

Overcoming loss

Brumfield family finds compassionate care at St. Jude **Giving hope**

Foundation in Philippines teams up with St. Jude to help kids Going the extra mile

St. Jude Hero is driven by compassion





hange is in the air at St. Jude Children's Research Hospital® – so fitting for the season.

Last month, we celebrated the opening of The Domino's Village, the newest patient family housing facility at St. Jude. This beautiful facility can house families in 140 one-, two- and three-bedroom apartments right here on our campus so patients don't have to travel for medical appointments. We're so grateful to our partners at Domino's and all our supporters for making this dream a reality.

But we also realize not every child with cancer can travel to Memphis and St. Jude, nor should they have to. We're incredibly excited that a new initiative by St. Jude and the World Health Organization will soon begin distributing consistent, quality assured cancer medicines to countries in need at no cost to those countries.

St. Jude is investing an estimated \$200 million in this effort, which will impact more than 120,000 children with cancer in 50 countries within five years.

This is all thanks to you.

These and other changes coming locally and globally will help more kids like Maelin, who you'll read about in this issue of St. Jude Inspire. Maelin came to St. Jude to be treated for Fanconi anemia, a rare genetic blood disease, and today, her mom says, "she's just the happiest,

most loving, most excitable human on the planet."

I agree with her mom. She is amazing and so inspiring.

And you help whole families like the Brumfields. Their oldest son, Nick, was 19 when he passed away from a brain tumor. His family was devastated, of course. Even more so when, just one year later, Nick's brother Jacob was diagnosed with a brain tumor.

St. Jude is caring for Jacob and monitoring the Brumfields' youngest son, Josh. The Brumfield family understands what St. Jude research can mean for the future, and how your support fuels hope. They've seen it first-hand.

As the temperatures cool and leaves turn color, I hope you'll embrace change. As Maelin's mom says, "Hope changes things."

I truly believe that, because at St. Jude we know change for the good can mean a second chance at life for kids everywhere, thanks to you.

puil

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Special thanks to St. Jude President and CEO James R. Downing, M.D., and St. Jude Communications and Public Relations.



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Foundation in Philippines collaborates with St. Jude to help children with cancer.



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**



CLEAR BASILING
FOR Chile
The boy from Chile
Teturned to St. Jude for

returned to St. Jude for an important medical check-up.

ву Monsy Alvarado - Alsac

ucas was excited, yet calm. He felt things were going to work out OK.

His mother, Daniela, was excited too, but worried about what was to come.

The flight from Chile to Memphis was more than 12 hours with a layover in Dallas. They had been to Memphis several times in the past, but this trip was different.

If all went as hoped, their journey to St. Jude Children's Research Hospital® would end with a huge sigh of relief and prayers of thanks. Lucas was just 3 years old when he arrived at St. Jude to receive cancer treatment. This visit. however, marked more than five years of being cancer-free – a milestone in cancer remission.

This anniversary also meant he would move to the St. Jude After Completion of Therapy (ACT) Clinic, which specializes in long-term follow-up for patients who had childhood cancer.

"I don't want to get ahead of myself, it's clearly a long-awaited moment and we pray to God to allow our beloved Lucas to reach it," Daniela said a few days before their arrival.

The days were cold when they arrived at St. Jude on a Sunday in March 2023. In Santiago, the capital of Chile, they were enjoying the start of autumn with sunny days and mild weather in the 70s and 80s.

But Lucas was content because he was visiting his second home, as he often describes the specialty research hospital. He was going to see doctors and other staff who had been with him throughout his treatment. His happiness was so great that undergoing medical examinations, some that required needle pinches and blood draws, did not dampen his joy.

"Some things are painful, and some others are not, but in the end, everything is [fun] here," he said.



Lucas fist bumps Dr. John Lucas, MD, following a check-up at St. Jude in March 2023.

Daniela, though, was cautiously optimistic. She could not help but think of all the days, nearly two years, spent at St. Jude living through one treatment after the next. During those days, she prayed that her little boy, her only son, would survive the high-dose chemotherapy, proton radiation, surgery, antibodies and a bone marrow transplant with all its after effects.

Once he completed treatment and they returned home, her prayers centered on his well-being and that the cancer would stay away.

"There is always a share of concern, which we obviously try to camouflage a bit," Daniela said. "But God is always great and accompanies us on this path and on this journey. And we always come with a lot of hope and with a lot of faith."

At home, Lucas was thriving, a boy who lived life to the fullest. He was in school. He had recently received the "all-around student" award. He was friendly, sociable and athletic. After school, he played soccer and football and enjoyed fishing. He was an avid skier and sailor, steering his own single-sail vessel. He has made many friends who are fellow sailors.

Sailing has been a sport practiced by his family for decades. Both his father and grandfather own boats named after St. Jude. One boat is named "St. Jude" and the other, "Memphis." Lucas is always ready to sail, a sport that allows him to feel the wind, breathe the sea air and feel the heat of the sun on his skin while taking in the ocean views.

"My goal is to keep sailing and keep having a good time," Lucas said. "I like navigating a lot because it gives me a lot of time with nature, and it is very entertaining."

Sailing was on his mind as he walked into his doctors' appointments at St. Jude at this five-year mark. He had been feeling back aches after long days of sailing. While he headed into his medical appointments, he wondered about his future exploring the ocean. Would he still be able to sail? Compete?

An alarming diagnosis

Lucas was 3 years old when he was diagnosed with neuroblastoma after experiencing severe stomach pain and vomiting. Neuroblastoma is a type of cancerous tumor that generally develops in the adrenal glands and almost always affects children.

Tests showed that tumors within Lucas' abdomen had spread to his spinal cord. The prognosis was poor.

"It was news that you never expect," said Daniela. "The pain is indescribable, it's like one is paralyzed."

Doctors in Chile referred Lucas to St. Jude, about 5,000 miles from Santiago.

Daniela and her husband, Carlos, had never been to the United States. They had planned to visit for the first time and had even bought tickets to take Lucas and his older sister, Sofia, to Disney World in Florida. But the cancer diagnosis scrapped those plans and the couple's focus turned to Lucas and getting him to Memphis as quickly as possible.

When she arrived at St. Jude,
Daniela remembered feeling
comfort right away. She met
doctors who told her they would do
all they could to save her son. She
was certain they would.

Through every new treatment, Daniela said, doctors kept her and her husband informed and encouraged them during tough times. She said she's grateful to nurses, staff and donors who continue to help children like Lucas. time they had been to Memphis was about a year-and-a-half earlier for Lucas' annual check-up. The first day was filled with appointments that included a blood screening and scans.

They made sure to stop by the chapel on the second day, one of their favorite places on the St. Jude campus, to say their prayers, to give their thanks.

By the second day of tests and medical appointments, Daniela was optimistic after being told that one exam they expected Lucas to undergo was canceled because all the previous tests and

OK to keep sailing. Lucas was already planning to participate in his second regatta on his return home.

"One of the things that worried me that I asked the doctor, is if I could sail and he said there would be no problem, and that is what I wanted to ask him." he said.

Daniela said Lucas, who is now 10, has been pushing for more independence.

"It was like a step towards greater freedom for him, and to be able to show that he already has the ability and strength to move on," she said.



My goal is to keep sailing and keep having a good time.

- Lucas, St. Jude patient



"Every time the road becomes difficult, and one is stumbling, the best memories I have is that there were always angels here in the halls of St. Jude who took you by the arm and made you keep walking," she said.

A future at sea

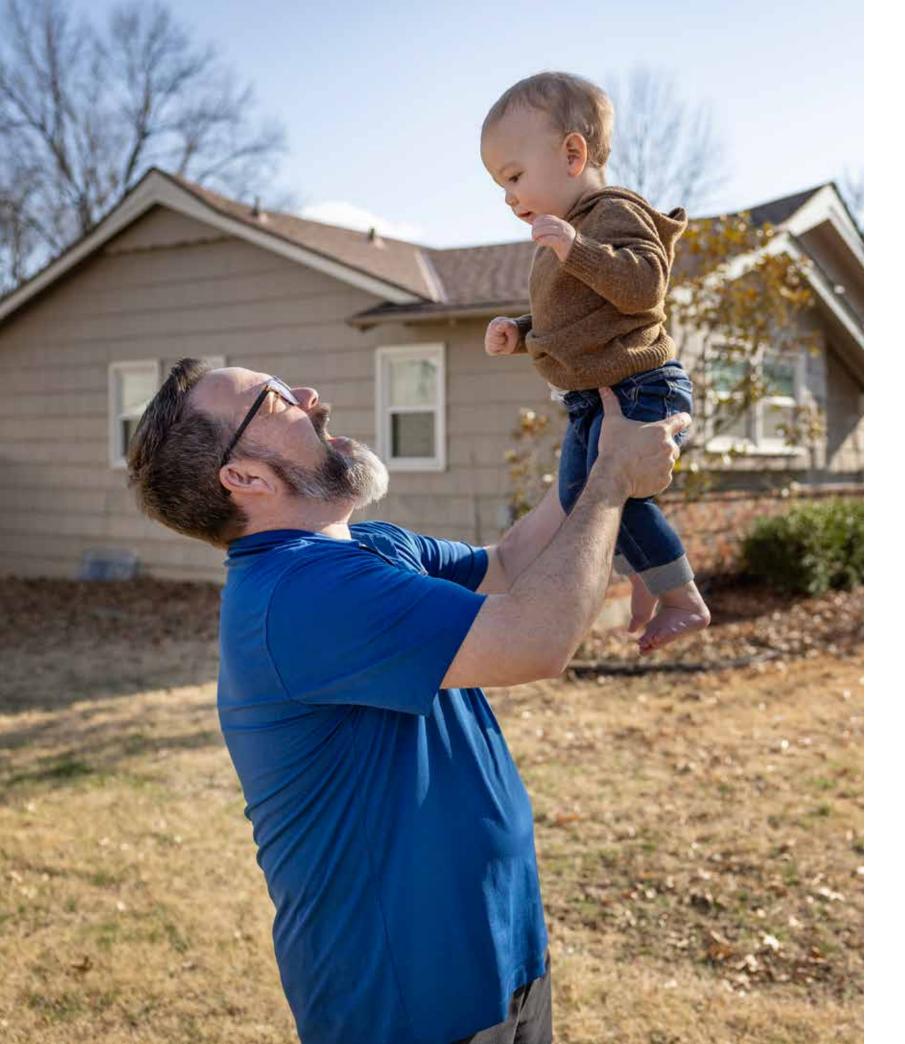
More than five years later, Daniela and Lucas found themselves walking the halls of St. Jude again. The last scans had turned out well. Doctors also checked Lucas' back.

When they met with Lucas' lead doctor, he told them there were no signs of cancer. They hugged, overwhelmed.

"I gave him my thanks for his dedication during such a long time of treatment," Daniela said. The doctor also gave Lucas the 2

Your donation can help ensure patients like Lucas can keep sailing. **stjude.org/ ImpactGiving**

Fall 2023



After two cancer diagnoses and a third scare, St. Jude offered compassionate

care for the Brumfield family.

By Ruma Kumar - ALSAC

Art by St. Jude patient Nick

hinking back on it now, the dream feels like an eerie premonition.

When he was 17, Nick Brumfield had a vision of a shapeshifting dragon, chasing him through a thick grove of oak trees. It was swift and everchanging until it forced him into a raging river. And then the dream ended as abruptly as it began.

The next morning in class, he drew the dragon on wide ruled notebook paper instead of taking science notes.

A year later, the usually athletic Nick, a kickboxer and avid outdoorsman, suddenly struggled with headaches, body weakness and shaky balance. This time, the swift shapeshifting force threatening his life wasn't a dragon. It was cancer.

When they recall that time, Nick's parents, Joe and Latina, remember their son's illness coming at the worst possible time for the family. Not that there's ever a good time for cancer.

It was the summer of 2010. The family of five was in the middle of a big move from Memphis to Springfield, Missouri, where Joe, a pastor, was about to lead a new church and congregation.

They were at a farewell party hosted by friends in Memphis when Nick, an experienced swimmer, nearly drowned in the pool and had to be pulled out by his father. His legs and one arm suddenly felt heavy and weak, Nick told his family.

He was rushed to a nearby hospital, where scans showed Nick had brain cancer known as anaplastic astrocytoma.

"It's horrifying. It's a train wreck in your life," Joe said. "As a parent,

you don't go through your life imagining, well, what will I do the day that my child is diagnosed with cancer? So, when you hear that your child has cancer, it hits you so hard because you don't anticipate it. There is absolutely nothing to prepare you to hear those words."

Nick's tumor was soft like jelly and had developed in the the thalamus - a deep-lying part of the brain responsible for relaying signals of sensation, such as temperature, pain and touch, and signals for movement.

He was quickly referred to St. Jude Children's Research Hospital[®], where doctors gave the family more sobering news. Nick's tumor was aggressive and likely to spread quickly. Joe and Latina said doctors told them Nick would have less than two years to live.



Jacob and Josh hold a portrait of their late brother Nick, who was treated at St. Jude and passed away from brain cancer in 2011. Jacob also had a brain tumor the following year and was treated at St. Jude.

Nick the hero

Because Nick was 18 when he was diagnosed, he was old enough to listen and understand as the doctors discussed his prognosis; and he was legally old enough to make decisions about his treatment, too.

What makes St. Jude unique, his doctors told him, is that they work closely with scientists to conceive, launch and run their own clinical trials.

This model, doctors told Nick, sometimes allows St. Jude to bring patients care that is not available anywhere else. There's a sense of urgency behind this work, too. After decades of steady rise in the United States – in part facilitated by research led at St. Jude – cure rates for cancer in kids plateaued. So, St. Jude increased investment in basic science research and clinical trials to develop newer, more effective and less toxic therapies, hoping to boost cure rates. This robust investment in research gives St. Jude scientists and doctors data to share with colleagues and clinics across the world.

As Nick sat in his hospital bed, his care team was about to leverage that cumulative knowledge built over decades through collaborations with experts in pediatric cancer from around the world.

Doctors were honest with Nick: It might be too late to help him survive his cancer, but what they would learn from his case could help another child live.

Nick listened quietly as they went through those details, and then before he signed himself into the study, his parents heard him say, "Well, if it will help somebody, then I'll do it."

Nick's father Joe wasn't surprised. He knew his son was fascinated by hero stories, movies like "Braveheart" and "The Last of the Mohicans." Stories that explore a dark time and the sort of character it takes to vanquish it.

"From the beginning of his diagnosis, Nick saw himself as a hero of sorts," Joe said.

Sobering prognosis

Nick had several surgeries that succeeded in removing portions of his tumor but not all of it because of where it was in his brain. He received more than six weeks of radiation and then nearly 15 months of chemotherapy, which made him nauseous and weak.

As difficult as his symptoms and treatment were, Nick told his parents he had a plan to enjoy at least one good thing every day. Sometimes, that good thing was eating a donut. Or a walk outside for just a few minutes. And on the days his nausea wasn't too bad, it was enjoying his favorite Mexican meal.

"We knew from the beginning that his prognosis was not good and yet St. Jude did everything they could," Nick's mom Latina said. "If he couldn't keep food down, they made sure that he was nutritionally getting what he would need through an IV. He had some deficits walking and using his arm, so he received physical and occupational therapy. St. Jude made sure that whatever time he had left would be quality time for him and for us. That meant the world."

And it was all free. Because of generous donations from supporters, Joe and Latina never received a bill from St. Jude for treatment, travel, housing or food so they could focus on helping Nick.

"When you're going through something so traumatizing, if you don't have to worry about what this is going to cost, it's just a huge blessing," Latina said. Nick passed away in October 2011, 16 months after his diagnosis. He was 19. He donated the tissue from his brain and tumor to St. Jude to help doctors and scientists better understand the brain cancer that took his life.

"I don't think it's really possible to put into words the loss of a child. It's terrible, awful. Because raising children – raising this other human being that you love so incredibly much – it changes us," Joe said. "So, when that person is gone, you lose a bit of yourself, too. A part of you dies with them."

Inspiration in life – and death

In Nick's last days, what his brothers and parents most remember is the peace Nick embraced knowing he had lived life on his own terms, in the fullest way he knew how. Seeing how he lived – and died – inspired the family's closeness, and faith.

They carried on the best way they knew how, with Joe and Latina focusing on family and finding humor and grace whenever possible. They spent their days helping their surviving teenage sons, Jacob and Josh, as they navigated high school, found first loves and became active in church mission projects.

They talked about Nick casually in conversations, during family dinners and birthdays, hikes and church youth trips because he was still a part of them even if he wasn't there.

They recalled the strangest details when they least expected it. Random things like when Nick dragged Jacob to the woods to catch cottonmouth snakes in the river bottoms. Or his daring habit of choosing the tallest tree to climb

or the biggest hill to skateboard down and, of course, go the fastest. They even joked how they never would've guessed it would be cancer that finally got him.

Nick lived his life at full tilt, his younger brother Josh said, "constantly at 110 percent."

His athleticism, his aloofness, his defiance made Nick such a dynamic and charismatic figure in their lives. His loss left them feeling hollow, but also grateful that they'd had the chance to know him as long as they did.



Another diagnosis

Joe and Latina decided to form a team and run in the half marathon during St. Jude Memphis Marathon Weekend in December 2012 to honor Nick's memory and the work the research hospital did to help him.

But suddenly, just months before they were due to run the marathon, their son Jacob woke them up in the dead of night in October and said he'd just collapsed and thrown up.



the tumor. Jacob didn't need further treatment like radiation or chemotherapy.

When they removed Jacob's tumor, Joe and Latina said doctors and researchers at St. Jude tested it against tissue samples from Nick's to see whether they shared similarities. There were none. But Joe and Latina said they were thankful for that moment when the loss of their older son helped doctors know more about how to approach treatment for their second son's condition.

The family also received genetic testing at St. Jude to see if there were mutations or patterns that predispose them to cancer. At St. Jude, genetic testing is done to help doctors and scientists better understand the origins of cancer in patients and families and discover the unique mechanisms at work that make the disease so devastating. In the future, genetic testing and sequencing could also lead doctors to develop ways to cure cancer, or even stop cancer from occurring in the first place.

Since both his older brothers had brain cancer, Josh asked for a scan, too. Shockingly, doctors found a dark spot on his brain as well, a "lesion" they called it. It was a shadow, a threat of something abnormal, but it wasn't cancerous.

Barely six weeks after Jacob's brain surgery and Josh's scans showing a lesion, the family was in Memphis running the half marathon to support St. Jude. They had 96 members on the team.

They had been through something few families had, having lost one son to brain cancer and then having had one rebound so quickly from it. Both treated at the same place, without receiving a bill from St. Jude, and a third son monitored for a brain lesion.

"It's been crazy to think that this is the way that life has gone, to even think that all this happened," Jacob said. "It almost feels like a memory in some ways. It's like some kind of dream. A crazy story that you don't really fully believe. But then you're like, no, this actually happened to me, to my family."

Given his history, Jacob was monitored over the years. He also enrolled in the St. Jude Long-Term Follow-Up Study protocol to help St. Jude collect information about the effects that childhood cancer and treatment has on survivors.

Enduring and emerging stronger

"Our family owes such a debt of gratitude to St. Jude for everything that they've done," Josh said. "Because of St. Jude and the way that they took care of us, there was always this silver lining of hope. We were constantly getting care from people that really want to see you do well."



He had a seizure as they tried to help him. And a terrifying reality hit Joe: Is this happening to us again? Another son with brain cancer?

Down the hall, their youngest son Josh said he panicked.

Am I about to lose another brother? he worried.

The next day, doctors at their hometown hospital confirmed the family's fear: Jacob had a mass in his brain. This time, in the frontal lobe, a different location from Nick's tumor, but it was irrefutable proof: Brain cancer had hit their family again.

"My immediate reaction was anger," Joe said. "This is wrong. This is unfair. For us to have two children in one family just felt punitive. It just makes you question everything."

Sense of hope

Pediatric brain tumors are the second most common type of childhood cancer, but they are affecting fewer than 5,000 kids in the U.S. each year. That's roughly five out of every 100,000 kids. Joe and Latina found themselves in a rare class.

But Joe and Latina said in that moment they felt a surreal sense of hope because they knew exactly where they had hoped to take Jacob: to St. Jude.

Within hours, the family's oncologist in Springfield referred Jacob to St. Jude and the family was on an ambulance to Memphis. Jacob was scheduled for surgery within days.

To the family's relief, the surgeon was able to completely remove

"Our family owes such a debt of gratitude to St. Jude for everything that they've done."

- Josh Brumfield, Nick's brother



And a decade later, both Jacob and Josh are doing well.

Like his father, Jacob became a pastor in a church in the foothills of the Ozarks in Northwest Arkansas. He is married and has a young son whose middle name is Nicholas to honor the uncle he will never meet, but who he will hear about, like legend.

Jacob has a barely visible scar on his head, the only obvious mark left of his time with brain cancer, aside from the occasional dark joke he cracks about surviving it.

Josh got married, too, and has a young son born within weeks of his brother's. He works on a crew that installs roofs, enjoys hunting and fishing like his late older brother, and is popular among his coworkers for making the best venison breakfast tacos. He lives a few miles from his parents' home in Kansas.

Josh's son is just about ready to start taking his first steps and likes to hear his father play folk songs on his guitar. When Josh goes in for occasional scans, doctors still see a lesion on his brain, but it has not grown or changed, so Josh doesn't focus on it.

"I've got a beautiful family. I've got a house to live in. I've got a job that I enjoy doing. Friends that mean the world to me, a church family that is supportive and I know I can rely on. And I've got two good dogs," Josh said.

"What else I could ask for?" he said.

Meanwhile, Joe and Latina are cherishing their lives as grandparents and are active leaders in their church.

On a breezy afternoon, as Joe pushed one of his grandsons in a swing under a large oak in their front yard, he said it is not always easy to reflect on what his family has endured, though he can say they are now stronger for it.

"Childhood cancer is horrific. It should never happen. There's that saying, 'Look on the bright side of things.' Tell me what the bright side of childhood cancer is. There's not one," he said.

"But there is St. Jude. And St. Jude is a difference maker. Because at a time when you need it most, hope is extended to you. Grace is offered, blessings are extended. You see that happen at every corner of that place.

"And it's hard not to be encouraged in a place like that where you're there because something horrible has happened to you. But what you find there is people helping you pick up the pieces of that busted up dream that you had of how things were going to go. And they tell you keep pressing, keep living."



Research and treatment at St. Jude is possible because of generous supporters like you. stjude.org/ImpactGiving



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This holiday season, we give thanks for our family of corporate partners. Support St. Jude by giving online or in-store through these brands.



LIFE AFTER TREATMENT

Pediatric cancer treatments save lives but can increase health risks for survivors during adulthood. St. Jude LIFE is an unprecedented research study that brings childhood cancer survivors back to St. Jude for regular health screenings throughout their adult lives to help understand the long-term effects of cancer treatments.

Q: What does your work here at St. Jude Children's Research Hospital® involve?

A: The St. Jude Lifetime Cohort Study hit the ground running in 2007 and is open to five-year survivors treated for cancer between 1962 and 2012 at St. Jude. Former patients visit every five years and undergo several days of comprehensive testing. We test for everything. It was initially for adults, but now the program has been enlarged. We have a human performance lab. We do strength and balance testing. We do exercise testing where they walk on a treadmill. If they aren't able to do that, we have a bike. We do neurocognitive testing. How are these adults doing with computation skills? Are they able to work? How are their social skills with friends, family? We see what their fitness levels are every five years. And there are interventional trials to decrease the risk of other cancers, heart disease, early diabetes, frailty. We measure over time and we measure for a lifetime. Long after I'm gone, this will continue.

Q: How is this information used?

A: We are now able to help their local physicians learn more about their problems and to intervene for them. We have over 6,000 patients including Dwight Tosh, patient #17, who was treated here in April of 1962. He comes every five years along with all these others.

Q: What happens to patients after the completion of their cancer treatment

A: The After Completion Therapy Clinic was established in the mid-1980s so the active treating doctors could transition their patients to a clinic where they could learn more about long-term problems. They knew that cancer was behind them, but the rest of life was ahead. They come to us when they're five years past diagnosis and at least two years past the end of their therapy, so the chance of relapse is pretty low at that point. We see them annually or more often if needed until they're 18 or reach high school or 10 years after their diagnosis. So, if they come to us as a 17-year-old, we'll see them until they're 27.

Q: What happens at the ACT Clinic?

A: We look at their treatment and find out what were the problems that were known to have occurred after that treatment over time. And (we) begin to educate them and their families. During these visits we do riskbased assessments. They see our social work team. We have neurocognitive testing. That's the most common problem after childhood cancer, neurocognitive issues – memory, processing speed. We begin to educate them and their families, so they are able to advocate for themselves. And we assist them with their local healthcare providers. I knew virtually nothing about this 16 years ago. We are now able to help their local physicians learn more about their problems and intervene for them. I've been blessed to be able to speak to large groups of physicians at statewide meetings and been well received because of the information I can share from St. Jude with them.

Q: Why is this so important?

A: The majority of adults treated for cancer during childhood do not receive ongoing care that considers screening and prevention of health risks related to cancer treatment. And many oncologists and most primary care providers are not familiar with risk-based health screening recommendations for childhood cancer survivors. Each year in the U.S. about 16,000 are diagnosed with pediatric, childhood and adolescent

70 or 80 and have a cancer diagnosis, you may lose 5, 10, 15 vears of life. If you're 2, you might lose 80 years of life.

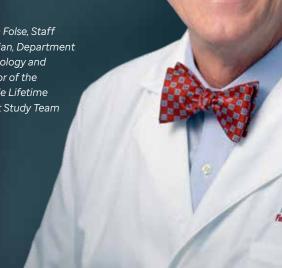
cancer. It pales in

comparison to adult

cancers, but it's still

huge. Because if you're

Dr. Tim Folse, Staff Physician, Department of Oncology and Director of the St. Jude Lifetime Cohort Study Team





Adalyn

Love strict Signat

From the moment they saw the photo of the smiling face from the adoption agency, Megan and Paul knew they would do anything for their new daughter.

By Karina Bland - ALSAC

Art by St. Jude patient Maelin

egan and Paul had filled out all the paperwork. They sat through interviews and attended training to adopt from overseas.

By May 2017, all they had to do was wait to be matched with a child. The email arrived without warning.

The attached photograph showed the smiling face of a tiny girl, almost 3 years old, with short, dark hair. In that moment, Megan thought, "Oh, there's my heart."

Megan and Paul had four sons. The boys knew the family was adopting, but their parents had shielded them from the ups and downs of the process.

Megan didn't realize her youngest, Sawyer, 6 at the time, was behind her until she heard him say, "That's my sister."

About 10 miles away, Paul had someone in his office when he opened the email and saw the photograph.

"That's my daughter," Paul told his colleague.

"We all just knew that she was meant to be ours," Megan said.

From that moment, Megan would do anything for her daughter – and she'd have to. To save her life.

'Your love is no different'

Megan and Paul traveled to China in September 2017 to bring their daughter home. They would name her Maelin-Kate.

Waiting in a government office, Megan thought about how the adoption agency had prepared them for this moment, explaining Maelin might be wary. Megan and Paul would look different from people she knew and not speak her language.

When Maelin appeared in the doorway wearing a yellow dress, Megan crouched down, a doll in one hand and lollipop in the other, Paul beside her.

Maelin went straight to them, walking off-kilter because one leg was longer than the other – and into Megan's arms.



"It was absolutely no different than holding my boys the first time," Megan said. "Your love is no different. It's not less than. It's the same exact feeling."

Megan and Paul spent two weeks in China, getting to know their daughter.

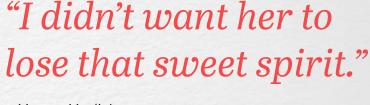
Maelin loved swimming in the hotel pool and eating in restaurants. She delighted in everything, squealing with laughter. "She just embraced life," Megan said.

She called Megan "Mama" and Paul "Baba," Chinese for "dad."

Their flight home to Alabama landed after midnight. Megan's parents brought the boys to the airport to meet them, and Maelin hugged everyone, even the dog once they got home.

Her brothers instantly adored her, nicknaming her "Mae-Mae." They'd later learn "little sister" in Chinese is "mèimei."

"You can't meet her and not love her," Megan said. "She's just so sweet and bubbly and adorable."



- Megan, Maelin's mom

Two weeks later, a pediatric orthopedist confirmed Maelin had hip dysplasia. She would need a series of surgeries that would put her in a body cast for months and her left hip back in its socket.

They had requested a child with medical needs and had expected this news. "We have access to incredible healthcare in our country," Megan said. "We really felt like we could change somebody's life."

What they hadn't expected was for routine lab tests to turn up something else.

A devastating diagnosis

Maelin's blood cell counts were unusually low, indicative that something was wrong, though not exactly what. Her pediatrician made an appointment for Maelin at the St. Jude Children's Research Hospital® affiliate clinic in nearby Huntsville.

Megan said a doctor there reassured them, "We're going to figure this out." On their way out, the doctor introduced them to the clinic's medical director who asked to see Maelin's test results.

She had worked at a clinic in Minnesota specializing in Fanconi anemia, a rare genetic blood disease, and recognized it in Maelin's lab work. More testing confirmed it.

Fanconi anemia is a rare and serious inherited blood disorder that leads to bone marrow failure. It prevents bone marrow from making enough new blood cells for the body to work properly. It can also cause bone marrow to make faulty blood cells. This can lead to serious health problems such as leukemia, a type of blood cancer.

There is no cure for Fanconi anemia.

The first time Megan took
Maelin to St. Jude in Memphis in
December 2017, she recognized the
building with a statue of St. Jude
out front from TV commercials. She
and Paul had been monthly donors
for years.

"You just never think that you'll ever be here," Megan said. She worried it would be scary and sad.

"It is all of those things, of course, but there's a lot of happiness there,"







Maelin in May 2019

Megan said. "There's a lot of hope there."

Even when it seems like there's no hope.

Treatment would include monitoring Maelin's blood and bone marrow, and transfusions to increase her blood cell counts. She would need a bone marrow transplant.

Finding a donor wouldn't be easy.

Searching for a donor

Patients usually find a donor among their relatives, but Maelin was adopted – and only a small percentage of potential donors on the national registry identify as Asian. None were a match for Maelin.

"There was no doubt in my mind, I would do everything for this to work. She is my daughter," Megan said.

Megan and Paul teamed up with a national online donor registry in the hopes of finding a match for Maelin. Megan went to every donor drive within driving distance, taking Maelin with her.

"This is who you're doing this for," Megan told those who registered.

She posted on social media, emailed family and friends and gave newspaper and television news interviews – anything to get the word out.

Someone told Megan she had a better chance of winning the lottery. She wasn't deterred.

"Don't tell me I can't do it," Megan said. "This is for my kid."

Megan printed flyers and went to colleges, corporations and craft shows, anywhere there would be people. She spoke at churches with Chinese congregations, accompanied by Maelin's pediatrician to answer questions. Saturday mornings found her in hardware store parking lots.

She carried swab kits in her purse and in her car.

"If you looked at me, I swabbed your cheek," Megan said.

She estimates she signed up more than a thousand potential donors.

"I just fought for her," Megan said. "I would do anything for her."

'Running out of options'

All the while, Maelin made regular visits to St. Jude. By summer 2018, her need for transfusions was growing increasingly frequent.

"We were running out of options," Megan said. Maelin needed a bone marrow transplant – and soon.

That fall, a nurse practitioner from St. Jude called Megan to tell her that not only was there a potential match for Maelin, but there were three.

Maelin was admitted to St. Jude in spring 2019 – 10 days before her transplant – to undergo chemotherapy and radiation treatments to destroy her failing bone marrow.

Megan was terrified Maelin wouldn't make it. She only cried in the shower, where Maelin couldn't see her.

She worried Maelin would blame her. "Would she think, 'My mom did this to me,' and hate me?" she said. Most of all, Megan worried this ordeal would change Maelin.

"She's just such a little joy," Megan said. "I didn't want her to lose that sweet spirit."

Maelin stayed in the transplant unit for more than two months instead of the expected 21 days, and then for another four months at St. Jude in family housing until she was healthy enough to go home.

She'd come back for check-ups, every two weeks at first and then every month, two months and six months.

But they could pick up the life they'd started from that moment Megan first saw Maelin's photograph and knew.

'Hope changes things'

Even after all she's been through, 9-year-old Maelin finds a reason why each day is the best ever.

"She'll say, 'I see a butterfly – it's the best day ever,' or,

'We ate spaghetti for dinner – it's the best day ever,'"
Megan said. A new pack of crayons.
Ice cream with her brothers. Petting the facility dogs at St. Jude.

"We joke that she has glitter in her veins because she's just the happiest, most loving, most excitable human on the planet," Megan said.

"Even the littlest things that we wouldn't find exciting, she thinks are just the best things ever."

Maelin taught her mother that – to find joy in the small things, and more. Every day is the best day ever, even the days when Maelin has to go back to St. Jude. People with Fanconi anemia are at high risk of developing other cancers, so doctors at St. Jude monitor Maelin closely.

"This place just has so many happy memories for her, and the people here are so good to her," Megan said. For Megan, the visits are a chance to show gratitude.

"They truly saved my daughter's life," she said.

"This place just has so many happy memories for her, and the people here are so good to her."

- Megan, Maelin's mom

At St. Jude, Megan learned that even at the worst times, there is good. The medical staff and researchers who work tirelessly. The donors who give and keep giving. The pervasive feeling of hope.

"Hope changes things," Megan said.

Hope for the best day ever.



You can help ensure patients like Maelin get the chance to pursue their dreams. stjude.org/ImpactGiving

EMBRACING HOPE, DEFYING LIMITS

St. Jude Hero goes the extra mile for the kids.

ву Betsy Taylor - ALSAC

ue Ellen Henderson of Evansville, Indiana opened her email one day in 2011 and saw something on the computer screen that changed her life.

It was a note from her friend Bob Fodstad, who had just run in the St. Jude Memphis Marathon® Weekend. She had donated to his fundraising event.

In his thank you letter to her, Fodstad described how it felt to run through the campus of St. Jude Children's Research Hospital[®], past the coral-colored buildings, past two little girls in wheelchairs who were clearly going through treatment. They held up signs that said "You're my hero."

Fodstad wrote about how he waved, blew them kisses and continued, but shortly after passing them, he had to stop running because he was so choked up that he couldn't breathe. "Never in my life, before that or since, have I had a feeling like that," wrote Fodstad.

The power of that mental image shook Henderson. She began to cry, thinking about those two little girls. She cries even now as she remembers it.

Before Fodstad had asked for a donation, Henderson hadn't even realized St. Jude sponsored a marathon. But now that she did, she knew she needed to be part of it.

Twelve years later, her support for St. Jude through fitness events as a St. Jude Hero has become, she says, "my purpose in life."

When she crossed the finish line at the St. Jude Rock 'n' Roll Nashville event earlier this year, she surpassed \$500,000 in total funds raised for St. Jude.

"He was a great kid"

To really understand why Henderson cried that day, a person would need to imagine a young boy running around at a family event, having the best time.

Her cousin, Ara Hertel, had the sweetest little child named Brock, who had lit up their lives. "He was a great kid. He was a jokester, you know?" said Henderson.

But Brock got very sick. He was diagnosed with acute myeloid leukemia, and his family took him to St. Jude for care. He passed away in 2001 when he was 10 years old.

Hertel channeled the loss of her son into fundraising for St. Jude, putting on activities in their local Indiana community. That astounded Henderson.

"That said a lot to me. You know, when you don't have a positive outcome, and you're still a champion for St. Jude, that says a lot," said Henderson. "That was really amazing to me.

"And so, when I saw that email from Bob, I was like, 'Oh, I'll have to run for St. Jude and honor Brock that way. And try to do something."

"They're always there"

A couple of years ago, Henderson was running the St. Jude Rock 'n' Roll Nashville event on such a hot day, it overwhelmed her.

"I got to about mile 11 and I thought, 'I'm packing it in. I'm done. I can't go on anymore."

Henderson's involvement with St. Jude fitness events had begun at a point in her life – her late 40s – when she wanted to make a change in her overall fitness and stamina.

Concerned about her long-term health, Henderson, who is now 61, had begun running. She says she's not good at it; she's not a natural. She refuses to even call it running, preferring the term "joggling" to describe what she considers to be her slow stride.

But she was dedicated and soon began seeking destination running events with friends. She lost 50 pounds.

"Hey, my mom's 93. My dad was 93 when he passed away," said Henderson. "So, I think I got some pretty good genes. I gotta take care of this body, because it's probably going to be around for a while."

Since then, she's run half marathons, 10Ks and triathlons. She's a member of the St. Jude Walk/Run committee in Evansville, and a national St. Jude Heroes Ambassador, providing guidance and morale boosts to other St. Jude Heroes who fundraise for St. Jude through fitness events.

On the hard days, like that sweltering day in Nashville, she thinks about Brock – and all the children who never chose the path of cancer but who've had to walk it just the same.

"No magic tricks"

Manda Traver of Mississippi had decided to run her first St. Jude Rock 'n' Roll Nashville event as a St. Jude Hero in 2014 and quickly realized she had a natural gift for fundraising.

> But there was a woman on the fundraising leaderboard who, week after week. always stayed at the top of the pack.

> > "Who is this woman?" she

wondered and began to feel almost

"I just felt that this woman, Sue Ellen Henderson, was the gold standard for giving, and I wanted to know how she did it."

They formed an instant bond when they met at the event, and today they serve together as St. Jude Hero Ambassadors. Henderson and her supporters put on car shows, sell barbeque lunches and hold special Bike Night events for motorcycle enthusiasts.

"She doesn't have big donors who write her big, fat checks," said Traver. "She has average, everyday people who want to help, who give her little bits every time they get paid. They say, 'I can't give you \$1,000, but I can give you \$25 a month.'

"That's my mission"

Bob Fodstad said he's "humbled" by what he started 12 years ago when he sent that email to Henderson, igniting her fundraising efforts.

He gives monthly to St. Jude as a Partner in Hope, and whenever Henderson asks for a donation to one of her fundraisers, he always says yes.

Henderson is celebrating her \$500,000 St. Jude Hero fundraising milestone, but it's not an ending.

"All I can say is, 'That's the first half.' I got another half in me, I think, before I quit," said Henderson. "So, I'd like to get to a million, but we'll see. That's my mission."



You can join Sue Ellen Henderson in supporting the St. Jude mission. Donate today at stjude.org/impactgiving

With love, from an aunt and uncle

Retired teachers use IRA gifts to honor great niece - a St. Jude cancer survivor.

By Yolanda Jones - ALSAC

ruce and Mary Jane Munsell celebrated and supported St. Jude Children's Research Hospital® for years before cancer hit close to home – their niece became a patient.

"It was more than 20 years ago when she was diagnosed, and at that time they gave her a 25 percent survival chance," Mary Jane recalled.

"She was in a clinical trial and she and one other child survived. It was a miracle at St. Jude."

The diagnosis was for acute myeloid leukemia, a difficult-to-treat blood cancer that St. Jude has made a priority in its research. In fact, the fiveyear survival rate for children diagnosed with AML has risen to around 70 percent, thanks to advances in AML treatment St. Jude helped introduce.

Their great niece is now in her late 20s and the mother of a toddler, and the Munsells continue to support children diagnosed with diseases like AML by making an annual contribution to St. Jude through a charitable IRA gift.

"We thought the IRA was a good way to contribute a little more and go in the direction we wanted to go with our support of St. Jude," Bruce said.

Retired high school teachers in their 70s living in Illinois, Mary Jane and Bruce celebrated their 55th wedding anniversary in 2023. They love spending time with their puppy, Bernie – a Bernedoodle (a cross between a Bernese Mountain Dog and a Poodle).

Giving to St. Jude through their IRA provides the couple a way to pay it forward and 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.

For donors over 70 1/2, funds transferred from an IRA account to a qualified charity may count toward the required minimum distribution and offer potential tax benefits to supporters.

"We channel our giving through our IRA because it is a great way to maximize the amount we give and the tax benefits, but most importantly our support helps children like my great niece and so many others," Mary Jane said.

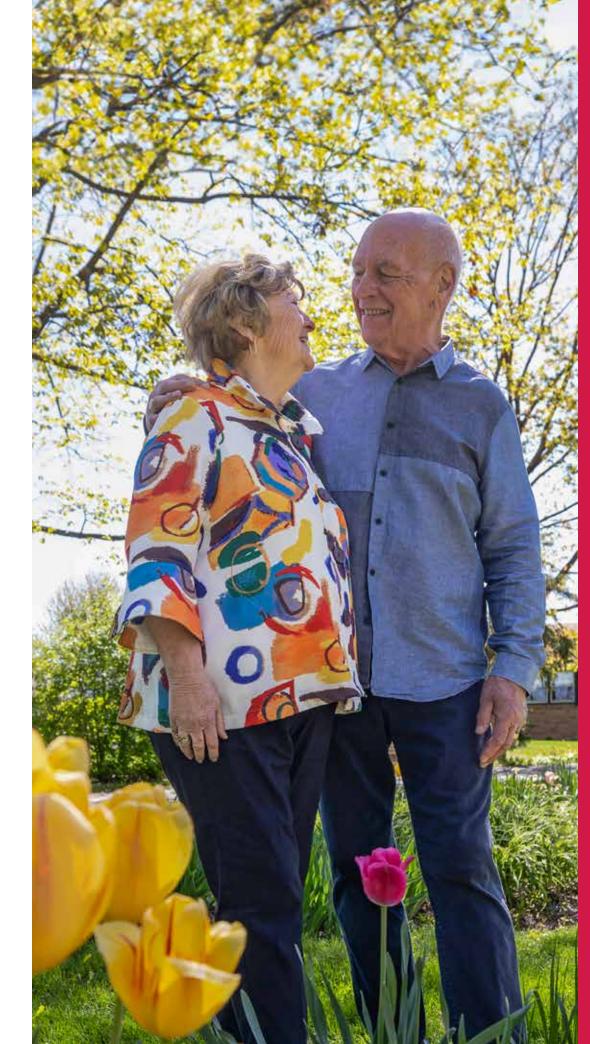
"We thought the IRA was a good way to contribute a little more and go in the direction we wanted to go with our support of St. Jude."

- Bruce Munsell, St. Jude supporter

Both Mary Jane and Bruce have visited St. Jude and were impressed by the research and the care put into every detail to provide comfort and healing for the children and their families.

The image of children being pulled by families in red wagons is a memory that has stayed with Bruce, along with the check-in process that is tailored to include the young patients.

"St. Jude recognizes who is most important and it is the children at the hospital," Bruce recalled. "This is why we support St. Jude. They help all these families every day, like they did our great niece, and we remain grateful."



OTHER WAYS TO GIVE

As you consider giving to charities like St. Jude, especially near the end of the year, you may want to ask your financial advisor about options that could allow you to make an even greater impact.

WITH CHARITABLE IRA GIVING

If you are over age 70½, you may give a gift (up to \$100,000 annually) from your IRA as a tax-free distribution to a qualified charity like St. Jude.

Charitable Gift Annuities

In exchange for an irrevocable gift of cash or marketable securities, a charity, such as St. Jude, agrees to pay a fixed amount of money to one or two individuals, for their lifetime. The amount paid each year will be a fixed dollar amount calculated as a percentage of your gift.

Donor-Advised Funds

If you have a donor-advised fund (DAF), you can choose to make a direct grant to support the work of St. Jude. You can also set up recurring grants from your DAF, such as monthly. Visit stjude.org/daf for more information.

Stock gifts

You may be able to make your charitable dollars go further by donating appreciated securities, such as publicly traded stock, bonds or mutual fund shares, to St. Jude. Appreciated securities are investments that have increased in value from the time they were purchased. By taking advantage of certain IRS tax incentives, you may be able to claim a charitable tax deduction for the full. fair market value of the securities, and pay no capital gains tax on the transfer.



For more information, go to stjude.org/ImpactGiving

HOUSE OF HOPE

Foundation in Philippines collaborates with St. Jude to help children with cancer.

ву Kristina Goetz - ALSAC

osephine Ramirez made her way to the front of the public hospital in Davao City, Philippines, cradling her 7-monthold baby and steering her 5-yearold, sick with a mysterious illness, only to be told they couldn't come in the emergency room. Not with a healthy baby.

It had taken them eight hours to get there by public bus. Josephine's parents had sold off 51 kilos – 112 pounds – of pigs to pay for the trip. They had to get in.

Josephine's older daughter Jovhen had been complaining about bruises

that started on her feet and had spread up her legs to her belly. It hurt when anyone touched the spots. Josephine couldn't find a doctor in Surigao del Sur, their province, to examine her. And doctors an hour away had already run every test available in the hospital. What they found was beyond their capacity to manage so they referred her to the big hospital in Davao.

Josephine didn't know anyone in the city who could take baby Jia so she could go into the hospital. In her desperation, she noticed a crowd at the waiting shed for the jeepney stop — a lean-to with no walls and a rickety roof — where patient families waited for loved ones.

Desperate to get help for Jovhen, Josephine handed her baby to a stranger, promising she wouldn't be gone long.

It would be 16 hours before
Josephine could get back for

her baby. And still, she had no answers about Jovhen.

A crowded hospital and a diagnosis

Jovhen was initially admitted to a pediatric ward for children with infectious diseases. At first, doctors thought she might have dengue fever, an infectious disease spread by mosquitos. But blood tests revealed a much more devastating diagnosis.

It was close to 2 in the afternoon, and Dr. Mae Dolendo, the physician

girl had been left alone since 9 a.m. when her mother left to check on baby Jia, and she hadn't stopped crying. Through tear-stained cheeks, Jovhen explained that her mother couldn't come to the third-floor ward because there was nobody to take care of her baby sister.

who'd read Jovhen's lab results, still

couldn't find her mother. The little

Dolendo asked a volunteer to go to the waiting shed to search. When the volunteer found them, she held Jia so Josephine could go inside.

Dolendo held Josephine's hand and spoke softly. Nanay, she said – Filipino for mother – Jovhen's diagnosis is leukemia. Josephine was shocked and began to cry. Is it curable, she wanted to know? Josephine remembered Dolendo's words: "Let's just pray." She gave Jovhen an 80 percent chance if she finished all of the treatment.

Dolendo told Josephine to call her husband, that she couldn't take care of both children alone. Though Bienvenido had planned to stay home and work to send money, he needed to come to Davao.

It would take him two days to get there.

So, Josephine headed back outside to the waiting shed where she and baby Jia – crowded skin to skin with 20 other people – slept, dodging raindrops slipping through the leaky roof. Josephine put a blanket over the baby to try to keep her dry.

"It suddenly hit me that here I am, trying to cure children with cancer, and I couldn't even provide the most humane accommodations, not only for the patients, but also for the parents," Dolendo remembered. "I was overwhelmed and humbled by the enormity of the task."

For two nights, Josephine and Jia slept in the waiting shed.

"It suddently hit me that here I am, trying to cure children with cancer, and I couldn't even provide the most humane accommodations."

- Dr. Mae Dolendo, House of Hope founder in the Philippines

"To be able to save a kid... is worth my whole life."

- Dr. Mae Dolendo

Then, Dolendo offered space in an abandoned kitchen at the hospital where the family could stay. She knew it wasn't a long-term solution and vowed that she'd build a transient home, so patients and their families had a place to rest.

She didn't believe kids with cancer could survive

Dolendo had been back in the Philippines for about a year when Jovhen came to the hospital in December 2005. Dolendo had always wanted to be a doctor.

Jovhen was treated for cancer in the Philippines.

When she was 17, her mother died of breast cancer, a tragedy that shaped her young life. She did her pediatrics training in Davao but shied away from oncology because she didn't believe children with cancer could survive. Almost all the pediatric cancer patients she saw died. She thought it better to be a gastroenterologist instead.

But then Dolendo trained in Singapore and had a month-long observership at St. Jude Children's Research Hospital® in the United States. She saw survivors who lived to adulthood and had children of their own. She realized that with the right diagnosis and treatment, children could live. She wanted to bring that hope back home to the Philippines. So, she established a pediatric oncology program in Davao City.

Those early days when Jovhen was a patient were often filled with frustration and heartbreak.

> Dolendo started with three beds and a chair. Sometimes, patients had to share an IV pole. Mamas and papas practically lived in the hospital, sleeping on floors because they had nowhere else to go. And despite being trained as a pediatric oncologist in one of the best medical centers in Asia, Dolendo often couldn't help. The parents - laborers, farmers, fisherman couldn't afford even

> > the cheapest medicine

that cost two pesos.

The survival rate was less than 10 percent.

"When you're working in a country with limited resources, when your options are very limited and very few, and you can't give so much to many of these kids who come to you very ill and suffering, it breaks your heart in so many pieces, and it's very tough to get these pieces back in place."

And yet, Dolendo persisted.

Letting go for hope on the horizon

Jovhen's father had to sell their home lot and red lauan trees sometimes called the mahogany of the Philippines – on farmland that he'd inherited from his father so his daughter could start chemotherapy. Bienvenido was a sentimental man when it came to his father's belongings, especially the land and trees – the same trees he used to build the family home. But he let it all go to save Jovhen.

For two years, Bienvenido tended to Jovhen in the hospital ward while Josephine looked after baby Jia and sourced chemotherapy and blood for transfusions for their sick daughter. All the while, Josephine and Jia slept on cardboard boxes in the crowded abandoned kitchen while cats and rats fought like siblings, Jovhen remembered.

In all that time, it never crossed Josephine's mind to give up and go back home. Instead, she talked to God.

"Give me a sign," she prayed. "Help me bring her back into our family, back into our home."

But Dolendo was making progress. In 2006 – after years of consulting with St. Jude doctors on difficult cases - a team from St. Jude visited



Dr. Mae Dolendo greets one of her patients who is staying at House of Hope during her cancer treatment.

the Philippines, and a partnership began. In 2007, the transient home Dolendo promised she would build opened. It was called House of Hope, and Jovhen and her family were among the first to settle in. They lived the last year of Jovhen's treatment in the home. Mamas planted okra, string beans and papaya on the adjacent vacant lots so families could eat nutritious food when funds were scarce. And they ordered medicine from outside the country together so they could save on shipping costs.

Jovhen finished chemotherapy in February 2008 and was declared cancer-free on March 6, her 9th birthday. She got to go back home.

With each patient she cured, Dolendo's efforts grew - from those first three beds to 10 in 2006 to today's 43-bed Children's Cancer Institute, one of the largest in the country. The survival rate slowly rose.

Still working to save lives

Today, cancer in the Philippines, an archipelago of more than 7,000 islands, is still quite scary, Dolendo said. It is estimated that nearly 5,000 children in the country develop cancer each year, but only about 30 to 40 percent are being diagnosed. Travel is difficult, and access to trained doctors isn't always possible.

Dolendo said there are only about 188 pediatric hematologists and oncologists for a population of 100 million.

But Dolendo and her team have helped increase the survival rate of

acute lymphoblastic leukemia, the most common type of childhood cancer, from less than 10 percent to 50 percent in her institution. Fewer patients drop out or discontinue treatment. And four House of Hope transient homes welcome patients and families for respite.

House of Hope Foundation for Kids with Cancer, named after its transient homes, is now part of the St. Jude Global Alliance, a global community of more than 200 institutions and foundations in more than 70 countries spread across seven regions with the goal of increasing the survival rates of children with cancer and other catastrophic diseases worldwide.

"The hardest is when you lose a child," Dolendo said. "And I go



through that many times. But with every kid I get to save, I get to be inspired. And I wake up in the morning, and I feel strong. I keep inspired to face another day and try to save another kid again."

A kid like Jovhen.

What a life is worth

Last year, Jovhen graduated college with a degree in accounting. She hasn't yet decided whether she'll continue on to pursue law. She knows she wants to give her mother "the good life" after all she sacrificed to help her live. All Josephine wants for Jovhen and all five of her children is for them to outlive her. And for them to live out their purpose, whatever it is that God has prepared for them.

Jovhen recounted her mother's and older sister's constant reminders for her.

"We need you alive and to live with us longer," she said. "We appreciate your hard work and desire to give back, but what do we do with your education, what you have attained with the courses that you graduated with, if it will shorten your life?"

But Jovhen is adamant. She believes that a good education is a way to a better life and to honor her parents. This is how she chooses to live her life after cancer.

That's what Dolendo works for every day – so kids like Jovhen can grow up to be whatever they want to be, to live full and long lives. "To be able to save a kid like that is worth one life," Dolendo said. "It's worth my whole life."

For more information about House of Hope Foundation for Kids with Cancer, visit www.kidsofhope.org.

It is estimated that 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, largely due 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.







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St. Jude Children's Research Hospital

Forever grateful

Lizbeth had been sick for weeks in the summer of 2021, unable to shake off a high fever. A visit to a hospital in her home state of Tennessee and several tests later revealed that the little girl had hemophagocytic lymphohistiocytosis (HLH), a rare disorder in which the immune system no longer works properly. Doctors referred Lizbeth to St. Jude Children's Research Hospital®.

Once at St. Jude, she was welcomed by doctors, a social worker and interpreters who spoke Spanish, her native language. Lizbeth received chemotherapy and a bone marrow transplant with stem cells from her older sister, Brihana.

Today, Lizbeth is 7 years old and is doing well, her mother said. Deysi said she will be forever grateful to St. Jude, its staff and the donors who make treatment possible for so many children, like Lizbeth. "May their reward come from heaven," she said.



You help bring hope and healing to patients like Lizbeth when you support St. Jude. Did you know many ways to give with non-cash assets - like stocks and IRAs - may present unique opportunities to save on taxes while furthering the St. Jude mission? Donate today at stjude.org/ImpactGiving