

ST. JUDE inspire



BILINGUAL EDITION 2020

Hand in Hand

Cancer bonds
Pepe's family

Dr. Brian Sorrentino
mission of
a lifetime

St. Jude Global
collaboration
is key

Puggle & Huckleberry
comfort and
companionship

Your legacy can help cure children with cancer



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—María Antonia Fernández,
St. Jude donor

St. Jude patient **Matthew**,
soft tissue cancer



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Faced as we are with a public health crisis and sharp spasms of social and economic turmoil, it's easy to get overwhelmed. In these times, we tend to forget how far we've come. We tend to lose sight of hope.

Those thoughts occurred to me the other day when a small item in the Memphis newspaper caught my eye. Under the heading "50 years ago," there was this bit of news:

"St. Jude Children's Research Hospital has achieved the first instance of a significant five-year cure rate for leukemia of any kind, it was announced yesterday," the item began.

It went on to quote Dr. Donald Pinkel, the hospital's pioneering medical director, discussing how St. Jude, since its opening in 1962, had been developing "unique treatment programs" for children with lymphocytic leukemia, or acute lymphoblastic leukemia (ALL) as it is called today.

Through those efforts, Pinkel said, St. Jude had achieved a five-year survival rate of 17 percent.

Let that sink in for a moment. A half-century ago, a five-year survival rate of 17 percent for children afflicted with the most common form of pediatric cancer was something to celebrate. It was, after all, a more-than fourfold improvement from the 4 percent survival rate for ALL patients when St. Jude opened just eight years earlier. Hispanic children have the highest incidence of ALL in the U.S. and are less likely than other children to survive the disease. Fifty years later, the survival rate for ALL now stands at 94 percent for kids treated at St. Jude.

I know it's hard to look too far ahead with so much uncertainty immediately in front of us. But in another 50 years, imagine all the further discoveries and cures likely to be made. Imagine how much closer we'll be to the dream of St. Jude founder Danny Thomas: No child should die in the dawn of life.

Donors like you have made this mission possible from the outset. We can never thank you enough.

Richard C. Shadyac Jr.

President and Chief Executive Officer, ALSAC

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Enrique and Leticia grew close with Markell and his family while their kids were St. Jude patients. Though both children died, the bond – and devotion to the mission – remains. Every year in the days leading up to Arianna’s birthday, Enrique and Leticia ask their circle of friends and beyond to commit #8ActsofKindness in memory of their daughter.

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The Mexican pop duo visited St. Jude to inspire our kids, and inspired us by taking time to answer questions about songwriting, career choices and singing in the shower.



You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate





Puggle

Birthday:
11-22-17

Breed:
Golden retriever



Huckleberry

Birthday:
12-10-17

Breed:
Goldendoodle

Follow Puggle and
Huckleberry
on Instagram
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PUGGLE & HUCKLEBERRY

NEWEST ST. JUDE EMPLOYEES OFFER FURRY COMFORT

BY BETSY TAYLOR · ALSAC

Two very popular new staff members have joined St. Jude Children's Research Hospital: Puggle, the golden retriever, and Huckleberry, the goldendoodle.

Since the St. Jude Paws at Play program launched in September 2019, the doggy duo has been doing things humans can't. The specially trained dogs work with patients to help them meet clinical goals, easing fears and calming patients during challenging situations.

Shandra Taylor, who works with Huckleberry, said the dogs have tangible effects, such as helping patients get through imaging scans without anesthesia. They're also good at encouraging patients to move around

after surgery, a crucial part of recovery. "It's so much more than just a social visit. There's something really magical about the presence of a dog," Taylor said.

The dogs came from a service school, where training started at a young age.

Karen Casto, director of the Canine Assistants hospital initiative, said Puggle and Huckleberry are a perfect fit for St. Jude.

"They are both super sweet and kind of intuitive about what people need and who needs them," she said. "We look for dogs that can handle the hospital environment and want to make all these wonderful new friends. That's why they were chosen."



the
family
that heals
together

Heather and Pepe weren't in treatment together, but each drew strength from the other, helping them survive the worst.

By Thomas Charlier • ALSAC

Heather treasures those photos showing her walking through St. Jude Children's Research Hospital with a little boy who barely came up to her knees.

She and her nephew Pepe are walking hand-in-hand in the pictures. For they shared a bond – not just as family members, but as cancer patients.

"We'll go to appointments together. We'll support each other and walk down the hall," said Heather of those not-too-distant days.

She was diagnosed with a rare form of leukemia at 17, a time when her focus was on college entrance exams and other concerns common to teenagers.

Her mother, Sonia, who for years had driven by St. Jude on the way to work, began taking her there, nurturing her through her lengthy treatment.

Less than a year after doctors declared Heather cancer-free, Pepe was diagnosed with a type of cancer called neuroblastoma. The son of Heather's sister, Tiffany, he was just 6 months old at the time.

For members of the close-knit family, a second instance of childhood cancer was almost impossible to believe. That was especially true for Sonia, who had seen a daughter, and now a grandson, afflicted with it.

"Tiffany, my daughter, called me and told me that it looked like Pepe had a tumor. I told her, 'No, it can't be,'" said Sonia.

"It's incredible when there are two in one family."

But Pepe's boundless energy and infectious spirit were a source of comfort to the family. So was Heather's history at St. Jude.

"When my sister got sick and she went through everything she went through, I saw that she came out well, and I thought to myself that Pepe will also come out well," Tiffany said.

Pepe spent three years in treatment, meaning he virtually grew up at St. Jude.

"For him, this is what he knew, it was normal, he didn't know anything else," Tiffany said. "His playground was the St. Jude hallways."

Like his Aunt Heather, Pepe now shows no sign of cancer. She dreams of a career as a child life specialist, while he wants to be a police officer or basketball player. As for the family, they are not at all bitter after dealing with two rare childhood diseases. They consider St. Jude not just a blessing, but a second home.

"For me, St. Jude – my heart is there," said Sonia. "The truth is, if St. Jude didn't exist, I don't know what would have become of my family."

As for Heather, she still thinks of those days and walking to appointments with Pepe. And of the connections that form between cancer patients, especially ones who are related.

"We just have a special bond," she said. "I just can't wait for him to get old enough to understand what he's been through."





A RACE FOR THEIR LIVES

BY THOMAS CHARLIER · ALSAC

DESPITE THE INEVITABILITY OF HIS OWN END OF LIFE, DR. BRIAN SORRENTINO WORKED TO FIND A CURE FOR SOME OF THE SICKEST KIDS IN THE WORLD.

C

olleagues chuckled when Dr. Brian Sorrentino, a tall, distinguished researcher known for his intensity and hard work, began wearing teddy bear-themed neckties and giddily greeting children who came in for checkups.

He long ago had quit practicing medicine, after all, and normally worked in the lab.

But Sorrentino, director of the Division of Experimental Hematology at St. Jude Children's Research Hospital, considered himself a physician-scientist, or, as he put it, a researcher with "the heart of a physician." And as he led a clinical trial aimed at curing a rare, devastating immune disorder, he relished the chance to see whether the bold new gene therapy regimen developed by his team was helping living, breathing patients.

One of the first clear answers came on a summer day in 2017 when a baby from Peru was brought in for his 9-month exam. Treated some seven months earlier, the boy appeared to be thriving. Not only had he tripled in size, but his little body was churning out immune cells that allowed him to crawl and explore like a normal baby,

without the sterile confinement usually required for kids born with the disorder known as bubble boy disease.

Sorrentino took a turn holding the baby and marveled at him. A photo from that day shows the 6-foot-3 scientist beaming a broad, toothy grin as he clutched the wide-eyed youngster.

"I held him and I said to myself, 'I can't believe we did this,'" he later recalled for the audience at an annual training event for ALSAC, the fundraising and awareness organization for St. Jude.

Sorrentino called it a "St. Jude moment" because it was then he knew the gene therapy he had spent 15 years developing offered hope that children born with the disease could enjoy normal lives. He knew he was on his way to introducing the word 'cure' into the lexicon of a genetic disorder that long had defied easy solutions.

But there was one crucial fact Sorrentino didn't know that summer day.

He didn't know that while he absorbed himself in battling a deadly disease in these infants, it was he who was dying.

“WENT AT LIFE WITH EVERYTHING HE HAD”

Brian Sorrentino lived fast, considering all he managed to squeeze into his 60 years. It seems only natural that he loved fast cars, a passion that drove indelible memories of him. St. Jude President and CEO, James R. Downing, M.D., remembers visiting a racetrack where Sorrentino was testing his sports car.

“He was all over the track – he’s bouncing through the corners, his back end is fishtailing out. He’s hollering and screaming and having a blast... That was Brian – Brian just went at life with everything he had.”

Sorrentino grew up mostly in the Hudson River Valley of New York. Early on, he was intent on following his radiologist father into medicine. That career choice likely was cemented by an ordeal that began when he was 17, when he found a lump on his chest.

He was diagnosed with Hodgkin lymphoma. Even in the mid-1970s, the disease was curable, but treatment involved chemotherapy and massive doses of chest radiation.

Sorrentino completed treatment and later went to medical school, then worked at the National Institutes of Health, where

colleagues remember a researcher who was as humble and kind as he was brilliant and persistent. At NIH, he trained under Arthur Nienhuis, M.D., who later became the fourth medical director and CEO of St. Jude, and recruited Sorrentino to work with him.

TARGETING BUBBLE BOY DISEASE

The disorder commonly called bubble boy disease is known to scientists as SCID-X1, for X-linked Severe Combined Immunodeficiency. Occurring perhaps once in every 200,000 live births, it’s caused by a defective gene that renders babies unable to produce immune cells. Without treatment, babies usually die in their first year from infection.

The condition can be cured through a bone marrow transplant with a fully matched sibling donor, but most patients don’t have one. Transplants from parents only partially restore the immune system.

SCID-X1 became an early target for the budding gene therapy field in the 1990s and early 2000s. In gene therapy, scientists insert a correct copy of the gene into a modified virus, which serves as a delivery vehicle for the gene and then “infects” stem cells to induce the production of immune cells.

A major problem, however, is there’s no way to predict where the virus will land on the cell genome. Early trials elsewhere were halted after patients developed leukemia because the virus they used activated adjacent cancer-causing genes.

Following successful gene therapy treatment for bubble boy disease, Omarion was able to escape sterile confinement and play outside with his mom.



HE HAD A LOT OF EMPATHY FOR THE FAMILIES AND THE CHILDREN HERE BECAUSE HE HAD LIVED IT, TOO.

— Suzanne Sorrentino

“Everyone in the field sort of thought, ‘Well, this is not a problem we can overcome,’” Downing said.

But at St. Jude, Sorrentino and his team set out to prove otherwise.

He employed a hollowed-out form of the virus that causes AIDS. To eliminate the risk of triggering cancer, Sorrentino put insulators on the virus to keep it from activating other genes. The final component of the therapy employed low doses of chemotherapy to clear space in the bone marrow.

As he and his team worked to launch a clinical trial to test the gene therapy on newborns, Sorrentino was going through personal transformations. Previously divorced, with two grown children, he married again in 2015.

“He was just so much fun to talk to...a marvelous man,” said Suzanne Sorrentino. She also noted her new husband’s passion for St. Jude, how it was elevated by his own childhood cancer experience.

But Sorrentino’s cancer treatment history had been surfacing in bad ways, as well. The after-effects of the radiation caused thyroid and heart problems.

The SCID-X1 clinical trial, however, was going well, with patients developing functional immune systems within months. One challenge had been enrolling enough patients, given the rarity

of the disease. Half came from other countries, including the Peruvian boy named Gael.

But less than a month after Gael’s exam, Sorrentino was diagnosed with lung cancer – the final, tragic act to that medical drama of his own. As a physician, he knew his condition was terminal.

The diagnosis gave new urgency to Sorrentino’s research. He continued to work at the hospital until he was too weak, and then monitored the project from home.

A week before Sorrentino’s death in November 2018, Ewelina Mamcarz, M.D., a St. Jude bone marrow transplant expert and lead author of the study, drove to his home and showed him the data. By then he was so sick he kept pain medicine nearby. But looking at the paper – seeing proof that his gene therapy worked – comforted him.

In one of his last conversations with his wife, Sorrentino said he felt he had been saved from lymphoma because there was “something big” he was meant to accomplish. “With the clinical trial underway and children’s lives being saved, he realized that he had reached that goal and it was time for him to go,” Suzanne said.

Days later, Sorrentino’s priest arrived to administer last rites.

Six months after Sorrentino’s death, the *New England Journal of*



Brian Sorrentino, M.D., holds Gael, a bubble boy disease patient from Peru, during a checkup in the summer of 2017, several months after he had been treated with gene therapy developed by Sorrentino’s team at St. Jude. Less than a month after this photo was taken, Sorrentino was diagnosed with the lung cancer that caused his death in November 2018.

Medicine published the SCID-X1 study, reporting that the first eight patients treated either had fully reconstituted immune systems or were progressing toward it.

His brother, Brent Sorrentino, said Brian knew the radiation treatment he had received might rob him of 20 years of life. But it had given him 40 years, too, and he used that time to bequeath decades of life to kids born with SCID-X1. “Brian said, to him, that’s a good trade.”

What’s left for friends and colleagues to remember, then, are the many sides to Sorrentino – the one who hurtled around that racetrack with abandon, going at life with everything he had, and the one who kept careful score and, by his reckoning, came out way ahead.



TELL SOMEONE THAT I AM HERE

Carlos Rodriguez-Galindo, M.D., traces the roots of the St. Jude Global initiative to war-torn Nicaragua on Christmas Eve, 1986.

Every night, Dr. Fernando Silva, director of the children's hospital (in Nicaragua), would visit the children, looking at all of them to try to figure out how he could distribute the resources. And when he saw a child with cancer, he put a cross beside his name, so that the nurses and the rest of the doctors would know this child couldn't be cured – that they should let the child die in peace. They didn't have the money and they didn't have the resources. Every day he put a cross beside the children that had to die.

This particular Christmas Eve, before he went home to have dinner with his family, he went by all the beds once again, and a little boy, who he had seen earlier in the day, came up and tugged on his coat. And the doctor remembered this little boy was an orphan who had lost

both parents in the war. He had been diagnosed with lymphoblastic leukemia. In 1986, here at St. Jude, we were curing 70 percent of the children with lymphoblastic leukemia. And just that morning, the doctor had put a cross beside his name.

And Dr. Silva said, "My child, what do you want?"

And this young boy said to him "Decile a alguien que estoy aquí." *Tell someone that I am here.*

A child, abandoned, who was going to die. In this moment, Dr. Silva thought, I cannot continue putting crosses next to the names of the children with cancer. We have to do something. In this moment, this child saying, "Tell someone that I am here," we began what we call this global movement to help children with cancer.

COLLABORATION IS THE KEY TO FIGHTING CHILDHOOD CANCER WORLDWIDE

By Carlos Rodriguez-Galindo, M.D.

Director of St. Jude Global
and chair of the Department
of Global Pediatric Medicine

Every child, everywhere. Our work is incomplete until we bring diagnosis, treatment and cures to all children with cancer around the world. Our founder, Danny Thomas, declared on the day St. Jude Children's Research Hospital opened its doors that "no child should die in the dawn of life." No child, period. Our home is Memphis, Tennessee, but our hearts and our souls are around the world, wherever the children are.

St. Jude has a history of humanitarian relationships with key partners around the world that dates back more than 25 years. Our impact was meaningful, but not scalable. St. Jude created the Department of Global Pediatric Medicine in 2016 to advance the field of global pediatric oncology and blood disorders. After a two-year strategic planning process, the institution launched St. Jude Global on May 24, 2018. This ambitious initiative works to ensure that every child with cancer and other catastrophic diseases in the world will have access to quality care and treatment.

THE BURDEN OF CHILDHOOD CANCER

It's estimated that more than 400,000 children develop cancer around the world each year, but only half of them are diagnosed; all others die without even having a chance. Nine in 10 of these children live in countries where cure rates are less than 20 percent. Because of

advances in the treatment of other life-threatening diseases, more children survive infancy. That means even more children stand the chance of developing cancer. But the greatest underlying factor in a child's chance of surviving cancer is where he or she calls home. For children in high-income countries, the five-year cancer survival rate is 80 percent. The harsh reality is the majority of children with cancer live in lower- and middle-income countries. The gap in survival rates is among the greatest disparities in health outcomes worldwide.

Unfortunately, many children in lower- and middle-income countries go undiagnosed or untreated. But a failure to diagnose isn't the only obstacle. A lack of appropriately trained staff, imaging and laboratory equipment, as well as a lack of access to more specialized techniques is a challenge. Through more education opportunities, we can help institutions around the world overcome these roadblocks to effective treatment and care.

In some countries, abandonment of treatment ends all hope. Even when treatment is available, many families abandon it because of their inability to pay, lack of social support or profound misunderstanding of the cancer diagnosis and possibility of cure. For many children around the world, treatment abandonment is the biggest threat to their lives.

“

...the greatest underlying factor in a child's chance of surviving cancer is where he or she calls home.

LAUNCHING OUR MOONSHOT

Together with our global partners, we will ensure more children have access to and continue the vital care that will mean more survive. There is hope. Taking Danny Thomas' legacy to the world is our moonshot. It's not easy, but moonshots by definition are difficult. We don't measure our successes in milestones, but it is important to pause and reflect on our journey.

In September 2018, St. Jude and the World Health Organization coordinated a high-level meeting at the United Nations General Assembly hosted by the Permanent Missions of Uzbekistan and Jordan. The event, Ensuring a Right to Cure: Improving Childhood Cancer Care and Decreasing Global Survival Disparities, was supported by the Permanent Missions of El Salvador, Moldova, Morocco, the Philippines, the Russian Federation and the United States.

In December 2018, the first annual meeting of the St. Jude Global Alliance was held on our St. Jude campus. There were 167 participants from 52 countries representing 96 medical institutions and 27 foundations. The Global Alliance is a collaboration of institutions with this shared global vision; it will facilitate collaboration, research and transfer of knowledge across seven key regions and a variety of cross-regional programs.

Applications opened for a unique Master of Science degree in Global Child Health at the St. Jude Children's Research Hospital Graduate School of Biomedical Sciences. Developed in collaboration with the St. Jude Department of Global Pediatric Medicine, the program offers students a transformative education needed to enhance the treatment and care of childhood cancers and catastrophic illnesses in an evolving world.

In April 2019, the first St. Jude Global Alliance membership agreement was signed,

marking a new era of expanded collaboration made possible by the St. Jude Global Alliance.

Also in April, St. Jude announced a collaboration with World Federation of Hemophilia. The collaboration with WFH will establish and facilitate a gene therapy clinical trial for treatment of severe hemophilia B patients in low- and middle-income countries.

COLLABORATION IS KEY

One of the common themes among these milestones is collaboration. Our work alongside WHO has a lofty but achievable goal to cure 60 percent of children worldwide with six of the most common types of cancer by 2030. We can achieve that work only through collaboration. It's key to addressing the issue of undiagnosed childhood cancers and to continue to improve treatment. The WHO Global Initiative in Childhood Cancer will achieve this goal through two important objectives:

Increase capacity of countries to improve access to quality care for children with cancer

Increase the prioritization of childhood cancer at the global and national levels

This work began in earnest with focus country engagement in WHO's six regions. As we work alongside strategic global partners on this initiative, we're also excited about how the St. Jude Global Alliance will contribute to the fulfillment of those goals.

The launch of St. Jude Global marked a milestone of a global movement that is making a difference in the world. But we can't look back with pride or satisfaction. Our journey is long, but we are underway. We don't so much look back as we glance quickly to remember from where we come, as we focus intently on the winding road ahead with both hands firmly on the wheel.



one BIG FAMILY

The unifying power of the St. Jude mission brings families together to support, and to remember.

They first met in New York City, at a photo shoot for St. Jude Children's Research Hospital – two families on separate cancer journeys, but with so much common ground over which to bond. And bond they did, the families of Markell, a teen with bone cancer, and Arianna, a young girl with a brain tumor.

"Markell was playing with all the other kids when we walked into the studio," said Arianna's dad, Enrique, recalling a relationship that began in 2010. "The kids were all laughing, they were having a great time. I said, 'Now here's a kid who knows how to command attention.'"

Weeks later, when the families were back in Memphis, back at St. Jude, they ran into each other in the waiting

room. Their journeys had intersected again. That initial connection had sparked something greater.

"And that was it," said Markell's mom, Monique. "Immediately, it was like we were all one big family."

They became inseparable – Markell's family (Monique and Markell, and Markell's siblings when they were visiting) and Arianna's family (Enrique and his wife, Leticia, and Arianna and her little sister).

Arianna's family opened their home to Markell's family for Thanksgiving. Markell loved Leticia's cornbread so much so that whenever he came over, she made it. Every time he felt sick, she made it. Even toward the end of his life, Leticia's cornbread was something he craved.

"It's not family, but they just get you," said Leticia, describing how relationships between St. Jude families can run so deep. "And it doesn't have to be the same culture or color. Nothing has to be the same, but the fact that our hearts hurt the same, and we're trying to find healing the best way that we can. And we have been able to do it together."

The families' relationship was on display in a 2014 video about Markell. There's Markell on screen, looking cool in shades, lighting up rooms with his smile, and announcing his beloved New Orleans Saints' first-round pick in the 2013 NFL Draft.

And there's Enrique on screen, telling a story from that first meeting in New York. He says, "I remember Monique told me, 'We ran into Tracy Morgan.' I was like, 'Oh, that's cool.'" Later, when Enrique asked Markell about meeting the actor and comedian, Markell corrected him: "No, Tracy Morgan met me."

Enrique laughs, then says, "So that's like the first memory I have of Markell. He's just always been a celebrity in himself, you know?"

As Markell's treatment became more difficult, as his cancer returned again and again, he and Enrique grew closer. They went to Memphis Grizzlies games together. They talked through the night. Markell told Enrique, "I love you like a dad."

The day before Markell's leg was to be amputated, he called Enrique with a request: Come play basketball with me.

"That's always stuck with me so much," Enrique says in the 2014 video. "To know that I came to essentially play his last basketball game, with his two legs, as a kid. I think the sun went down before he got tired. It was a good day."



The next image in the video is a close-up of Markell. "That's my boy, 'Rique. We always hang out together. Always go to games. He always take me places. He do a lot for me, and that's why I love him."

And likewise, when Arianna's cancer returned and nothing more could be done for her, Monique and Markell embraced Enrique and Leticia, helping them through a world of firsts without Arianna – first birthdays, first holidays – after she died in 2014. In the end, yes, the families would come to share the ultimate loss, the loss of a child to cancer.

Except that it wasn't the end. Because the bond that was forged between the families at St. Jude would stay strong and even grow. After Markell's death, Monique moved her family permanently from Louisiana to Memphis, where Enrique and Leticia and their family live. The two families – in step, as always – participated together in the 10K at the St. Jude Memphis Marathon Weekend. The course took them through the campus of St. Jude, where their children were treated – Markell for osteosarcoma,

Above: "I miss his personality the most. He lit up a room." Markell and his mom, Monique, were there for their friends, Enrique and Leticia, through a world of firsts without their daughter, Arianna, who died in 2014. Enrique remembers his friend Markell as a superstar. "He's just always been a celebrity in himself, you know?"

Below: Arianna with her dad, Enrique. The families' relationship began in 2010, and the parents have remained close, leaning on each other for support through the loss of their children.



“It’s not family, but they just get you,” said Leticia, describing how relationships between St. Jude families can run so deep.

a type of bone cancer; Arianna for a rare brain cancer called ATRT – and a deep friendship was born.

“And I’m sure we’re going to cry,” Leticia said before that weekend. “And I’m sure we’re going to laugh. Because you can’t help but think of the memories between us and them and our kids and not laugh, because they were crazy.”

Then she recalled one of those crazy moments – when Markell was losing his hair because of chemotherapy, and her children began pulling it out and gluing it to his face. “And they made him a beard with his hair,” Leticia said, laughing at the memory.

That marathon weekend was only the second time Monique had returned to St. Jude since Markell’s death in 2016. It was the first time back for his siblings. A weekend filled with thoughts of Markell – a boy who endured six-and-a-half years of treatment, who lost a leg but never his spirit for life; a boy who, when he died at 16, practically his entire high school turned out for the funeral.

“I miss his personality the most,” Monique said. “He lit up a room. We’d stay up talking all night. Believe it or not, I even miss arguing with him.”

When Monique decided it was time to visit St. Jude, her first time since Markell’s death, Enrique was there to walk into the hospital with her.

“Being a bereaved mother is not easy,” Leticia said. “There were times Monique wanted to give up, but she hasn’t. She wants to make Markell proud. The pain we feel is so intense and constant, and sometimes it’s hard to continue fighting. But she does every day, with such grace and beauty.”

Enrique and Leticia know the struggle so well. They lived it with Arianna. For a year-and-a-half, she was cancer free. Then the cancer came back. She died just before her eighth birthday.

“We had an eighth birthday party for her early,” said Enrique. “But she was so sick, she had to leave before the piñata.”

They put the piñata away, determined to save it for another day when Arianna felt strong enough to swing at it, to crack it open and shower the floor with candy. When Arianna found out the other kids didn’t get to put on blindfolds and try to break it open, she broke down in tears.

“But the kids didn’t get any candy,” she cried, a sick girl putting others first.

Putting others first is the St. Jude way, and a way of life for families like Markell’s and Arianna’s. Remembered by their “one big family,” brought together by St. Jude and still on the journey, the best way they know how – together.



#8ActsOfKindness

In honor of their daughter, who passed away just before her eighth birthday, Leticia and Enrique Ramirez vowed to do eight random acts of kindness. And they invited everyone within their circle, via social media, to do so as well.

Participation has grown exponentially over the years, and the acts of kindness have involved picking up a restaurant tab for a perfect stranger, dropping off school supplies for special teachers and volunteering for the day at a soup kitchen. Things that depended on human contact. This year, with the coronavirus threat, they wondered if it was safe to ask others to participate. Leticia knew it would have to be different, that people would need to be creative.

“To me, it’s going to be more impactful because it’s going to be from their own backyard,” she said. “Think about the little old lady down the street who might need her yard weeded, you know? You don’t even have to talk to her or approach her. You can just go one afternoon and Weed Eat the front yard.”

In the end, Arianna the empath, the old soul, guided their decision. She was always proactive with her kindness. And so were others. The response this year was overwhelming and “solidified the fact that this is what we’re supposed to be doing,” said Leticia. “And it solidified that people are remembering Arianna every day, not just on her birthday.”

That part of you that does good, that helps out, that demonstrates your care for others through acts, big and small? That’s Arianna. That’s who she was, and that’s how we remember her.

You can help ensure families never receive a bill from St. Jude for treatment, travel, housing or food. stjude.org/donate





INSPIRED QUESTIONS: RIO ROMA

BROTHERS JOSÉ LUIS ORTEGA CASTRO AND RAÚL ORTEGA CASTRO, BETTER KNOWN AS MEXICAN POP DUO RIO ROMA, VISITED ST. JUDE CHILDREN'S RESEARCH HOSPITAL. THEY SAT DOWN TO INTERVIEW FOR OUR INSPIRED QUESTIONS SERIES, MUSING OVER THE SONGWRITING PROCESS AND HOW ST. JUDE ENERGIZES THEM.

What do you like most about performing with your brother?

Raúl: Well I enjoy his songs and I really like the way he composes music, he's a wonderful composer. I like the fact that I know him so well. When I sing, I don't have to guess like I would if I were singing with someone else. It's innate and it just happens and I don't even have to think about what he's going to do next. We mesh together somehow strangely, it works. I enjoy myself because they're his songs, and to perform them before an audience – it's my slice of heaven.

José: And the truth is that, although we are very different, the music

brings us together. But on stage, it just works. It's unexplainable.

If I was not a singer, I'd be a ...

José: If I weren't a musician, I would have liked to be a doctor. But one day I came in contact with a microphone, and I couldn't let go of it. It's hard to stop singing.

Raúl: I always said I would've liked to be a pilot, but now that I think about it more ... I might have liked to work in non-profit, at a place like St. Jude.

During your visit, did you learn anything about St. Jude you didn't already know?

Raúl: So many things. The success of St. Jude is in the details. They

think not only of the patient, also the whole family. Something that surprised me a lot is how they think of the patient siblings. It's one of the thousands of details I've seen. They think of everything, that is the secret.

José: Yes, the details and the love and commitment they have for each of the patients. It is very nice to know in this world, where there is bad news on a daily basis, here is this monument to humanity.

You're writing a song for St. Jude. How did your visit inspire you?

Raúl: What inspired us at St. Jude is the love. We are very romantic, we sing about love ... we have songs about romantic love mostly. St. Jude inspires a love of life. You see all the posters and the drawings made by patients. Despite difficult situations they express something so beautiful about life – “be strong,” “you can do it” – what's more inspirational than that? It won't be easy, but there will be a lot of ideas to choose from and something incredible will come from this experience.

José: A happy song. Emotional, but very happy.

Describe St. Jude in one word.

José: Humanity.

Raúl: This is heaven. Heaven.

Do you sing in the shower?

Raúl: I don't understand why people sing in the shower. I sing everywhere except in the shower.

José: Yes. You get the echo, you get the natural reverb. It helps people get a little more confident about singing. I used to sing a lot in the shower and I composed in the shower, too. Everybody sings in the shower.

Raúl: Not me.

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