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501 St. Jude Place



When her cancer returned, Luna made the journey from Guatemala to St. Jude

# Looking to the stars

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• ST. JUDE

**SPRING BILINGUAL 2023** 









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The new Family Commons offers St. Jude patients and families classrooms, play areas and private spaces.



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/donate** 



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



hen automaker Kia came to town to make an advertisement highlighting our partnership, several St. Jude patients took part.

It was a thrill for them to be part of the process. It was a story I know they'll tell forever.

But there are always stories within the stories, aren't there?

Luna, featured in this issue of St. Jude Inspire, was one of the kids taken on a holiday journey that day. As colorful LED lights and animated narwhals and deer slid past the car windows, she gasped in amazement. Off camera, she danced on set and laughed with the crew.

It was a special day for all of us, as it was for Luna and her dad. Luna, as you'll read in these pages, has lost some of her eyesight.

But that day, in the backseat of a very cool, all-electric, Kia EV6, as the cameras rolled and magic happened, she was treated to sights she'll carry forever. She was given a memory to last a lifetime.

We are grateful to Kia for making this magic a reality. And we are so grateful to all of our supporters and partners for all they do for our kids, not the least of which is providing these moments that mean so much for those going through such difficult times.

In the pages ahead, you'll read about some of these special patients.

You'll learn about Claudita from Culiacán, Mexico, who saw snow for the first time while at St. Jude being treated for ALL in 1994 (talk about a memory!). Not only would she survive, but thrive – today, she has two children of her own.

But remember, there are always stories within the stories. Claudita's mom, Claudia, wanting to help kids back home with catastrophic pediatric diseases like her daughter's, founded a foundation to help support the local children's hospital.

That foundation is her legacy. The support St. Jude provides its global partners is yours.

Thank you for all you do from Luna, Claudita and kids everywhere who are able, because of your support, to live out their hopes and dreams, making memories and sharing their stories.

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

# **PROMISE FULFILLED:** HONORING A FRIEND AS A ST. JUDE HERO

#### By Monsy Alvarado - ALSAC

They were boys, sharing the same name and living in Tegucigalpa, the capital city of Honduras, surrounded by mountain views and colonial architecture.

Luis Fortín was the new classmate in a third-grade class at a bilingual school. Luis Enrique was already a student there. They became friends, and years later would often get together on weekends or when they were looking for things to do.

"He went to my house and we got into trouble together," Fortín recalled with a laugh.

In 2010, when Luis Fortín was 18 years old, he moved to Chattanooga, Tennessee, to join his mother who had moved to the United States earlier. Fortín enrolled in college to pursue a degree in chemical engineering.

Months later, he heard from a friend in Honduras: Luis Enrique was also in Tennessee, but for very different reasons.

He was a patient at St. Jude Children's Research Hospital, being treated for bone cancer.

#### Two friends, reunited

Luis Fortín and Luis Enrique connected via social media and made plans to see each other. Fortín made the five-hour trip from Chattanooga to Memphis, one he would make several times over the next four years.

During visits, they would spend hours at local parks and at restaurants trying different foods while they talked about their lives and the challenges of adjusting to the customs and traditions of their adopted homeland. They missed their friends and the lives they led in Honduras, but when they shared time together, they relived those moments.

"It was very easy to remember the good times in Honduras," Fortín said. "When I visited him, it was like having a piece of home closer to me in Chattanooga."

Fortín explored Memphis with Luis Enrique, who had fallen in love with the city while he received treatment. Some days, they drove around, sightseeing with the windows down, music blaring and taking selfies to send to friends back in Central America. For hours they forgot their worries and lived in the moment.

"He took me to the lake, he liked to take me to the zoo," Fortín recalled.

Fortín also visited Luis Enrique at St. Jude, where he saw first-hand the help and support the specialty research hospital and its staff provided his friend. He also saw how much the hospital inspired Luis Enrique to help others.

Luis Enrique often shared encouraging words with new patients. He loved to play music at the hospital and was known for taking his chemotherapy on the second-floor observation deck where he would play guitar and sing to the younger children.

"He loved to go there, as he was one of the older patients there, he took that role very seriously," Fortín said. "It's weird to say, but the experience at St. Jude and all the opportunities that St. Jude brought him helped him grow as a person. It's incredible all the happiness that St. Jude brought him in his life."

While being treated at St. Jude, Luis Enrique asked Fortín to walk with him in the 5K during the St. Jude Memphis Marathon<sup>®</sup> Weekend. But Fortín was studying for finals at the University of Tennessee at Chattanooga and couldn't make it. The following year, Luis Enrique asked again. Fortin, still in college, declined once more but assured his friend that after graduation they would walk together.

In February 2015, Luis Enrique passed away at age 22. Fortín never got the chance to walk with his close friend.

"That was very difficult," Fortín said. "He asked me to walk the 5K to live the experience with him."

#### A promise fulfilled

Fortín doesn't recall what reminded him of the St. Jude Memphis Marathon sometime in the summer of that year, but he registered, remembering the promise he had made to his friend that he would participate after graduation. By the time he registered though, there were no spots left in the 5K event, so he signed up for the full marathon.

He had never run before, so he began to train, and a month before the race he began to feel pain in his knee.

He stopped training, hoping to give his knee time to heal for the race. He didn't run again until the marathon. But two miles into the run, he felt pain in his knee and he thought of his friend, who felt pain in his knee prior to being diagnosed with cancer. "Maybe a message from him," crossed his mind.

"I thought, well, I'm going to finish it with a lot of anguish," Fortín said. "I finished it. It took me six hours, but I finished it."

Fortín has continued to run every year to help St. Jude continue its mission of finding cures for childhood cancer and helping others like Luis Enrique.

"When I'm going through pain, I think about my friend and how he went through this super hard battle, so I can suffer for two hours," he said after completing the half marathon in December 2021. "Throughout the race I have him in mind. That's the reason I do it and I can't wait to do it every year and honor him. I know he will be proud. I wish I could have participated with him."

Through his running, Fortín has raised thousands of dollars for the research hospital as a St. Jude Hero.

"I know that Luis didn't survive his battle against cancer, but they were able to offer him a lifestyle where he and his family didn't have to pay a bill from St. Jude, and that his family didn't have to worry about that," he said. "To know that I'm supporting that cause, that means everything to me."



You can help end childhood cancer because no child should die in the dawn of life. **stjude.org/donate** 

# \* A LIGHT IN THE \* DARKNESS

COVER STORY

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

By Monsy Alvarado and Ruma Kumar - 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.

"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.



<sup>44</sup> There's something powerful about the moon.

> Luna's dad explaining his daughter's name

St. Jude doctors use the genetic information to avoid over- or undertreatment. The genetic information learned also could help by identifying inherited cancer genes. There is also a greater emphasis on quality-of-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

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.



You can help ensure patients like Luna get the chance to reach for the stars. **stjude.org/donate** 



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, giggles

# <sup>44</sup> There is humanity (at St. Jude) that I just don't think exists anywhere else.

嵀 Mario, Luna's dad

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 little girl 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 Imagine Academy by Chili's at St. Jude, 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."





# \* Memory of \* CLAUDIA BLANCO

#### A mother's life's work still helping children with cancer in Mexico.

#### By Kristina Goetz - ALSAC

Claudia Blanco was 7 years old and had never seen snow.

It was almost Christmas, 1994, and her family's bags were packed for a trip to Pinetop-Lakeside, Arizona. Claudita – little Claudia, as the family called her – was the youngest of five and her mother's namesake. She was tense with excitement, ready to trade the Alamo trees and balmy weather of her home in Culiacán, near the western coast of Mexico, for Ponderosa pines and a wintery wonderland high in the White Mountains.

But Claudita's grandmother noticed the little girl ate as much as the big kids yet seemed emaciated. At school, Claudita had fallen playing hide and seek, and the cut on her knee kept bleeding.

Claudita's aunt, a pediatrician, insisted Claudita be taken for bloodwork. If she was anemic, high altitude could be dangerous. Claudita's doctor found she was anemic and had a high white blood cell count – a sign there might be a problem with her bone marrow. She also had purplish spots on her neck.

Claudita was diagnosed with acute lymphoblastic leukemia and needed a pediatric oncologist, but this was 1994, and there weren't many in Mexico. The Blancos found one named Dr. Eduardo Altamirano.

But Claudia, Claudita's mother, noticed how rundown the hospital looked. Doctors were skilled, but all she saw in the makeshift ward were dark stairwells and dirty sheets. If the family stayed in Culiacán, there was no guarantee the hospital would provide chemotherapy. And the Blancos might've had to find – and buy – everything from IVs to cotton balls to support her treatment.

Years earlier, in 1988, when Dr. Altamirano arrived in Culiacán to set up a pediatric oncology unit, there was no chemotherapy,



antibiotics or equipment – not even a blood bank. Practically nothing to treat children with cancer in any comprehensive way. Change had been slow, despite his best efforts.

As a pediatric resident, Dr. Altamirano had seen Dr. Donald Pinkel, the first medical director and CEO at St. Jude Children's Research Hospital in the United States, speak at a conference. It was the first he'd heard of the research hospital's reputation for successfully treating kids with cancer. There was a doctor in Mexico City who'd done a rotation at St. Jude. She would know who to call for a referral.

St. Jude accepted Claudita as a patient.

The Blancos celebrated Christmas in Culiacán and arrived in Memphis late on Dec. 26.

There was the statue of St. Jude Thaddeus, the patron saint of hopeless causes. Claudia's grandmother had a deep devotion to him, and Claudia kept his holy card. "What better way to have him," she said. "To be at a hospital named after St. Jude."

# Children with cancer in Culiacán deserve to live, too.

Chemotherapy was hard, and so were bone marrow aspirations.

Friends back home asked Claudia what they could do to help the family, but the Blancos had all they needed at St. Jude. Claudia asked them, instead, to support families at their local pediatric hospital. They went, but so many children died they didn't want to go back.

"And that was when I felt even more that we had to support the hospital," Claudia vowed.

Around the start of Claudita's treatment at St. Jude, Dr. Altamirano began to draft articles of incorporation for a group that could raise money for children with cancer in Culiacán. For years, he realized that going to conferences meant nothing



without funding. The group started with friends, including Oscar Blanco, Claudita's father. Oscar and Claudia had large, prominent families in Culiacán. They'd offer support, too.

Dr. Altamirano called it Grupo de Amigos de Niños Afectados de Cáncer – Group of Friends of Children Affected by Cancer. GANAC, for short. Their goal was to buy chemotherapy drugs because that was the most urgent need.

By the end of 1995, Oscar was still traveling back and forth to Memphis to see his daughter, so he couldn't commit to the cause full time. Claudia was in Memphis, too, with their other children while Claudita continued treatment.

Over the next two years, GANAC held fundraisers and gained sponsors.

Meanwhile, Claudita slumped along in treatment. She developed

severe osteoporosis, broke one ankle, then the other, then the first one again. First, she walked with crutches and was later confined to a wheelchair. She couldn't walk for a year and was sometimes terrified to try. Instead, she crawled.

But Claudita was improving. She would survive. The Blancos were so thankful they wanted to give other children in Culiacán the same chance their daughter had.

In June 1997, with Claudita in remission, the Blanco family headed home. Shortly after their return, with Claudita feeling well, Claudia began volunteering at the same hospital her daughter was diagnosed with cancer.

She became fond of a little girl, maybe 5 or 6 years old. One afternoon, after they'd been playing, Claudia left to talk to a nurse.



"All of a sudden, I heard this girl who had been smiling, laughing out loud with me, crying out in pain – such a wail – so I asked, 'What happened to her?' And that was when they told me: 'We just did the marrow aspiration on her without anesthesia. We don't have it.'"

Claudia ran out of the hospital, haunted. She felt angry, powerless and a great sense of injustice. She told her family what she'd witnessed and then everyone she knew. "This is it," she told herself. "Now, I understand that I have to work hard and raise money to be able to equip the hospital."

## Improvements and impediments

GANAC raised half the money and another organization put up the other half – \$20,000 to \$30,000 USD. The state-of-the-art anesthesia machine was so out of place, Claudia remembered, that one doctor said it looked like a Rolls-Royce.

GANAC began to raise more money and hired staff. The foundation also received a large donation to have a real office where people could work.

In 2000, Hospital Pediatrico de Sinaloa in Culiacán joined the International Outreach Program established by St. Jude Children's Research Hospital. The program was designed to address the global disparity in pediatric cancer survival rates by using a "twinning" model to foster one-on-one relationships with hospitals. In 2018, St. Jude Global was launched. This model, which replaced the outreach program, is focused on more regional collaboration.

GANAC also partnered with ALSAC, the fundraising and awareness organization for St. Jude, and



learned how to raise money at home for themselves.

Since its humble beginning as that first group of friends who wanted to help children with cancer in Culiacán and all 18 municipalities of the state of Sinaloa, GANAC has grown exponentially. Today, the foundation provides funding for medication, patient care, transportation and housing. It also supports the local hospital by funding medical equipment, supplies, professional training and salary support for medical oncology staff.

"Donors, they place a lot of trust when we say that we have an agreement with St. Jude," said Asminda Zazueta, GANAC's director. "Donors are assured that their social investment is really going to be invested well."

#### 'Never have I felt so satisfied and happy'

For decades, the Blancos dedicated their lives to the care of children with cancer in Culiacán and all of the state of Sinaloa. Claudia remained a driving force behind the GANAC operation even after she herself was diagnosed with cancer. She died last August after a long battle with the disease.

Claudia's commitment to the cause remains an inspiration to staff, Asminda said. She often reminded them to stay close to the families.

Claudia saw all five of her own children grow to be happy and healthy. Claudita got to experience snow for the first time in Memphis – just a month after they arrived for treatment. Now, Claudita is married and has two children of her own. All of Claudia's children, in some way, are dedicated to GANAC.



Claudia Blanco, founder of GANAC, and her daughter, Claudita, a St. Jude cancer survivor.

Claudia didn't see the foundation as her legacy but rather an example to leave her children about the gift of service. "As we say, we don't take anything with us the day we leave this world," she said.

Despite the continued difficulties children with cancer face in Culiacán – and her own health struggles – Claudia said in her last interview with St. Jude Inspire that she was encouraged.

"I have a great team there at GANAC with great willingness, drive and enthusiasm to work," she said. "I admire and respect them. Never have I felt so satisfied and happy." \*

St. Jude Global launched in May 2018 to train clinical staff in hospitals and clinics around the world. share cutting-edge research and strengthen partner health systems so even more children receive quality care across the globe. At ALSAC, the fundraising and awareness organization for St. Jude Children's Research Hospital, we teach foundation members of The Global Alliance best practices in fundraising, marketing communications and operations. There are more than 210 hospitals and clinics from 68 countries and more than 60 foundations from 52 countries.

GANAC in Culiacán, Mexico, is one of those foundations.

# **Child's play**

St. Jude patient Nash and his dad take a break in the new 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.

No.

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Your gift will help more patients like Nash get the treatment they need. **stjude.org/donate**  Your gift can make a lasting impact on the lives of St. Jude kids.

St. Jude patient **Eli**, pictured with his mom

You can help sustain the lifesaving work of St. Jude Children's Research Hospital<sup>®</sup>. Whether you make a planned gift, name St. Jude as the beneficiary of your life insurance policy or make a gift from an IRA charitable rollover, you're making a decision that impacts lives. Each gift type offers unique benefits and helps ensure St. Jude families can focus on what matters most – helping their child live.

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