







feel a tangible sense of hope stepping onto the campus of St. Jude Children's Research Hospital each morning and seeing the buildings alive with powerful research and tender care.

But to see those same buildings lit up at night is to know the research is continuing.

Childhood cancer never rests and, thanks to you, neither does St. Jude – through night and day.

The promise St. Jude won't stop until no child dies in the dawn of life is one Danny Thomas made to the world in 1962. It's the promise Yanin and Shane relied upon when their son, Max, at just 4 years old, was found to have retinoblastoma, a cancer of the eye. (*St. Jude Inspire*, Summer 2020)

It was at least his second bout with the cancer and Max's world, sadly, was going dark. He'd already had one eye removed by the time Yanin and Shane adopted him from an orphanage in China, and shortly after arriving in his new home in the U. S., doctors found active tumors in his remaining eye.

Yanin and Shane rushed Max to St. Jude for lifesaving treatment. And during a 21-day period before the surgery to remove the eye — a three-week window of light before his vision was lost — they rushed him through a lifetime of sights in hopes he would retain those memories.

Today, Max lives a life in darkness, but one brightened by hope and possibility. If the darkness can't hold Max back, then neither will it stifle the work of St. Jude, thanks to you.



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



Less than a year ago, Khurram, a first-time father, was grappling with a terrible prognosis. Not for him, but worse: for his infant daughter. Then came a chance for a cure. Khurram reflects with gratitude on how life has changed.

REFULDAD REFULDAD

n a Friday in November, I received a message about the meaning of my life. On that day, my wife, Sarah, and I welcomed to the world our beautiful baby girl, Imani. Days later, I turned 33. That birthday, holding my daughter in my arms — I couldn't imagine a better gift. I couldn't imagine a better blessing.

Flash forward a month and Sarah and I were exhausted, euphoric and deeper in love every day with our little force of nature. There's a photo from around that time of the three of us in our kitchen, a candid snap of my beautiful wife and me laughing with Imani asleep in her arms. Soon, I would wish I could have stopped time at that exact moment.

Because at 5 weeks old, Imani would be diagnosed with a cancerous brain tumor. Glioblastoma is a grim diagnosis. But my wife and I are both doctors; we have faith in medicine. Imani underwent surgery at a children's hospital in our area, but afterward, she rapidly declined. She entered hospice. I prayed. I wept. I purchased my baby's burial plot.

As a father, seeing your child gravely ill is the worst possible thing imaginable. As a physician, seeing your child gravely ill and not being able to help is a double nightmare.

At the point we were warned Imani had less than two weeks left, I was broken inside. Over and over I kept thinking, "I never got a chance to hear her laugh."

Then something astounding happened. On December 24, I spoke with an oncologist at St. Jude Children's Research Hospital, who said, "I've treated this before and some people have even been cured." Was it foolish to hope, I wondered? But if we believe in medicine, we also believe in miracles.

Sarah and I took our tiny, critically sick baby to Memphis.

At St. Jude, Imani started an experimental chemotherapy. Slowly but surely, she began to thrive and put on weight with the help of a feeding tube. She began to roll over. She began to smile. By March, the tumor had shrunk enough for a long and complicated surgery to remove it. She underwent four more months of chemotherapy and is home now.

My strong, beautiful, resilient and perfect Imani! I believe I was always meant to be your dad. You have shown me unbelievable things, my baby girl. Through you, I have learned that people are still good. I have learned that God provides in

the darkest moments. I have learned that no matter what, family and friends are the most important part of life.

You have kept your head up through unimaginable things and, because of that, I've tried to keep mine up as much as I can.

My dreams are only about you and for you. I thank God that I can finally feel as though they will be fulfilled. And one day, Imani, when you're older, I'll tell you the story of how St. Jude came to the rescue when all hope was lost.

We were at rock bottom. Now, Alhamdulillah, we are on the road to recovery. We have passed milestones we never thought we'd see: Imani's 6-month "birthday," her first New Year's, her first Ramadan.

Oh, and in April? In April, I got to hear my daughter's laugh.









A "LARGER THAN LIFE" SOCCER STAR



big toe. For a young woman with a compromised immune system, a simple stubbed toe quickly deteriorated into a blackened wound, followed by blisters, fevers, skin infections, bone infections and painful operations before surgeons finally had to remove much of her toe.

But of all the strange aspects of that episode, perhaps the most surprising is that Anna can laugh about it now, especially when she thinks of the stranger who unwittingly set things in motion. "I just think it's funny that he's out there living his life and has no idea I had a toe amputated. I see some humor in it."

If nothing else, the story illustrates how Anna, a 23-year-old college student and star soccer player, fought through all of cancer's ups and downs, all of its random cruelty, to emerge, well, laughing. It's little wonder she draws inspiration from a verse written by Indian-born Canadian poet Rupi Kaur:

the world gives you so much pain and here you are making gold out of it.

Anna's pain came from acute myeloid leukemia, a type of blood cancer, and the gold she's spun from it defies simple measurement.

She's tapped a newfound strength and determination to return to the soccer pitch an even better player than before. And as Anna's story has circulated across the Memphis area, she's helped rally the city's soccer community — especially its professional team — around the mission of St. Jude, where she underwent treatment.

"Unless it affects you, I don't think people know the magnitude of this place," she said.

A 'SPECIAL SUMMER'

Anna actually knew about "this place" – St. Jude – before her cancer treatment. During the summer of 2018, she interned as an events coordinator at Target House, a long-term lodging facility for St. Jude patients and their families. Fluent in Spanish (her parents immigrated to the U.S. from Argentina), she worked extensively with Hispanic patients as she organized summer camps and other activities.

It was a "special summer," she said, followed by an eventful fall. As Anna began her junior year of college, she took on part-time work helping with the launch of the Memphis 901 FC soccer team, while also playing center forward for her college team.

While at five feet tall she often was the shortest player on either team, Anna could be the most dominant. Over the course of two home games one weekend, she scored four goals and, as a result, earned honors as Gulf South Conference Offensive Player of the Week.

"She had a great year for us, not only the stats that she had, but her all-around play," said Kieron Heblich, her soccer coach. He praises Anna's technical skill and savvy as a player. "She's got a very good soccer brain. She knows what she's doing."

But even before the 2018 season began, Anna experienced unexplained physical problems. During workouts, her legs would throb with pain, then go numb. She responded by splashing water on them until she could get up and run some more. She also had occasional neck paralysis, vision problems, night sweats and sinusitis. In the dorm, friends often had to help her to bed, and on road trips she would sleep the entire way on the bus.

"I was sick for probably a year with symptoms," she recalled.

'I WOULD'VE BLED OUT ON THE FIELD'

In December 2018, Anna went in for a postseason checkup because an earlier doctor's exam found her platelet count to be low. The findings were ominous. "The leukemia was already widespread throughout my body, so I had to be at St. Jude the next day."

Anna also learned from tests that, in some respects, she had been lucky during the playing season. "Had I gotten an injury, I would've bled out on the field because I didn't have platelets to clot my blood," she said.

After he learned of the diagnosis, Anna's coach marveled that she could play at such a high level while fighting the obvious effects of cancer. He went back and reviewed the video of one of Anna's four goals during that one weekend home stand. Over and over, he watched her use deft footwork to beat her defender and then line a perfectly aimed kick into the corner of the net from a difficult angle. "As good a goal as I've seen," he called it.

"She's larger than life, she really is," he added.

As her family and friends rallied behind Anna, the players, coaches and officials of Memphis 901 FC, a team in the United Soccer League, offered their support. During her treatment in 2019, the team streamed into St. Jude to visit her, take a tour and donate platelets. Players from as far away as New Zealand and Trinidad learned about the research hospital and its mission. "It was very moving for all of us," Coach Tim Mulqueen said.

In Anna's honor, the team added the St. Jude logo to its jersey, and now



Prior to the pandemic, Anna worked as a visiting-team liaison for the Memphis 901 FC Soccer club, as well as serving a role helping St. Jude patients and families attending the matches. During her treatment, the team toured St. Jude, becoming staunch supporters.

10 percent of the sales of each jersey sold to the public goes to the research hospital.

Treatment lasted about seven months, and despite bouts with sepsis and other complications, there were lighter moments. Friends would come spend the night, watch movies with her or take her to the St. Jude Imagine Room and enjoy the wall-sized interactive video screen there. To Anna, St. Jude seemed more like her dorm than a hospital.

With her final round of chemo ending on June 30, 2019, Anna was hoping to be ready by August to begin training for her final season of college soccer.

'A COMPLETE ACCIDENT'

The gathering at the restaurant exactly one week later would dash those plans. Looking back, Anna describes the toe injury as the result of a perfect alignment of highly improbable factors: the position of her feet in her open-toed shoes, the angle at which the man's foot struck the toe, and so on.

"You couldn't recreate that if you tried," she said. "It wasn't like I was at fault. It wasn't like even he was at fault. It was a complete accident."

Doctors at St. Jude told her the sources of the fungal infection she suffered included spores from soil on the man's shoes and spores from the air. During the numerous procedures to cut away dead skin, Anna tried mind games as a means of coping.

"I removed myself from the situation, acting as if it was someone else's toe."

Anna didn't feel sorry for herself, however, especially when doctors told her another St. Jude patient on her floor had developed a major fungal infection in her knee as a result of a fall.

"They were like, 'You're trying to save your toe; she's trying to save her leg.' That just put everything into perspective for me. I was never sad once about my toe."

Despite doctors' best efforts, all of the monitoring and surgeries on the toe, the infection spread to the bone

in less than two weeks, posing a life-threatening risk. In the weeks after the amputation, Anna had to wear a boot and use a wheelchair. Her legs had lost nearly all their muscle. With the help of St. Jude, she learned to walk again after seven weeks of being immobilized, and then she underwent months of anti-fungal treatment. Still, Anna has high expectations for her final year of college soccer. "If anything, I think I'll be better than before."

NO LOOKING BACK

When friends mention how unfair it was she had to go through such an ordeal, Anna tells them everyone endures life's downsides – whether it's an unhappy childhood, divorce, grief or financial hardship.

"I had a relatively fine childhood. It was time for me to go through something."

Anna returned to class last fall and went back to work with the Memphis 901 FC soccer team. Prior to the pandemic, she served as the visiting-team liaison, helping opposing players and coaches with logistics and familiarizing them with Memphis and AutoZone Park, where the games are played. She also played a role in the expanded presence of St. Jude with the team by identifying patients and family members who would come watch the games for free in a suite at the stadium.

As for her future, Anna plans to work with a non-profit or humanitarian group. She might pursue a career at St. Jude or ALSAC, the fundraising and awareness organization for St. Jude. At St. Jude, she said, "everyone is always in a good mood, everyone leaves knowing they've changed someone's life in some way."

She should know, because of what happened to her at St. Jude. "I was granted a new life."

For a brief but intense period, life gave Anna so much pain. Yet there she is, still making gold from it.

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





here aren't enough hours in the day for Kate, a college senior, but she resolutely fits you in during a break from biochemistry homework. If tonight is a "good night" for this biology and philosophy major on the pre-med track, she'll be all done studying and to bed by 1:30 a.m. But if it's a "bad night," a night with too much to do and not enough time, she might not turn in until 3:30 a.m.

You could ask a thousand questions and still not know how Kate does it now...

How she undertakes her daunting pre-med undergraduate coursework...

How, before the pandemic, she found time for her side gig as manager of her collegiate women's gymnastics varsity team...

How she competed on her collegiate club gymnastics team – claiming second place honors in the national women's decathlon last year – and with a prosthetic leg...

Or how Kate did it then.

How she survived cancer twice and the loss of her leg. And didn't let that stop her. And got back on the gymnastics mat.

Something having to do with strength of character and facing challenges head on...

Something about tenacity and pushing herself to perform at the highest level...

Something about the utter faith she could do it.

You can listen, and you can appreciate, and you can gain insight, but you cannot know. That X-factor, that indefinable thing that makes Kate herself and no one else, it fascinates and draws you to her.

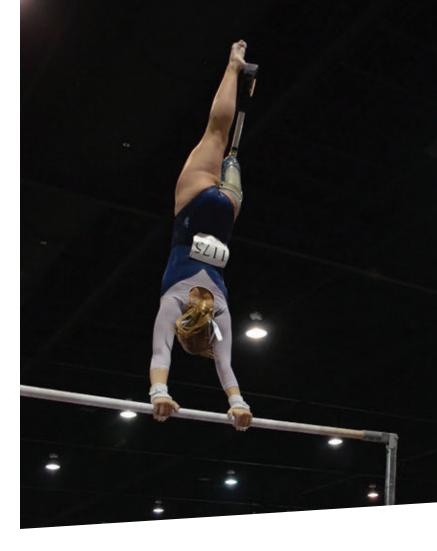
Now Kate, 21, has her sights set on medical school.

Without St. Jude Children's Research Hospital, she might not be here. Here, as in: right here with her biochemistry homework spread before her. Here, as in: life saved.

'I CAN MAKE IT WORK'

Kate has done gymnastics since she was 8, so she's accustomed to balancing – literally and figuratively, it turns out. It's kind of her superpower.

"My parents always felt very strongly that school could not come at the expense of gymnastics," said Kate. "I think that's served me well in college because clearly



I have a lot of things that I like to do. Balancing them can be a little bit tricky, but I make it work."

Her path here hasn't been easy. When she was 12, a series of strange infections turned out to be symptoms of acute myeloid leukemia. Complications from her first round of chemotherapy led to the amputation of her leg, which took place on the same day as her bone marrow transplant. "She was up on crutches the day she lost her leg," her mom, Barb, said. "Within a week of getting her prosthetic leg, she was learning to run."

She relapsed just as she was planning her return to gymnastics competition. When her family's insurance company refused the treatment plan her doctors recommended, they obtained a referral to St. Jude, where "insurance would never be an issue," said Kate.

Her experience at St. Jude molded her career ambitions.

"I really found that I enjoyed learning along with the medical students and the residents," said Kate. "The doctors would make sure they were teaching them as they were providing care to me. ...Clearly I didn't know a whole lot, but there were little puzzle pieces that I

liked putting together as much as I could."

A bone marrow transplant at St. Jude followed and, finally, a return to the sport she loves. "There are only a handful of gymnasts with a prosthetic," Barb said. "It's a very difficult thing to do."

But Kate has always been drawn to the difficult thing.

Any other year, when she's not cramming for an exam or competing in club gymnastics, Kate helps with practices as team manager for the women's varsity gymnastics team. At home meets, she makes sure the judges and volunteers know what to do, and she ensures the paperwork and scoring are entered.

In 2019, Kate competed for the first time in the lower Decathlon Level at the National Association of Intercollegiate Gymnastics Clubs. She won second place.

PEERLESS

Kate's not perfect, she insists. Because no perfect person would break her prosthetic so much.

She damages her prosthetic leg regularly by falling on it, overstressing it, using it in ways it was never intended. A piece breaks off, or something gets snagged. "Yes, so I'm really good at breaking it," said Kate. "Maybe they're not meant to be used for 15 hours of gymnastics a week? Who knows?"

But even a break has the potential to become an opportunity for innovation.

"A while ago, we were really worried about me hooking it on the bar because there's kind of a curved running blade," said Kate, "so I told

There's something about the feeling of doing your skills on the bars right, where you feel the force of it pulling on you. It's just a cool feeling to know that you are creating all this power. It's like you're flying. It's amazing.

Visit **stjude.org/kate** to see Kate stick her landing on the uneven bars.



my prosthetist, 'Hey, here's what I want to do, and here's what I'm concerned about.' And he said, 'Alright, give me a couple of hours,' and he came out with this custom little piece that I can fit over the top of it."

Returning to gymnastics after her leg amputation and cancer treatment, Kate felt acutely aware she was blazing a trail, but since then, she's begun to hear about others with prosthetic limbs competing in gymnastics. "I don't think anyone's competing at the level I'm at," said Kate, "simply because I've been doing it a lot longer."

She took her MCAT this summer and after graduation next year, Kate hopes to be the first of her kind yet again: an amputee gymnast medical student.

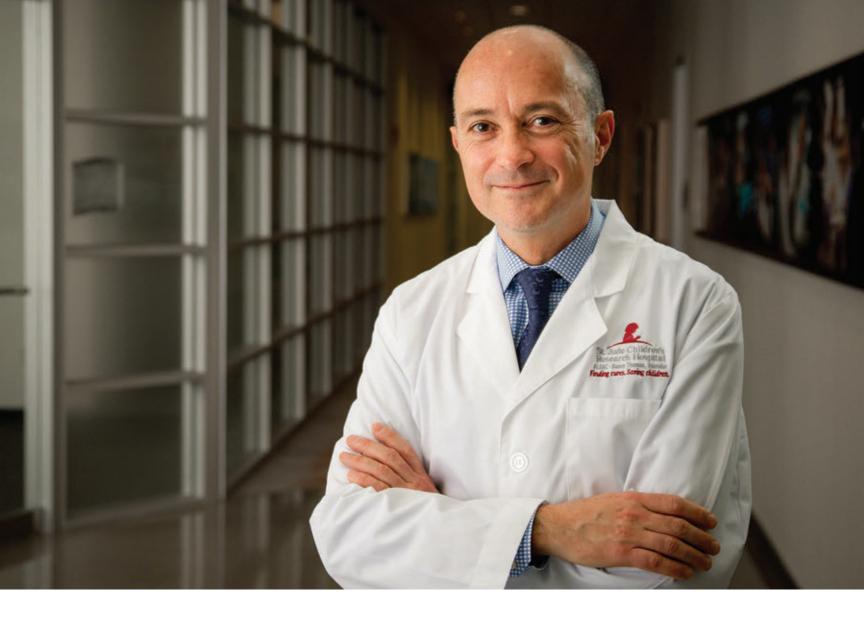
And then someday, a doctor. "I want to do for someone else what my doctors have done for me," said Kate. "I want to be the person that saves that kid's life."

SHE'S FLYING

Before you get off the phone with Kate, she promises to find some gymnastics photos and send them. You get them seconds later. Not one minute of wasted time.

That desire to do more, still more, always more – to storm the palace and take the prize. To do the hardest things. She's always been this way, even before the cancer thing, even before the leg thing.

For Kate, the only limits are time and gravity, and sometimes not even those things can stop her. Because when the force of who she is meets the pressures against her – that's when she's flying.



11 MILLION CHILDREN WILL DIE OF CANCER IN THE NEXT 30 YEARS.

HERE'S HOW WE COULD SAVE HALF OF THEM.



n another time, under different circumstances, Dr. Carlos Rodriguez-Galindo and his colleagues might have attracted the world's attention to the singularly audacious goal they outlined recently: Preventing the deaths of more than 6 million kids from cancer.

The Lancet Oncology Commission, co-chaired by Rodriguez-Galindo, who also chairs the Department of Global Pediatric Medicine at St. Jude Children's Research Hospital, published a report concluding that without additional investments in healthcare systems, some 11 million children age 14 and younger worldwide will die of cancer between now and 2050. Most of the deaths were predicted for low- and middle-income countries, where access to care is limited and childhood cancer cases routinely go undiagnosed.

The report also found, however, that with global increases in healthcare spending totaling about \$20 billion a year, more than half of those deaths – an estimated 6.2 million – could be prevented. Furthermore, it said, every dollar spent on the effort would bring a threefold return in economic benefits.

"That was work we were hoping would call the attention (of) governments, call the attention of the major decision-makers," Rodriguez-Galindo said.

Unfortunate timing, however, deprived the report of the attention Rodriguez-Galindo hoped it would receive. Published by *The Lancet Oncology* journal in March, it came out just as the burgeoning COVID-19 pandemic began dominating news cycles. "We got zero calls from the media," he said.

The experience hasn't deterred Rodriguez-Galindo from his quest to prevent what he calls needless deaths from pediatric cancer around the world. As director of St. Jude Global, he's leading an initiative that works with doctors and institutions in about 60 countries to improve care and expand access to healthcare while also providing education about childhood cancer.

The challenge is daunting because while 4 of 5 kids getting cancer in higher-income countries like the U.S. survive, the statistics are reversed in low- and middle-income nations, where 4 of 5 die.

Of the 400,000 children around the world afflicted with cancer each year, only half are diagnosed, Rodriguez-Galindo said in a recent video discussion with St. Jude donors. "So 200,000 children every year die in agony, with no access to care."

"Of the 200,000 diagnosed," Rodriguez-Galindo continued, "maybe only a third actually may be cured. So the bottom line is that only about 20 percent of children who develop cancer today ... actually can be cured."

Because it represents just a tiny fraction of all cancer cases, pediatric cancer tends to get left behind when governments set funding and policy priorities. But when measured in terms of the number of years of healthy life it robs, childhood cancer ranks among the world's most burdensome diseases and "is actually a public health and a global health emergency," Rodriguez-Galindo said.

Every day, hundreds of children are dying ...
And that is because of inaction. This is not because we cannot prevent (the deaths), this is not because we cannot do something. It is because we don't do anything.

- Dr. Carlos Rodriguez-Galindo

To address that emergency, Rodriguez-Galindo and the nearly four dozen other internationally recognized experts who authored *The Lancet Oncology* report prescribe a six-step course of action they say would "tackle the unacceptable inequalities" in care between rich and poor countries. The measures include covering childhood cancer as part of universal healthcare plans, ending out-of-pocket charges for treating cancerstricken kids, and building national and regional networks to improve access to care.

Rodriguez-Galindo said the "major strides" made by St. Jude, like those that have increased the survival rate for acute lymphoblastic leukemia from 4 percent to 94 percent over the last six decades, need to be extended globally.

"All the progress we have made is nothing unless we can really think about how to make that a goal for children in the world." he said.

The real tragedy, Rodriguez-Galindo said, is that so many kids in poorer parts of the world succumb to cancers that are curable in affluent countries.

"Every day, hundreds of children are dying ... And that is because of inaction. This is not because we cannot prevent (the deaths), this is not because we cannot do something. It is because we don't do anything.

"And that is the major catastrophe here, that cost of inaction, that we cannot protect the most vulnerable in our societies."



wonderful memory, wrapped in a Christmas

miracle

From a brief stay at St. Jude, a family's devotion to the cause was born.

ost St. Jude stories begin with the devastating words: Your child has cancer. They're the words Scott and Kerri Kruse were preparing themselves to hear when they brought their 3-year-old daughter, Andie, to Memphis just before Christmas in 2006.

It had started back home in Dexter, Missouri, with a stubborn cold before a family ski trip, and a visit to the

pediatrician that "went south in a hurry," Scott said.
Their doctor brought in other doctors, worries mounted and a consensus formed: It looked like leukemia.

Instead of a family vacation, they were St. Jude-bound. They arrived at 11:30 that Friday night, met with doctors until about 2:30 a.m., then were told to settle in at patient housing for the weekend. A bone marrow test on the following Monday would tell them if it was leukemia.

BY DAVID WILLIAMS · ALSAC

"Every church in town (in Dexter) was praying hard," Scott said.

And then Monday finally came, not with those dreaded words — Your child has cancer — but with what their St. Jude doctor called "a Christmas miracle."

Andie didn't have leukemia, after all. Instead, she tested positive for mononucleosis and the Epstein-Barr virus, from which she would recover.

"We got to pack our things up," Scott said, and go home with "a wonderful memory and a wonderful story."

It's not just a story about an unexpected diagnosis. In Scott's animated telling, it's about the family's full experience at St. Jude those three days, how they were so immediately and completely embraced, and how it profoundly affected them.

Fourteen years later, Scott is a veteran St. Jude Hero and star fundraiser who champions the cause every chance he gets.

Having run five St. Jude Memphis Marathons, he qualified to run this year's Boston Marathon – not as a fast runner, mind you, but as a prodigious fundraiser: A select number of spots are reserved every year for a team of St. Jude Heroes, who are required to raise a minimum of \$10,000 each.

Scott blew past that amount. He was at about \$38,000 when the world changed, when the pandemic put a halt to the Boston Marathon, and essentially every other large gathering.

For a first-timer in the famed race, it was like Heartbreak Hill, without the hill.

But a hero's got to be heroic. So Scott, forced to walk, not run, for exercise this spring because of a



It's not just a story about an unexpected diagnosis. ...it's about the family's full experience at St. Jude those three days ...

back injury, had an idea. He'd bring the spirit of the Boston Marathon to his neighborhood. He'd recruit Kerri and Andie, now 16, and older daughter Addie, 20. And they'd all walk, relay style — with a paper towel roller for a baton.

"I thought, holy cow, if we could just set a number," he said, "and it ended up being a marathon, that would be so cool."

So one April day, Scott donned a St. Jude T-shirt and cap. He walked about five miles, then logged his mileage in chalk in the driveway. Then Kerri walked about five miles. Then Addie and Andie took their turns. From there, they all just rotated until they'd reached a collective 26.2 miles.

"Then we challenged another family," he said.

In the weeks that followed, at least seven other families staged their own version of the "COVID-19 Family Marathon Relay."

Scott's only regret was that he didn't turn it into a fundraiser for St. Jude. It just didn't seem right, though, given the toll the pandemic was taking on families and the economy. But if he couldn't raise money, he'd raise awareness.

Anything for St. Jude, he said. Anything for the place that filled those three fraught days with so many memories – and wrapped them in a Christmas miracle.

Scott still marvels at how it turned out. They were told it was almost certainly leukemia. They were bracing for the words, and the three years of treatment that would follow. Instead, they got to go home after three days — three days they've never forgotten.

The family still has Andie's patient bracelet; they put it on the family Christmas tree every year. And Scott carries in his wallet the card that served as the room key for their patient housing facility and their meal card — a reminder that St. Jude is a place where families never receive a bill, a place where the majority of funding comes from donations.

Not that the Kruse family needs a reminder.

"Stuff like that sticks with you, and stuff like that is the reason you just want to keep giving," Scott said. "It never leaves us."

SEARCHING FOR THE NEXT PANDEMIC FLU VIRUS?

THERE'S ANOTHER FACTOR TO KEEP IN MIND.

By Mary Powers

Member of the Communications Department at St. Jude Children's Research Hospital

efore COVID-19, influenza was the virus most associated with pandemics. The 2009 H1N1 pandemic swine flu virus was the first pandemic of the 21st century. The virus killed upward of 575,400 people worldwide. Federal health officials estimate 60.8 million U.S. residents were infected and close to 12,500 died.

In the middle of the current pandemic, St. Jude Children's Research Hospital scientists are working hard to enhance the global flu surveillance system and improve their ability to recognize animal viruses with the most potential to cause a pandemic. Current flu surveillance includes monitoring a variety of environmental, epidemiological and viral factors.

PANDEMIC POTENTIAL EXPANDED

Research led by Charles Russell, Ph.D., of St. Jude Infectious Diseases, identified another trait to consider when evaluating the pandemic potential of animal viruses. That is the stability of the hemagglutinin (HA) protein. The findings appeared this summer in the journal *eLIFE*. Meng Hu, Ph.D., a postdoctoral fellow in Russell's lab, is the first author.

HA is the surface protein the flu virus uses to bind to and invade host cells. HA binding preferences vary by species. To bind human cells, the HA of avian and swine flu viruses must adapt. HA also triggers the immune response that combats the infection. A novel HA puts the immune system at a disadvantage, forcing it to play catch up after infections have started. Investigators currently track both aspects of HA – binding and novelty – to spot animal viruses with pandemic potential.

Russell and his colleagues reported that HA stability in mildly acidic conditions like those in the human upper respiratory tract also factor into the pandemic potential of swine flu viruses.



This work drives home that we need to think about these HA properties as partners that travel together. Both are necessary for viruses to become transmissible in humans. Surveillance systems should be expanded to reflect this.

- Charles Russell, Ph.D.

SETTING CONDITIONS FOR AIRBORNE TRANSMISSION

Scientists knew HA binding is just one step. Infection requires that binding be followed by fusion of virus and host cell membranes, then release of the viral genome into host cells and production of more flu virus. Human flu viruses have a relatively stable HA. Protein activation and viral genome release occurs at a mildly acidic pH of 5.5 or less. The HA is typically less stable in animal viruses. Their preferred pH, or the pH of activation, is typically higher at pH 5.5 or above.

Researchers reported that HA stability promoted airborne transmission of swine flu viruses in laboratory models, which model human flu infections. Airborne transmission is an established indicator of flu viruses with pandemic potential. "This study and others show that the stability of the HA protein should be considered along with receptor binding when evaluating the pandemic potential of a flu virus," Russell said. The findings build on Russell's 2016 paper that showed that a human pandemic flu virus lost its pandemic capacity Hemagglutinin acid stability as an essential property of pandemic viruses.



Hemagglutinin is carried on the surface of the flu virus. The virus needs the protein for binding to and infecting host cells.



The pH at which human flu viruses are activated.



The pH at which avian and swine viruses are activated.

when the HA was destabilized. The paper was published in the Proceedings of the National Academy of Sciences (PNAS).

The viruses varied widely in HA protein stability and included HA genes that are closely related to the 2009 pandemic virus. When researchers compared airborne transmission in laboratory models, the virus that transmitted most effectively had an HA that was stable and adapted for binding the human receptor.

"This work drives home that we need to think about these HA properties as partners that travel together," Russell said. "Both are necessary for viruses to become transmissible in humans.

Surveillance systems should be expanded to reflect this."

The swine flu viruses in this study were collected as part of the hospital's role as a Center of Excellence for Influenza Research and Surveillance for the National Institutes of Allergy and Infectious Diseases. The institution is also a collaborating center with the World Health Organization Global Influenza Surveillance and Response System.

THE MISSION TO MAKE A RARE DISEASE EXTINCT

By Kim E. Nichols, M.D.

Faculty member in the Oncology Department and director of the Cancer Predisposition Division at St. Jude Children's Research Hospital

cientists recently unearthed a dark secret hidden in the fossilized tail of a duck-billed dinosaur buried in the depths of Canadian soil. The unusual discovery in the lizard-like hadrosaur could potentially yield clues to a rare disease still found in humans today.

AN INSIDIOUS DISEASE

An examination of the creature's remains found evidence of tumors resembling an immune disorder we know as Langerhans cell histiocytosis (LCH). The cancer-like condition occurs when too many cells known as histiocytes build up in the body. LCH and other types of histiocytosis, such as hemophagocytic lymphohistiocytosis (HLH), are extremely rare. When found, they occur primarily in children.

Like the dinosaur sneaking up on its prey, histiocytic disorders stealthily attack bones and organs within the body. Chemotherapy and other conventional anticancer therapies have helped many patients with some forms of histiocytosis, but other patients develop long-term chronic and life-threatening health effects. More than half of patients diagnosed with HLH will die from their disease.

THE INVESTIGATIVE TEAM

Because we know so little about these conditions, we have collaborated with scientists at other institutions to learn more about the genetics and mechanisms that drive LCH, HLH and other rare histiocytic disorders. St. Jude is the coordinating center for the North American Consortium for Histiocytosis, known as NACHO, a group that brings together histiocytosis experts to facilitate laboratory and clinical research. St. Jude hosted the Histiocyte Society annual meeting

last year, which drew more than 200 international histiocytosis clinicians and scientists who shared their latest research on these conditions.

EXPLORING THE SCIENCE

These collaborations have already uncovered new information that enhances our understanding of these similar, yet very different, disorders. For example, one recent discovery revealed up to half of patients with LCH tumors harbor a specific genetic mutation in the BRAF gene. The findings help pave the way for new drugs designed to target the mutation in patients with LCH.

Our research team studied how the chemotherapy drug ruxolitinib helps block signals that cause HLH-associated inflammation. Along with Melissa Hines, M.D., from the Division of Critical Care, we expect to launch a Phase II clinical trial in late 2020 to evaluate a new treatment for HLH that combines ruxolitinib and dexamethasone, a steroid.

The trial builds on years of amassed data showing that ruxolitinib can rapidly and robustly curtail hyperinflammation in a variety of immune-mediated disorders. Our goal is to offer patients a more effective therapy with fewer side effects than current treatments.

Up to 40 children with newly diagnosed HLH and up to 20 children with relapsed or refractory disease will participate in the study.

Although the excavated hadrosaur and his dinosaur brethren no longer roam the earth, histiocytosis has not suffered the same fate. With persistent digging by us at St. Jude and scientists elsewhere, perhaps one day this disorder will also be a relic of the past.

THE

FACTOR

In praise of the unsung hero of strength and comfort at St. Jude

By David Williams · ALSAC

Mary Browder didn't ask if she was going to die. She asked if she was going to lose her hair.

What does a mother even say to her daughter in that moment? The answer was yes, of course. It's what chemotherapy often does.

But this is what moms do – they find a way to comfort their daughters and sons, to steel and inspire them. Soothe them. Skinned knee or cancer, it's no matter to a mom whose child is hurting. And so, as they stood one day in St. Jude Children's Research Hospital, where Mary Browder, then 10, was being treated for Hodgkin lymphoma, her mom saw a chance to be, well, motherly.

"We saw this beautiful girl walk by, bald-headed," Renee said. "And she had her head up high. She was probably 16 or 17, and I pointed her out to Mary Browder. I said, 'Look at that beautiful girl.' I said, 'That's going to be you in another few weeks, and you're going to walk like that."

In fact, when the time came, they didn't just make baldness something to rise above. They made it "fun" – Renee's word.

"We used water colors to paint her head and we found fun hats," she said. "She put a hat on backwards at an elementary school festival after a teacher painted Charlie Brown's face on the back of her bald head. That was my personal favorite."

Spend much time hearing the stories of St. Jude patients and families, and you might come away thinking moms are the secret superheroes of the place. All due respect to the doctors, and the science they apply to saving young lives, but proton beam therapy has nothing on a mom in full protective mode.

Art by St. Jude patient Jaxon Fall 2020 21

Take Allison, whose daughter Jessica was diagnosed with acute lymphoblastic leukemia (ALL) at 9 years old.

"Jessica and I have a very strange, kind of a symbiotic relationship," Allison said. "If I'm a mess, she's a mess. If Mama's freaked out, I should be freaked out. So I couldn't. I couldn't. I had to be strong. I had to be strong because I had to get her through it.

"Now, there were times I'd go out in the backyard and scream. But she didn't hear it."

More than two decades later, Jessica thinks of all the fear and worry her mom kept hidden for the sake of her sick, scared little girl.

"I should ask my mom a lot of questions about how she felt and what she experienced," Jessica said. "Because she's always been so strong. And I think she would have internalized a lot of the emotion and how scared she was. Some of it you can just read on people's faces, but she really kept a lot of it to herself."

What to say, or not. What buttons to push, threads to pull. Mothers just know. It's their superpower – one of them.

Consider Nick, a quiet kid with a reflective nature. When he was diagnosed with ALL as a young teenager, his mom had a suggestion: Write down your thoughts. Keep a journal. Tell your story.

"For me, it was like, write every day," Tangela said. "I don't care if today was hellish, you know. Or today was awesome. Or, 'I felt like crap.'

"Even if you don't talk about it, write about it. ... It'll turn into a story."

Nick's stories turned musical, his St. Jude experience set to rap beats



– songs about "sanitizers, face visors and separate cups," about friends made and lost, and the beanie he wore when chemotherapy took his hair. The experience helped transform him, from shy kid to dynamic performer. All because Nick's mom made a suggestion, pulled a single thread? That was the start of it.

Or there's the story of Christopher, a 10-year-old boy in Puerto Rico when he was diagnosed with ALL – just as his mother was preparing to be married to her fiancé, William. So the wedding was put on hold, the family moved to Memphis for treatment at St. Jude, and Jessica – who had gone from anticipating one of the best days of her life, to any parent's worst nightmare – did what moms do:

"I gave all my heart, my strength, as a mother to be happy around him," she said. "Even though maybe my happiness was fake, I knew that if he saw me sad, he was going to be sad, too."

And when that wasn't quite enough, what was a mother to do?

"She started dancing and singing to me, so I could get my joy back," said Christopher, now 18.

She danced? And sang? Really? Where was this?

"It was in the hospital, when I was getting my bone marrow transplant," Christopher said. "I was in really bad shape. She, as a mother, saw me like that, really bad, and she made something for me to appreciate life."

Moms are champs at adapting. They're queens of creativity. They protect and guide us, champion and inspire us. And sometimes we get a chance to give them a proper thanks.

So it was for Christopher's mom, whose wedding happened, just later than expected, with her son in remission and the venue changed – to the chapel in the Danny Thomas/ALSAC Pavilion, on the St. Jude campus.

The icing on the wedding cake? Christopher walked his mom down the aisle.



DON'T HAVE A STRUGGLE YOU HAVEN'T Sounds like a country song, right? Just maybe

Sounds like a country song, right? Just maybe because when life gives you a second chance, you live it like Jessica Turri. Like most good Nashville ballads, hers tells an unforgettable tale, from childhood cancer to TV scripts and, yes, country songs.

Hear Jessica's remarkable story in a new unscripted podcast series available at **stjude.org/flashpoint** or listen on your favorite podcast app.













St. Jude patient Zac has been fighting cancer for eight years. His mom, Amy, describes how his determination has never flagged, and how gaming and friendship have helped him — especially now.

THROUGH GAMING, MY SON ZAC CHOOSES JOY OVER CANCER.

Gaming and Zac go way back.

No one in our family can remember when Zac first started playing video games, but our best guess is at 4 years old. We remember him setting the timer on the microwave himself when he was a very little boy to track the screen-time limits we gave him.



It would have been just about two years later that Zac was first diagnosed with cancer – Burkitt lymphoma. He was 6.

During that battle with cancer, he would even be playing his Nintendo DS as he was rolled into the Procedures area. And he always wanted us to have it ready for him to play as soon as he woke up in Recovery (and usually told us which game to have ready prior to him going to sleep). If you've ever spent significant time in a hospital, you know that most hospitals are pretty boring. We were glad he had an outlet to help pass the time.

Following months of treatment that included a bowel resection, his scans looked good, and we hoped and prayed cancer was behind us forever.

It was not to be. In 2016, on the day before his 11th birthday, a biopsy confirmed Zac had metastatic osteosarcoma. Now Zac became a patient of St. Jude Children's Research Hospital. From June 2016 to February 2017, at St. Jude, he had multiple rounds of chemotherapy, two thoracotomies to remove lung tumors, amputation of his right leg above the knee and radiation to his left leg. I mean, can you believe what this kid has gone through?

But Zac adjusted like a champ to his "new normal," walking well with his prosthetic leg and going back to St. Jude every three months for scans.

Unfortunately, eight months after we went home, his scans showed tumors in both lungs. This was a monster we were fighting. More

THROUGH IT ALL, ZAC HAS BEEN ADAMANT THAT HE ISN'T QUITTING

chemotherapy, more thoracotomies, an immunotherapy trial and ultimately, amputation of his left leg above the knee in January 2019.

But something really special happened during this time, too. Zac met his best friend and fellow St. Jude patient, Carson. What a blessing their friendship has been.

Since we met in the surgical waiting area in December 2017, the boys have spent hours gaming together when they're both at St. Jude, and playing together online and via FaceTime when they're apart.

I've often had to laugh as I've walked through our house carrying laundry or whatever only to glance over and see Carson, via screen. Like, "Oh, hey, Carson." He and his family are family to us. And the boys are often more concerned about each other than they are about themselves. It's a very sweet friendship. One thing about St. Jude is you make friends from all over, and gaming is a wonderful tool for these kids to stay connected no matter where they are.

Zac returned home from St. Jude in March 2019, but developed wrist pain that May. We hoped it was just a sprain, but scans soon showed recurrence of osteosarcoma at multiple sites — right wrist, right upper arm, both lungs, one rib. Did I mention this kid has been through some stuff?

Through it all, Zac has been adamant that he isn't quitting! Even battling cancer for the fifth time, he still has his faith, positivity, crazy sense of humor – you should hear the one-liners and amputation jokes that roll off his tongue – his care and concern for others, his love of life and his smile. And it goes without saying he still has his passion for gaming. You can tell how much Zac









loves video games when you look at the sockets of his prostheses. On one leg he has Super Mario characters. On the other leg, Pokémon.

An example of his determination: Zac hates to take pain medication, he doesn't like the way it makes him feel. Plus, his reaction times are slower, which doesn't improve his playing abilities. On the day after Zac's first thoracotomy (an incredibly painful surgery), he asked his nurse what time his surgeon would be coming to see him the next morning because he wanted to be up in a chair playing games when his doctor arrived. And sure enough, early the next morning Zac was up in a chair playing Punch Out when his surgeon rounded. And after his most recent amputation surgery, Zac took no narcotics after being discharged from the hospital. He used games to distract himself from the pain.

When we arrived back at St. Jude to start round 10 of chemotherapy, we had no idea what was in store for the world. Because of the COVID-19 pandemic, Zac and I spent most of our time in St. Jude housing, leaving almost only for medical appointments. At this time in particular, it was so wonderful to hear him laughing and talking with friends from home and from St. Jude while gaming online.

We all have choices to make as we deal with life's difficulties and uncertainties. We may not be able to control or fix the situation, but we can choose how we respond to it. We choose hope. We choose joy!

Zac and Carson are best friends, spending their time playing video games together. See how throughout treatment, gaming has helped them both cope. stjude.org/zac



Celebrated artist Derek Fordjour, inspired in his youth by St. Jude and its embrace of art, donates painting for auction

PAIRON PAINTER of hopeful causes

hen the artist Derek Fordjour toured St. Jude Children's Research Hospital last year at the invitation of former Memphis Mayor A C Wharton, it was "mind-blowing" to see how his hometown institution had grown. But in another way it was just as he remembered, from his days as an artistic boy growing up in Memphis – the very picture of

way it was just as he remembered, from his days as an artistic boy growing up in Memphis – the very picture of inspiration, a colorful place where walls were canvasses, where design was all part of the art of healing.

"We were drawn to it," said Fordjour, who used to play on the grounds with his little brother, Richard, back in the days when a much smaller St. Jude campus was adjacent to St. Joseph Hospital, where the boys' dad was an oral surgeon.

"I was, of course, very drawn to the art. Because St. Jude would always have a mural or it would have prints hanging. Now I know, in retrospect, that that was very intentional around creating a lively environment for patients. But even as a kind of art-interested kid, I found myself very often inspired and gravitating to go look at their walls."

Picture it, if you will: A boy of about 12, attracted to a pediatric cancer hospital – not scared of the place, not feeling unwelcome, but drawn there.

"I was never clueless that there was something serious happening, and that people needed care," he said. "But the environment was uplifting, you know? And also inviting. We never felt like we were unwelcome or that we were intruding.

"Hospitals can be very serious places. But the two things that I knew were that this was a warm and friendly place that cared about art and color or design, and that we were welcome there.

"And I'm telling you, being two small Black boys who are unsupervised at that time in Memphis' history, you know,





I see artists' role in society as people who share our lived experience through art, rather than sort of sitting high and making political calculations about the world.

that wasn't always the case. But St. Jude kind of became a safe haven for us, in that way."

More than three decades later, at 46, Fordjour is a rising star based in New York City with a painting last year selling for \$137,500, more than doubling pre-auction estimates. He's been written about as "one of the art world's most coveted newcomers" and collected by the likes of Jay-Z.

But the hometown-kid-made-good is still being inspired by St. Jude — literally so: He's creating an original work of art that will be donated to St. Jude and auctioned to raise money for the cause. As he talked, he'd yet to put brush to canvas. The piece was still just swirling about in his mind.

"I want to capture the joy and optimism that has remained consistent in my thinking about St. Jude," he said. "As a child who was very sensitive to aesthetic environments, I think of the experience of any child moving through there and encountering a piece.

"That's what's going to drive the image."

Portrait of the artist as a young Memphian

His art is full of life and color, pageantry and politics. His subjects include marching band drum majors, cheerleaders and – spotlighting a frequent sight in horse racing's early days that's rare today – black jockeys.

His 2018 painting "Half Mast," commissioned by the Whitney Museum of American Art and reproduced billboard-sized for outdoor display, reflects on the violence in the country at that time. It shows a crowded scene populated by law enforcement and civilians (some are students, some havetargets on their backs, some are seen only in silhouette), amid teddy bears and balloons suggesting makeshift memorials.

The Whitney described it as a "portrait of this divided moment in U.S. history" that "speaks to loss and abuse of power," and yet, the museum added: "Painted brightly in his signature graphic style, the work points to the possibilities of a future civic movement or celebration."

While critics reach for adjectives to describe his work, Fordjour seems more interested in stretching the

bounds of the noun art. A major solo show earlier this year at the Contemporary Art Museum St. Louis featured dirt floors, corrugated metal walls and simulated rainfall on the roof – framing his art, as it were, with a sense of place. The show's name? SHELTER. For what he calls his "most ambitious show yet," this November in New York's Petzel Gallery, he's collaborating with a puppeteer and musicians. Ask Fordjour to describe his own style and he laughs. Tough question, he says. But he promises a good answer.

"I'm honest," he said. "I'm honest in my work."

Which is to say, his art is reflection of his life, of growing up in Memphis with "extremely generous" parents who emigrated from Ghana and would open the family home to immigrant students in need of housing.

There were the religious tent meetings his parents would have on Third Street, "and the sensation of wearing church shoes outdoors," he said, "where I kind of first got that sensibility of being out in nature but also having a spiritual experience."

There was the Mississippi River close by, and the frequent family visits to Brownsville, Tennessee, giving the city boy a taste of rural life. And there was art everywhere, everywhere art – from St. Jude, to Central High School, where a teacher named Bill Hicks "got a lot of us started on a lifelong journey with art," to visiting the Memphis Brooks Museum of Art and Dixon Gallery & Gardens. So if you've met Fordjour the artist, it seems, you've met Fordjour the man.

"This is who I am," he said. "I see artists' role in society as people who share our lived experience through art, rather than sort of sitting high and making political calculations about the world.

"I think I'm just telling my truth."

The artist and his assistant

If you want a sense of how inevitable it was that Derek Fordjour would become an artist, ask his first assistant – little brother. Richard.

"At a young age, he was getting commissions to do things. I think

when he was maybe 10 years old he was commissioned to do a banner for the church," Richard said. "The banner was so large we had to do it in our backyard. I was always there, helping him.

"Then when you move on from there to middle-school age, I think he was at the time doing some airbrushing on denim for people. They were coming over to pay for it. I was helping him kind of churn that out.

"I have never not known him to do art. Even when he was wasting time, just being a kid, I'd look up and he would have belted out a whole portrait of something, without even trying."

Richard, four years younger, remembers the first time a fuss was made about big brother's art, but not in a good way. They were in elementary school and Derek "had drawn in a text book on every page, almost like a flip-art kind of thing."

Mom was summoned to school and Richard, probably a first-grader at the time, tagged along. "The teacher pulled the book out and flipped through it," he said. "I remember sneaking a look. I was thinking, 'Wow, this guy really is good.' It looked like you were watching a cartoon."

In retrospect, the teacher might have confiscated the book not as evidence, but as an investment. That idea didn't escape Richard, who followed his father's career path – he's a dentist in Washington, D.C. – but had a keen eye for art. Call him the world's leading collector of Derek's early work.

"I've got a lot of stuff from when he was in the eighth grade, ninth grade, 12th grade, that was just sitting in our attic," he said. "I now have it, and a couple of those pieces are up in my house here in D.C."

When Richard looks at Derek's art today, he doesn't just see his brother's creativity. He sees his brother in all his



complexity – taking on "deep and heavy things," but expressing it in art with a "fanciful effect to it, or some sort of celebratory aesthetic."

"The juxtaposition between his kind of jovial side and his intellectual side that I see in his art is a direct reflection of who he is," Richard said. "I think that's definitely him shining through."

The art of healing

It's sort of the art of life, isn't it? How dots connect and allow us to see the larger truths of the world. Like how Derek, as a boy in Memphis, would watch St. Jude founder Danny Thomas' star-studded, fundraising telethons on TV more as entertainment than anything else. But then...

"I had a friend growing up who had sickle cell," he said.
"It wasn't until I learned that he had to go to St. Jude that I connected everything. I connected this entertainment that I was watching, and this really fun, wonderful television show" with the fact that "the only hope for my friend was going to St. Jude.

"So maybe the seeds of philanthropy were planted in my mind very early. That you can use something like entertainment to save a life. And that was very young that I realized that."

It was a powerful lesson for an artist to learn. If a joke or a song could save a life, so could a picture, a painting. So, just as Danny Thomas, a struggling comedian-turned-Hollywood-star, put his hospital in Memphis because the need was there, so is Fordjour, a New York City-based artist, showing us how his heart remains in his hometown. In addition to his painting for St. Jude, he's planning a local art camp — Contemporary Arts Camp Memphis — to begin in summer 2021. The patron painter of hopeful causes, anyone?

"I'll tell you," Derek said. "As an artist, like a comedian, I would imagine sometimes the product of your work can feel futile. That you're not impacting real-life issues. That you're doing something that is, in many ways, removed from real life."

When he's feeling like that, though, Derek knows just where to go. Where he was drawn as a boy. Where the art of healing makes room for the healing power of art.

St. Jude.



Give thanks for the healthy kids in your life, and give to those who are not.

Kaitlyn is a sweet-natured child with eyes that can light up a room. Just after her first birthday, she was diagnosed with soft tissue cancer and referred to St. Jude, where she received world-class care and therapy. When you donate to St. Jude, you're supporting the research hospital that has helped push the overall childhood cancer survival rate from 20% to more than 80%. And we won't stop until no child dies from cancer. After further treatments, Kaitlyn remains cancer-free and as vibrant as ever. Her mom, Jazniquiana, has one wish every parent can relate to, "Whatever kind of life she wants to have, I hope it's happy and pain-free."

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