukemia (ALL). He was a rambunctious, giggling 2-year-old when the daycare called saying he was fussy. This child was never sick, Melissa said. But on this summer day in 2019, Kamryn didn't want to walk and spent the day whining. So, Melissa was worried.

A pediatrician initially diagnosed him with an ear infection, but when Kamryn seemed to feel even sicker and complained of pain along his legs more than a week later, Melissa took him to the emergency room.

This time, the doctors said it "looked like leukemia," Melissa said, and referred her to St. Jude Children's Research Hospital.

"I went numb when I heard that, but I kept thinking they're not sure what it is and I'm going to hope for the best," Melissa said.

Melissa was born and raised in Memphis. She'd heard of the research hospital and its work.

Over the years she'd encountered neighbors and friends who'd run races, volunteered and donated money toward the St. Jude mission to find cures for cancers and other catastrophic diseases in children.

Melissa had heard hopeful stories of children defying odds and relieved families; determined scientists and helpful doctors; and she prayed that Kamryn's story would be part of this narrative.

When she walked onto the rose-hued campus on a blistering August day, she was wracked with a worry she could not shake: *I might lose my son*.

Doctors at St. Jude confirmed that Kamryn had ALL, the most common childhood cancer in the world.

They placed him on a treatment protocol called Total Therapy 17. It's the first ALL protocol at St. Jude guided largely by analyses of the patient's genes. Doctors and scientists sequence genomes of leukemia cells and normal tissue cells, then see how well the patient's disease responds to the first rounds of therapy so that treatment can be individually tailored for kids to minimize side effects while eradicating the cancer. **66** It was a dark moment, hearing leukemia, you know it's cancer and all you can think about is death.

- Melissa, Kamryn's mother

"It was a dark moment, hearing leukemia, you know it's cancer and all you can think about is death," Melissa said, growing tearful remembering that day. "I was so sad and just overwhelmed about what was going to happen."

But she found comfort and reassurance quickly, she said. First from a team of doctors who explained how the protocol was developed through research and testing over decades. And next, from a support team made of St. Jude nurses, social workers and therapists who answered questions about the treatment journey and its myriad effects on both kids and caretakers.

The protocol doctors offered Kamryn featured a mix of steroids and potent chemotherapy medicine, and it had been tested and refined 16 times since the 1960s. The treatment plan is born out of a sustained effort by doctors at St. Jude to continuously evaluate new and better ways of treating ALL.

Each study builds on the results of previous clinical trials, as well as discoveries made by St. Jude researchers working with scientists at institutions around the world.

Thanks to those collaborations, scientists at St. Jude are now learning more than ever about ALL. In fact, St. Jude scientists recently helped lead the nation's largest comprehensive analysis of how genomes contribute to ALL, using samples from nearly 2,800 patients collected over a decade. They studied patterns of alterations in the genomes of leukemia cells and found new genes potentially responsible for the development of ALL.

Researchers found further evidence that ALL is not one single disease that affects every child the same way,



Initially, I was overwhelmed. But at St. Jude I got this newfound hope. I am so grateful for all the research and the support.

- Melissa, Kamryn's mother

but rather a collection of subtypes, some progressing differently in children. The subtypes have distinct alterations that pose different risks for children and support the need for more precise targeted treatment. These are the kinds of learnings that helped doctors at St. Jude tailor care for Kamryn.

"Initially, I was overwhelmed. But at St. Jude I got this newfound hope. I am so grateful for all the research and the support," Melissa said.

It took more than two and half years of treatment, but Kamryn is now cancer-free.

Melissa watched her son learn to take pills before learning to read, swim or ride a bike. She learned about how to comfort Kamryn as he received medicines intravenously, and she practiced different ways to manage the irritability Kamryn experienced after taking steroids. She was relieved when a nurse discovered music and singing would help Kamryn cope with the pain and fear he felt from needles and blood draws.

Today, 6-year-old Kamryn is a living, breathing symbol of progress: a testament to how St. Jude has steadily refined treatment protocols to boost survival rates for ALL from less than 5 percent when the hospital was founded in 1962 to about 95 percent today. And the advancements have improved patients' quality of life, too.

Kamryn's memory is "impeccable," his mother said. "He remembers every student, every teacher he meets, and they remember him."

He is among the best and most prolific readers in his kindergarten class and particularly enjoys reading about dolphins. He's starting to learn karate. He sings all the time, sometimes silly tunes he makes up with his mother to get ready in the morning and sometimes gospel songs for inspiration.

"I know I'm the mother and he should look up to me, but I look up to him." Melissa said. "He handled everything with such grace."



You can help ensure patients like Kamryn keep reading and singing. **stjude.org/ImpactGiving**



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- 3. St. Jude Orchid Tote 659600000......\$50.00
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Art by St. Jude patient Ty

COVER STORY



St.Jude patient

the everyday — and her special day

By Linda A. Moore - ALSAC

Diagnosed with brain tumors, Allie wasn't expected to walk for high school graduation, or down the aisle. he clouds on a rainy and overcast December day could not dampen the untold joy at the wedding of Allie and Parker.

Dressed in all white, like countless brides since the 1840 wedding of England's Queen Victoria, Allie had chosen a gown with a sweetheart neckline and a bodice covered in lace. She wore a rhinestone headband with a veil that was arranged low at the back of her head and did nothing to hide her thinning hair. Allie has never worn a wig or tried to conceal from herself or the world the obvious evidence of her cancer treatments. Not in her everyday life. And not on her wedding day.

"That's just not my personality to wear a wig. I'm blessed that I have any hair at all," the bride said.

After being diagnosed twice with brain tumors while still a teenager, Allie said she was not expected to live to graduate high school. But because of the groundbreaking work being done at



St. Jude Children's Research Hospital, Allie has finished high school and graduated from college. And now, she's married.

"Not one of these milestones would have been reached without St. Jude," said Allie, now 24.

The wedding was magical, held in a nearly all-glass jewel box of a venue, with lots of windows surrounded by forests and fields, decorated with fresh, white flowers and a white cross. It was witnessed by family, friends and



other St. Jude patients, many of them in tears. And all were there to revel in this joyful celebration.

"She beat the odds with the treatment from St. Jude," said Allie's mother, Debbi.

Ten years ago Allie's life took a decidedly unwelcome turn.

At 14, she was the captain of her middle school dance team. It was 2013 and dance was life. However, while dancing at a January pep rally, Allie forgot a routine they'd been performing the entire school year. She also had episodes when she could hear her friends and everything around her, but couldn't respond.

Doctors initially thought Allie's episodes could be a precursor to migraines. As a precaution, she was sent to a neurologist. That's when an MRI revealed a tumor the size of a golf ball in her brain. Because of its configuration, the doctors believed it would be benign. This wasn't what her parents wanted to hear, but they hoped it would be manageable.

"We were still devastated our daughter had a brain tumor, but we thought, 'surgery and we'll move on," Debbi said.

With her brain surgery pending, Allie still performed at a national competition. Her team even placed first in the hip-hop category.

Sadly, after a more than eight-hour surgery on Valentine's Day of 2014, they received more devasting news. Allie's tumor was malignant.

"And our world stopped, completely stopped and hasn't been the same since," Debbi said. "There's not one day that it's not on my mind. Not one day." Diagnosed with a grade III anaplastic ependymoma, Allie was immediately referred to St. Jude while still in recovery at a local children's hospital.

"It's like Debbi said, it was kind of there was our world and our life before that day and then after," said Eric, Allie's dad. "It's changed our world completely."

The family, including Allie and her older brother, had volunteered in years past with the FedEx St. Jude Championship golf tournament. Now, they were on the other side – as a St. Jude family.

"I believe God gives his strongest warriors the biggest battles. She's definitely right up there."

- Parker, Allie's husband

Allie was too young to fully understand her diagnosis, but old enough to know cancer was bad. Her treatment included 33 rounds of radiation and eventually she was able to return to school and her dance team.

Then, in 2015, doctors found another brain tumor, this one a smaller high-grade neuroepithelial tumor. Allie had another brain surgery, and full spine and full brain radiation.

It was around that same time that Debbi was diagnosed with breast cancer. Mother and daughter were in their fights together.



Allie celebrates her college graduation, a milestone that she and her family once thought she might not reach.

But one thing the family never worried about was the cost of Allie's treatment. No family ever receives a bill from St. Jude for treatment, travel, housing or food—so they can focus on helping their child live.

Allie fought through the side effects of her treatment, including hair loss and fatigue. She finished high school and started college.

Then, she met Parker.

Parker says he knew very early that Allie was "the one." They'd only been dating a short while when his family dog died. When Allie sent flowers, it was an act of kindness he couldn't resist.

Even before he met Allie, he knew about her cancer. They grew up in the same town in Tennessee and attended rival high schools. They went to the same university and had mutual friends.

Once, while home on a college break in 2016, Parker took a cycling class where the fees were donated to St. Jude in Allie's name. He was there. She was there, in the very same room. But like the plot of a romantic comedy, neither knew that a few years later, they would meet and marry.

They finally met in 2019 when Parker was visiting their college campus after graduation to celebrate a friend's birthday.

They hadn't been dating long when she told him the details of her cancer. He admired her even more after learning about her St. Jude journey. "Every milestone is that much sweeter, that much more important because we didn't think that she was going to make it."

- Eric, Allie's father

"I believe God gives his strongest warriors the biggest battles. She's definitely right up there," Parker said.

Allie and Parker are planning a future that includes children.

Allie said doctors told her spinal radiation could impact her ability to have children. So, at their recommendation, her eggs were harvested and frozen in a procedure called oocyte cryopreservation.

Allie fully intends to use them, but just doesn't know when.

"God will have the perfect time for us," she said.

For Parker, St. Jude is powerful. "St. Jude and its relentless pursuit to make sure that no kid dies of cancer and that every kid who gets diagnosed with cancer is cured, it's powerful stuff," he said.

None of Allie's milestones could have happened without St. Jude and its generous donors, her dad said.

"Every milestone is that much sweeter, that much more important because we didn't think that she was going to make it," Eric said. "She wouldn't be here without St. Jude. It is saving lives." Cancer, Allie said, is terrible, no matter the age. But the battles that patients at St. Jude wage are different from those of adults, like her grandfathers, who both died from cancer.

"These kids are just praying to make it to their fifth birthday party. Whereas, my grandfathers got to graduate high school, graduate college, get married, have kids and grandkids. These kids are just trying to make it to a birthday party," she said.

Last year was a very busy and productive one for Allie and Parker with her graduation, their wedding and renovating their first home. (Plus, their new puppy, Lizzie, is in training to be a support dog for Allie.)

Finding a house in the hot housing market and in their price range wasn't easy. They credit divine intervention.

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On the way to see the house for the first time, they prayed, Parker said.

"I asked for a sign. And then the first thing we see in the house is a St. Jude magnet on the fridge," Parker said.

With college, a wedding and home renovations behind her, Allie is still moving forward with her life.

"This is the best I've felt in 10 years," she said days before her wedding.

Now, she works for ALSAC, the fundraising and awareness organization for St. Jude, so stories like hers can happen for more and more children.

Meanwhile, Allie's tumor is still there. She gets annual scans at St. Jude and said the tumor is stable and doesn't impact her daily life.

Parker and Allie don't talk about the tumor very often.

"The only time we may actually talk about it is when we pray about it," Parker said.

"We pray that it stays stable and that I get to live a long life. But we don't talk about it on the regular because it's not something we want to dwell on," Allie said. "I just appreciate that I'm alive and I'm trying to do my best with living my best life."

You can help ensure patients like Allie get to celebrate those special moments. **stjude.org/ImpactGiving**



WATCH ALLIE'S VIDEO

store . 9

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RIPPLE EFFECT

Robin Segal is living an active life and treasuring time with family.

By Monsy Alvarado - ALSAC

obin Segal started a new tradition a few years ago. She blows out her birthday candles every year with her two young granddaughters, Mila and Stelly, on Thanksgiving weekend. The three share birthdays around the same time in December.

It is during family gatherings like these – having long conversations after a big meal with her daughters or walking along the beach on summer days – that Robin often pauses and gives thanks for her life of more than 70 years.

Decades earlier, her future as a mother and grandmother were not a given. When she was in her early 20s, Robin was diagnosed with cancer and underwent radiation treatment at St. Jude Children's Research Hospital. The research hospital in Memphis was a decade old at the time.

"The hospital gave me a great gift, many gifts I should say," she said. "I am able to live my life, I have a beautiful family and I could not ask for more. I often think, 'Look how lucky I am." "The fact that they still support past patients and use that research to further success stories of current patients is what is incredible."

- Victoria, Robin's daughter

Since her time as a cancer patient. Robin has lived a life filled with important milestones and ordinary moments. She built a career in retail, fell in love, married and gave birth to two healthy daughters. She chose to be an at-home mom while her daughters were growing up in New York City, a period when days were filled with play dates and school and swimming activities.

She later divorced, returned to work and now has an active life which includes working at a periodontist office and going to the gym most days. When she visits her granddaughters in Maryland, she likes reading and going to the playground with them.

"I really like to go along with their imagination, and what they come up with is fascinating," she said. "Their presence is amazing to me, and I just can't get enough of them." Her oldest daughter, Pamela, describes her mother as resilient and someone who has not forgotten her Southern roots, and is always polite and hospitable. Her mother also has not forgotten her time at St. Jude, and its importance in all their lives.

"It's a place where miracles happen," said Pamela, who recalls being an elementary school student when she first raised funds for St. Jude at a Read-A-Thon. "It has allowed us to be alive, to be born, and that is the most amazing part of it. There is a ripple effect to think about and the impact it has had beyond that one individual."

A new move interrupted by cancer

Robin was 21 years old when she went out on her own to New York City, thousands of miles away from her home state of Mississippi. A young woman with a future of endless possibilities. She knew no one in the Big Apple, but her father had grown up there and moving was a dream come true.

A year after her big move, while talking on the phone, Robin placed her hand on the left side of her collarbone and felt a lump. It prompted her to make a doctor's appointment. The first and second doctor she saw described the size of the lump as pea-sized and indicated it was nothing to worry about and would likely go away.

When she visited Mississippi a few months later, her parents took her to the family doctor, who said the lump, now the size of a pecan, did not seem right and scheduled its removal. Biopsy results came back showing Robin had Hodgkin lymphoma, a cancer that starts in the lymph system and causes affected lymph nodes to get larger.

"Am I going to die, am I going to be able to live through this?" Robin recalled her first thoughts after hearing the diagnosis. "I remember the fear I had."

Robin's father, Burt, wanted a second opinion, so he drove the results to Memphis, about 75 miles away, where the diagnosis was confirmed.

"And then our journey started," Robin said.

It was 1972, and their family doctor knew about the work happening at St. Jude. The doctor told her parents the hospital was studying Hodgkin lymphoma and she was referred to St. Jude.

"They were willing to take me on as a patient, and ... I went through the whole process of tests," she said.

Her father went to the billing office the first day to pay for his daughter's tests.

"We didn't know that at St. Jude you didn't pay for treatment, so he had no idea," Robin said. "At the billing office, they said this is something we do for our patients."

Doctors at St. Jude found that the cancer was localized in Robin's upper torso and recommended she receive 30 aggressive treatments of radiation, she said.

Robin said her treatment also involved surgery to remove her spleen and appendix. For a little over a month, she and her mom would travel to Memphis every week for radiation therapy and stay at a hotel paid for by St. Jude. She remembered, at the time, the hospital was in one building and surgery was performed next door at St. Joseph's Hospital, which was located there at the time.

Robin remembered that St. Jude was connected to the other hospital via an underground tunnel.

She also recalled a sense of community among St. Jude patients and their families.

"It was always a kind and warm place," Robin said.

After she completed treatment, doctors told Robin she was better and would have to return for yearly checkups.

"I started to see my local doctor in New York, which is what I did, and here I am 50 years later, so it's pretty amazing," Robin said.

Resuming life

Robin married a few years later, and then gave birth to her daughters. She volunteered to help raise funds for St. Jude and attended a St. Jude fundraising event while pregnant with her oldest daughter. There, she met Danny Thomas, founder of St. Jude. At the same time, her father organized events in Mississippi to fundraise for the research hospital.

These days, Robin participates in St. Jude LIFE, the long-term follow-up study. The research study on patients brings childhood cancer survivors back to St. Jude for regular health screenings throughout their adult lives. "It's not only a learning tool for them, but also a learning tool for me, to learn things that are going on with me that I otherwise would not know," she said.

Soon after the start of the COVID-19 pandemic, Robin reached out to doctors at St. Jude because she was worried about virus exposure and what it could mean for her. They explained what she should do to keep safe.

"They are just a phone call away," she said.

Her youngest daughter, Victoria, said what stands out is how St. Jude remains part of her mother's life. She has seen her mother on the phone on long doctor's calls.

"The fact that they still support past patients and use that research to further the success stories of current patients is what is incredible," Victoria said. Robin said she and her family are in awe of the work and advancements made at St. Jude to help children with cancer. Several members of her family and extended family continue to participate in events that raise awareness and funds for the hospital.

"I've got my life and I was very lucky," Robin said. "To see the growth of the hospital since my first encounter with it and what it has become today, and all the work that they do, it's just pretty amazing."

Your gift can help ensure more patients like Robin grow up to become mothers and grandmothers. **stjude.org/ImpactGiving**



A LIGHT IN THE DARKNESS

A little girl named after the moon fights repeated bouts of leukemia while St. Jude works to save her life.

By Ruma Kumar and Monsy Alvarado - ALSAC

he most common childhood cancer in the world, acute lymphoblastic leukemia (ALL), has waned and returned for 8-year-old Luna three times.

First in her native Guatemala, and then in Memphis at St. Jude Children's Research Hospital where Luna has received a host of therapies – chemotherapy, bone marrow transplant and immunotherapy – to try to eradicate the cancer in her blood.

Still, signs of the cancer remain as Luna is monitored 3,300 miles from home, away from her mother and brother, with her father, Mario, to support her at St. Jude.

Mario always dreamed of having a daughter and knew her name long before she was his. Luna. Moon. A light in the darkness.



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There's something powerful about the moon.

Luna's dad, explaining his daughter's name

"There's something powerful about the moon," Mario said. "It moves the Earth's tides. The moon is in the legends of people hundreds of years ago. And that strikes me as something really beautiful."

Luna was a toddler living in Guatemala when she started to feel ill in 2017. Her parents noticed that their usually energetic girl spent too many hours sleeping.

At first, Luna was treated for an infection before doctors diagnosed her with ALL. She was sent to a specialist and underwent two years of chemotherapy at a pediatric cancer hospital in Guatemala.

A relapse days before Christmas in 2019 led doctors to refer Luna to St. Jude. Mario didn't know much about the research hospital, but he prayed it would provide a lifeline for his little girl.

The first few days in Memphis were filled with doctors' appointments. Mario soon felt support from the staff at St. Jude. Even during the COVID-19 pandemic, which forced shutdowns throughout the country only a few months after their arrival in Tennessee, he said he was in regular communication with doctors and other staff at St. Jude.

Mario watched as doctors at St. Jude incorporated comprehensive genomic analysis into Luna's clinical work-up, ensuring a customized treatment for his daughter.

St. Jude doctors use the genetic information to avoid over-or under-treatment. The genetic information learned also could help by identifying inherited cancer genes. There is also a greater emphasis on qualityof-life issues with St. Jude staff working to help survivors thrive into adulthood.



Eleven months after they'd arrived in Memphis, Luna and her father were given the OK to return to Guatemala in November 2020.

They had just settled back into a new normal when small red spots appeared on Luna's legs about a month after their return home. Mario, who had completed three years of medical school before deciding to become an acupuncturist, thought it was likely a sign that his daughter's platelets were low. After several tests, a trip to the emergency room and countless sleepless nights, he was told Luna's leukemia was back.

Doctors at St. Jude asked Mario to return to Memphis. Luna underwent another bone marrow transplant and received more chemotherapy. In December 2021, she was treated with CAR T-cell therapy, a type of cancer treatment that reengineers some of the body's natural immune cells to make them better at destroying cancer cells. She is now being monitored.

Luna lost some of her vision during treatment. She can see things within six feet of her, but the world beyond that is a hazy place. Luna doesn't let that discourage her.

She hops and skips when she moves around, even in unfamiliar spaces. And when she speaks,

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There is humanity (at St. Jude) that I just don't think exists anywhere else.

关 *- Mario,* Luna's dad

giggles punctuate her sentences. She is curious and eager to learn, and when she loves something, she lets the people around her know right away by forming a heart with her hands.

Even with limited vision, she insisted on visiting the Memphis zoo to learn about animals she had not yet seen, Mario said. The occupational therapists at St. Jude gave her a digital magnifying glass, the size of a smart phone, to amplify objects in the distance. She was thrilled to be able to see the lions and giraffes through this new tool, her father said, and she carries it around wherever she goes.

"They not only offer new treatment without a cost to us, but along with that treatment comes empathy and a lot of warmth," Mario said.

Luna recently celebrated her 8th birthday at St. Jude. Staff members make sure birthdays feel special. They bring colorful balloons, presents, and sing "Happy Birthday," showering the patients with confetti. Mario has recorded those special moments and said those gestures mean the world.

"There is humanity here that I just don't think exists anywhere else," Mario said.

While receiving treatment, Luna participates in the school program called the St. Jude Imagine Academy by Chili's, where she spends hours coloring, molding animal shapes with modeling clay and learning new English words. In physical and occupational therapy, Luna runs, does yoga, plays baseball and jumps.

Mario doesn't know how long treatment will last for Luna, but is hopeful for her future. His daughter, after all, is talking about her future of one day being a math teacher.

"For us, St. Jude has been a blessing, it has been something incredible, because it has not only meant that Luna is better, but that there are possibilities for her."



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



The Polaris Program aims to advance human spaceflight while raising funds and awareness for St. Jude.



Crew

- Philanthropist and St. Jude partner Jared Isaacman is commander of the mission, just as he led Inspiration4 in 2021 raising more than \$250 million for St. Jude.
- Pilot Scott "Kidd" Poteet is a 20-year veteran of the Air Force flying F-16 fighter jets.
- Mission Specialist Sarah Gillis trained as an aerospace engineer.
- Mission Specialist and Medical Officer Anna Menon is a mission director at SpaceX.

Spacewalk

The crew will attempt the first-ever commercial spacewalk with SpaceXdesigned spacesuits that allow exploration outside of the capsule.

Trip

435 miles (700 kilometers) above the Earth.

Rocket

Falcon 9 is a reusable, two-stage rocket designed and manufactured by SpaceX and will launch the Dragon spacecraft into space.



Spacecraft

The Dragon spacecraft, capable of carrying up to seven passengers, is the first private spacecraft to take humans to the space station.

1972

The last time astronauts flew this high into orbit. That same year, St. Jude announced research improving childhood leukemia survival from nearly zero to 50 percent.



any Dragon mission and endeavoring to reach

Jared Isaacman

5 days Polaris Dawn crew will spend up to five days in orbit, flying higher than

ever flown.

the highest Earth orbit

70 secs

Time it takes Falcon 9 to reach supersonic speed after liftoff.

1.7 million

Pounds of thrust generated by the nine Merlin engines on the Falcon 9 rocket at sea level.



Spring 2023 23

Scott Poteet









ву Zack McMillin - Alsac

s often and abundantly as Carnival Cruise Line passengers have rewarded Lee Mason's faith in their spirit of fun and generosity, last fall the veteran cruise director worried maybe he'd asked too much.

He'd hit upon a new way to blend Carnival's support of St. Jude Children's Research Hospital with its reputation for unforgettable fun. As the maiden transatlantic voyage of the new Carnival ship Celebration neared the U.S., Mason would walk the ship's track for up to 24 hours, if passengers were to donate \$28,800 for St. Jude – calculated at \$20-per-minute for total 24-hour duration.

Carnival passengers had met Mason's previous audacious challenges, like when he promised aboard the Carnival Splendor, to shave his head if passengers pledged \$15,000. To which the guests responded to his call to action, exceeding his proposed target, raising \$40,000. It was on the same Splendor cruise that a grandmother stopped Mason to show him a photo of her baby granddaughter – in a hospital room, attached to IVs giving her body the medicine needed to fight cancer.

"Thank you for your passion," Mason remembers her saying. "It's because of St. Jude I still have my grandchild."

Reflecting on his hikes around the Celebration track, he thought of Bridget, a St. Jude patient with a prosthetic leg because of bone cancer, and how she confidently

Carnival cruise directors mix fun and purpose to rally support from passengers for St. Jude. toured the Celebration with him following the naming ceremony. He thought of her artwork on board helping infuse the voyage with a greater sense of purpose, and the words of Bridget's mother, Jamie, that Mason said "will stay with me forever."

"Thank you so much for what you do," Jamie had said to Mason. "But not just for St. Jude, not just for Bridget, not just for me ... but thank you for every parent who has ever received that awful news their child is not well."

Mason and other cruise directors have played such an integral role in the partnership with St. Jude (more than \$25 million raised since 2010) that the annual cruise director conference is held in Memphis, with St. Jude tours included. When Carnival emerged from the industry-wide cruise shutdown in 2021, the company raised its St. Jude fundraising goals, aiming to hit the \$33 million in the next four years. The centerpiece of those efforts is a final-day dance party called "Groove for St. Jude."

As Mason's walk gained momentum, his onboard duties were taken over by Mike Pack, the Carnival Fleet Cruise director who was on board the Celebration. Pack has his own playlist of inspiring stories of St. Jude support from passengers when he was a ship cruise director.

"St. Jude is part of our cruise culture and identity – it's embedded at the heart of everything we do," Pack said. "For many of the Carnival family, as we call them, St. Jude has become near and dear to their hearts as well. And then there are people, maybe on their first Carnival cruise, already passionate about St. Jude, really respecting Carnival and adding to their experience."

That passion propelled Mason on his walk, accompanied by his mother and other Carnival guests, including a woman in her motorized scooter. Mike brought pizza and lemonade, and Mason ate as he walked.

It soon became evident Mason would not need 24 hours – the per-minute fundraising was well exceeding \$20. Lee's new friend, sidelined because her scooter ran out of charge, stayed and called out final laps and fundraising totals – more than \$40,000 for the walk and more than \$60,000 after the final "Groove for St. Jude" celebration.

"Oh, it means so much because I say it and I mean it, that I know some of us have lived a blessed life and can give an extra \$10 or \$50 or \$100 for those kids at St. Jude," Lee said. "I feel so fortunate to have this job with Carnival. I have this platform and I believe using my voice and passion for St. Jude, it balances my own scoresheet."

Just before Christmas, Mike Pack, Lee's boss, was back at his home in England tuned into a virtual holiday celebration featuring St. Jude patients and parents. With a 1-yearold daughter now, Mike says the St. Jude connection with Carnival is even more meaningful for him.

He found the words of one mother during the call, of patient Victoria, especially poignant.

"I am forever in gratitude to you," she said. "Nothing in this world will be enough to say thank you that I can celebrate every holiday with her. And your contributions not only help us, they help the whole world."

> 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/ImpactGiving**

St. Jude supporter Lee Mason

By Kristina Goetz - ALSAC

How do you explain childhood cancer

when there's no word for it in your language?

Akua Sarpong lost a daughter to cancer in Ghana and now heads a charity that partners with St. Jude to help other families through the same journey.

> n Ghana, people speak more than 70 different dialects – and not one of them has a word for cancer.

The closest in Ga is *helon fala*, deep skin wounds. In Twi, it's *kukram*, a deep wound that never heals – or simply *owuo*. Death.

> "Where do you even start?" asked Akua

> > :::::

Sarpong, executive secretary of Lifeline for Childhood Cancer Ghana, a charity that works to save the lives of children with cancer. "I can't break it down to a family. And if I can't break it down, how do I explain symptoms? How do I explain the treatment procedure?"

In this West African nation where education is limited, literacy is low and healthcare is difficult to access, the understanding of cancer is often shrouded in mystery or tangled in taboo.

Sarpong's organization, a member of the St. Jude Global Alliance, works to educate parents to recognize early symptoms of cancer and to demystify the disease: Cancer is neither a curse nor contagious.

"Because of the myths and the belief system, that's why we have such low survival rates," Sarpong said. "Because normally, if a parent hears that their child has cancer, they'll convince themselves that their child will die anyway. 'So, let's just take the child home and keep the child in. Eventually, the child will die."

Sarpong, a well-educated, middleclass entrepreneur who speaks three languages – two Ghanaian dialects and English – knew what cancer was. But she didn't know that children could get cancer until her own daughter was diagnosed on April 23, 2016.

"I had three children," she said. "A boy and –" she stopped herself. "I struggle to say, 'I had' and 'I have.' To me, she's still here."

When Sarpong's twins were just 17 months old, the older one – headstrong but sweet – stopped eating. She had headaches. She was lethargic. But the general practitioner said she must be teething. When the bright little girl's stomach bulged slightly, Sarpong sought a pediatrician for a second opinion. That doctor said it was probably constipation or gas.

As the stomach bulge grew, Sarpong returned to the doctor. An ultrasound showed a mass in her daughter's stomach. When Sarpong read the report, she noticed a word she'd never seen before: neuroblastoma.

She had no idea what it meant. Sarpong went back to the pediatrician for answers. "And she said, 'Oh, gosh. Your child has cancer," Sarpong remembered.

She said the word in English.

"What?" Sarpong said. "'Your child has cancer. Oh, you should go to the hospital immediately.' Please. Slow down. My child is supposed to have constipation or gas, according to you. How does it go from constipation to cancer? I mean, I was traumatized."

Sarpong's daughter was referred to Korle Bu Teaching Hospital in Accra. It took 10 days of tests to reach a final diagnosis: It was rhabdomyosarcoma, a cancer of the soft tissue.

Treatment began immediately, but Sarpong's daughter didn't respond well.

The doctor suggested Sarpong take her to South Africa – nearly 3,000 miles across the continent – for more sophisticated treatment. Sarpong could afford it – a luxury few Ghanaians have – so they boarded a plane in June.

Finally, after three months of chemotherapy and a surgery in September, the tumor was gone. Sarpong and her family celebrated. She took her daughter back home to Ghana to continue treatment.



By March 2017, Sarpong's daughter was well enough to go back to school. But then, at a checkup that August, the oncologist felt something on the girl's belly.

Her daughter had relapsed. Sarpong's daughter died April 28, 2018.

Sarpong needed an outlet. That's when she learned Korle Bu Teaching Hospital was looking for a way to direct donations to the pediatric oncology unit. Sarpong became one of the founding members of Lifeline for Childhood Cancer to raise funds for the treatment, care and cure of children with cancer in Ghana.

Last August, basic pediatric cancer care was added to the national health insurance program, but only for four types: Wilms tumor, Burkitt lymphoma, acute lymphoblastic leukemia and retinoblastoma. The coverage is not comprehensive.

"It's out of pocket so, really, if we don't do it, the children will die," she said. "... Our incomes are low. So, between buying food and buying chemotherapy for a family, you think about it."

Lifeline for Childhood Cancer Ghana provides funding for medicines, psychosocial services and job training for mothers whose children are in treatment. LCCG also helps fund the Rebecca Akufo-Addo/GHAPACC Sunshine Hostel where children and their families stay at no cost while they receive treatment.

LCCG is now working on a capital campaign to raise more than \$1 million for a new pediatric oncology ward at Korle Bu, which will increase the number of beds from 25 to 40. Sometimes, the ward is so full that children sleep on mattresses on the floor. There are only two major urban centers and five pediatric oncologists in a country of 32 million people.

In 2020, LCCG became a St. Jude Global partner to gain expertise and guidance on how to raise money to help more kids with cancer in Ghana live. In 2022, Sarpong visited the St. Jude campus in Memphis for training along with other foundation members from around the world.

Sarpong is hopeful for the future of children with cancer in her country. And her work will continue in honor of her daughter.

"She was beautiful," she said. "Her name was Akua Anane Akuoku Sarpong."

It was the first time in Sarpong's story she said her daughter's name. It means a girl born on Wednesday – and a fighter.

"I am grateful to my daughter, for what she did for me and where she's brought me. This was never my pathway. No. I never would have imagined I would be here. But I think God had a purpose, and I think that purpose was through my daughter. She lives on."

THREE unite for the St. Jude **MISSION**

Joining forces to fight cancer and honor their kids, they embarked on the ultimate endurance test.

By Betsy Taylor - ALSAC

hree dads – Chris Frunzi, Chris Corbett and Tim Sparer – who probably never would have met had it not been for St. Jude Children's Research Hospital, joined forces last fall to compete in an ultimate endurance test: the St. Jude IRONMAN 70.3 Memphis.

The trek honored their children Jackson Frunzi, Calvin Corbett and Sierra Shuck-Sparer; as well as Bennett Frunzi, who passed away from brain cancer on April 3, 2021, when he was 3 years old. St. Jude provided their care.

The grueling event – a 1.2-mile swim and 56-mile bike ride, topped off by a 13.1-mile run – required months of training. But as Frunzi said, "This little triathlon" – which reduces some participants to tears and leaves others collapsing in a heap at the finish line, if they even finish at all – "is nothing compared with what Jackson and Bennett have been through" as children undergoing treatment for cancer.

A way of coping

Frunzi's two young boys, Jackson and Bennett, were diagnosed with cancer within months of each other in early 2019.





#CalvinStrong

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BENNETT

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St. Jude patient dads (front to back) Chris Corbett, Chris Frunzi and Tim Sparer prepare to cross the finish line of the St. Jude IRONMAN 70.3 Memphis with photos of their children in hand to the cheers of spectators.

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That's when the 6-foot-9,

300-pound police officer, who says, "I'm not a runner, I'm not a biker, I'm not a swimmer," turned to fitness as a way of coping. "Exercise has always been a good stress reliever for me."

He began going to the gym and running up and down the steps at St. Jude patient family housing. He said the exertion was even more beneficial for him than talk therapy.

When Frunzi saw a social post about the St. Jude IRONMAN 70.3, he decided to not only register, but encourage two other St. Jude dad friends, Corbett and Sparer, to do the same.

Supportive texts

Ever since hearing about the St. Jude IRONMAN 70.3, Chris Corbett, who already had one IRONMAN under his belt, wanted to compete in his son Calvin's honor while supporting St. Jude.

Calvin's treatment at St. Jude for rhabdomyosarcoma, a soft tissue cancer, began in 2018 and has included proton radiation therapy and chemotherapy. Today, the jokey kid who loves Huskers football is back home and doing well.

An injury prevented Corbett from participating in the St. Jude IRONMAN 70.3 the previous year. Like Frunzi, Corbett is a big guy at 6 feet, 6 inches, so the two men traded tips on nutrition – specifically, how to carb-load during the event.

Getting in the workouts wasn't easy for Corbett, a dad of four whose career as a train engineer requires many hours far from home.

The three dads kept in touch by text messaging to provide support to each other.

"I would text him, 'Hey, I had a crappy workout. Bad day. Just not feeling it today," said Frunzi. "And just hearing that another (person felt the same), you know ... kind of keeps us all going."

Friends through hardship

Tim Sparer jokes that at 5 feet, 11 inches and 175 pounds, he's destined to be known as the short guy on the team, but that's OK with him. This was his fourth IRONMAN and first for St. Jude.

Sparer met Frunzi in 2019 when the latter gave him a lift to the auto mechanic after his car broke down at St. Jude. "Chris is just such a super nice guy," said Sparer. "Just went totally out of his way (even) with two kids in treatment and, you know, totally helped me out in a really tight situation, and I always appreciated that."

Sparer's daughter, Sierra, had been undergoing treatment for medulloblastoma, and Bennett was newly diagnosed, so during the car ride to the mechanic, Sparer shared what to expect during treatment.

They've been there for each other through Bennett's brain tumor recurrence and Sierra's, as well as Bennett's passing last year.

"Definitely talking to someone who's been through it makes a difference," said Sparer.

Today, Sierra attends college as a Public Policy major, balancing her coursework with maintenance chemo.

Unstoppable

The three dads hope their personal stories will motivate other parents of kids who have cancer to begin a fitness journey of their own. They also hope their feat brings awareness of childhood cancer and much-needed funds for St. Jude.

"(St. Jude) is one of the best places," said Frunzi. "If you have cancer and have to go somewhere for treatment, the doctors are amazing. Everyone is amazing, so we're trying as a family to give back to the hospital and kind of get more people involved and donating."

Even now that Bennett is gone, Frunzi says Bennett's doctor has been unstoppable in his quest for a cure for patients who have treatment-resistant medulloblastoma. "He still hasn't given up," said Frunzi. "He texts me, you know, usually once a month, or I'll text him just to see how research is going and see if he has any breakthroughs because I'm waiting for the day that he calls us and says, 'Hey, I've figured it out."

Through all the hours of training and grueling competition, Bennett and Jackson motivated Frunzi, and he had a special reason to celebrate Jackson at the event.

Jackson's treatment at St. Jude for acute lymphoblastic leukemia and acute myeloid leukemia included 14 months of chemotherapy, as well as two bone marrow transplants.

October 1, the day of the St. Jude IRONMAN 70.3 Memphis, marked

the two-year anniversary of when Jackson received his mother's lifesaving cells through a bone marrow transplant at St. Jude.

Jackson has been cancer-free ever since.

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



Help St. Jude give every child with cancer a chance

St. Jude patient Myla, pictured with her mom

Thank you for being a monthly donor.

Because of your selfless generosity, families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live. You can maximize your support to help even more St. Jude kids. Consider making an additional one-time gift this month to make an even bigger impact. Your support helps St. Jude make it possible for children to live, no matter where they live.

\$25

Could help St. Jude provide one day of meals for a patient in the Kay Kafe, the hospital cafeteria

\$50

Could help St. Jude provide one bone marrow needle for a patient



Could help St. Jude provide a red wagon used to transport patients through the hospital



Scan the QR code to visit stjude.org/hope and make an even bigger impact.





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501 St. Jude Place Memphis, TN 38105

Phoenix's amazing progress

Phoenix was only 17 months old when he, his mother and grandparents drove one Christmas Day from their Arkansas home to St. Jude Children's Research Hospital[®]. Phoenix was sitting in the car seat, smiling and playing. His mother and grandparents, though, were deep in prayer. Days earlier, an eye specialist had discovered tumors in both of Phoenix's eyes and referred him to St. Jude.

Doctors at St. Jude confirmed Phoenix had bilateral retinoblastoma, a cancer of the retina, and soon began treatment that included aggressive chemotherapy to save the right eye which had more than one tumor. Phoenix, who has autism, responded well to the treatment, which lasted more than a year. "He has his vision because of St. Jude," his mom, Pamela, said. "I wish people could see his journey, and see where he is now. He is amazing."

You help bring hope and healing to patients like Phoenix 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? Learn more at **stjude.org/ImpactGiving**