ST. JUDE

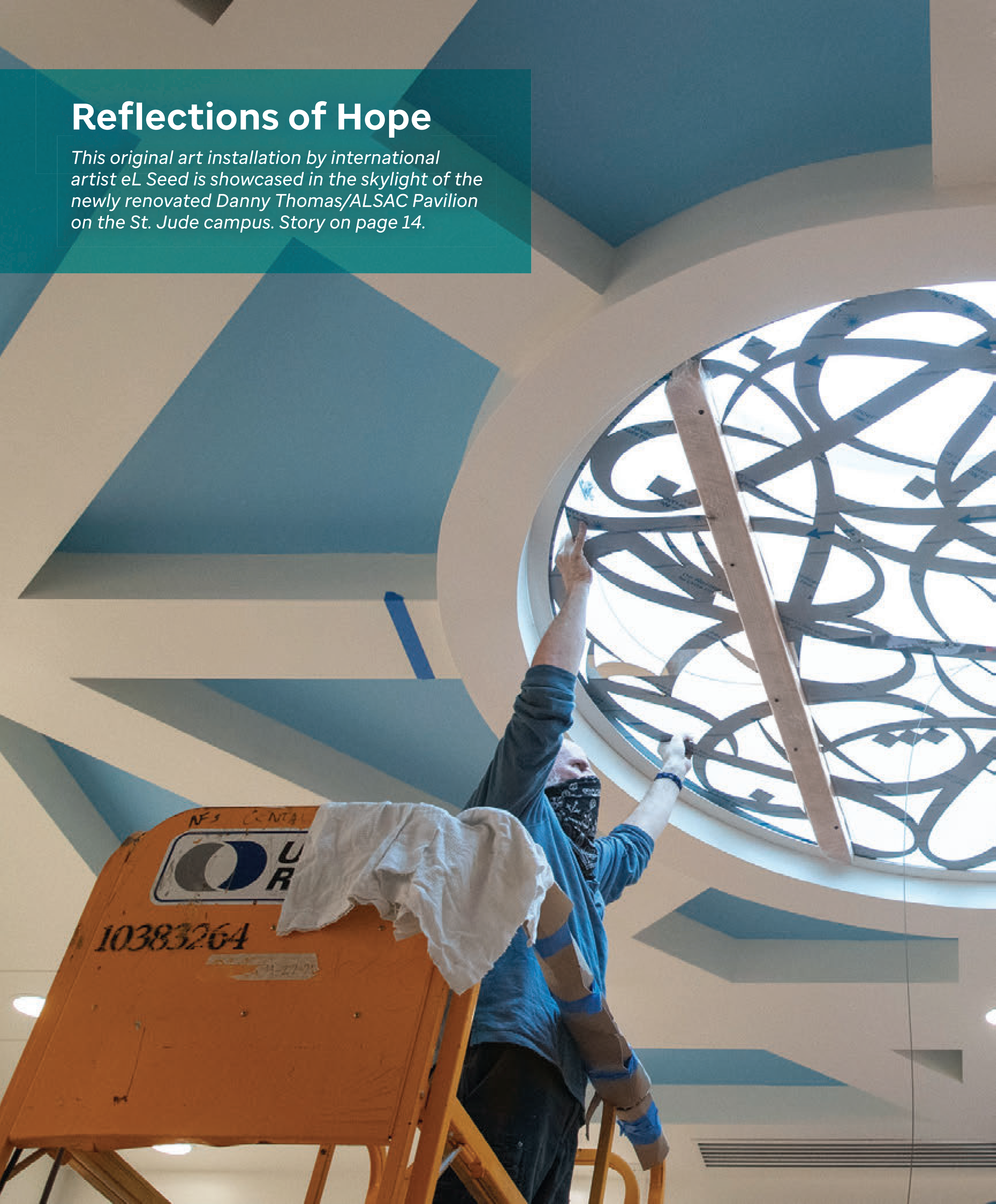
inspire

SUMMER 2021

New Beginning for Azalea

'What your daughter has, we can fix it.'

Plus: How an **$11.5 billion** plan will help St. Jude save more kids like Azalea



Reflections of Hope

This original art installation by international artist eL Seed is showcased in the skylight of the newly renovated Danny Thomas/ALSAC Pavilion on the St. Jude campus. Story on page 14.

FROM THE ALSAC PRESIDENT AND CEO

This edition of *Inspire* previews the historic $11.5 billion investment St. Jude Children's Research Hospital is planning over the next six years. We believe it will have a profound impact on kids around the world who face cancer and other catastrophic diseases.

And it's only possible because of your generosity.

The new six-year St. Jude strategic plan, approved by our Board in March, is as audacious as our founder Danny Thomas would have wanted.

The plan expands and accelerates research into the deadliest forms of childhood cancers – the ones still to be solved despite decades of progress on most types of cancer – while also aggressively expanding work in other key areas including blood disorders, pediatric neurological and infectious diseases.

And through a tripling of the global investment of St. Jude, it also supercharges the work to impact more of the 400,000 kids who are diagnosed with cancer across the globe each year; kids who rely on the emerging collaboration of St. Jude, the World Health Organization and a coalition of international partners as their lifeline.

It's so humbling to know St. Jude is tackling this only because of the nearly 11 million active donors who year after year stand with us.

Your unflagging support allowed us to fund the prior six-year plan that was at the time the most ambitious ever for St. Jude. And with your continuing, steadfast support, we'll do it again now – in the midst of a pandemic – without borrowing a dime.

That's not just humbling. It's inspiring.

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

United States: Hayley Arceneaux, cancer survivor, will travel to space

-France Info

Hayley Arceneaux: Cancer survivor joins first all-civilian space mission

-BBC News (England)

Inspiration4: Meet the second crew member of SpaceX's all-civilian space mission. Meet 29-year-old Hayley Arceneaux.

- The South African

Cancer Survivor Heading to Space

-BLOOMBERG

ST. JUDE AROUND THE WORLD AND INTO SPACE

News of St. Jude physician assistant Hayley Arceneaux's planned trip to space made headlines around the world earlier this year. Hayley, a St. Jude childhood cancer survivor who will be part of the world's first all-civilian mission to space later this year, represents the mission's pillar of Hope.

To learn how you can get involved in this historic mission, visit ***stjude.org/Inspiration4***

Come Fly with Me: Elon Musk reveals world's first 'all-civilian' spaceflight crew as seats filled on private SpaceX trip

-The Irish Sun (Ireland)

She Beat Cancer at 10.
Now she's set to be the youngest American in space.

-The New YorkTimes

Cancer survivor joins first all-civilian space mission to raise money for children's hospital

-Stuff (New Zealand)

Are We There Yet?
The Space Exploration Podcast

-NATIONAL PUBLIC RADIO

Youngest American to go into space is also a cancer survivor

-RTL Today
(Germany)

Survivor of cancer set to blast off into space

-Shanghai Daily
(China)

As a child, she beat bone cancer; now she's headed into space

-THE PENINSULA QATAR

Space X, the first crew of space tourists in orbit

-VANITY FAIR ITALY

Survivor of cancer set to blast off into space

-THE ECONOMIC TIMES
(India)

A GRANDFATHER'S LEGACY OF CANCER RESEARCH GIVES HIS GRANDSON HOPE

DR. CHARLES PRATT SPENT DECADES RESEARCHING PEDIATRIC CANCER AT ST. JUDE. NOW, HIS FAMILY IS GETTING HOPE FROM THE INSTITUTION WHERE HE MADE HIS LIFE'S WORK.

BY SONYA WALTON · ALSAC

Benton vividly remembers his father's retirement in the fall of 2001. The gathering was in celebration of Dr. Charles Pratt, who enjoyed a distinguished 36-year career at St. Jude Children's Research Hospital, researching some of the rarest pediatric cancers. Benton thought that would be his last visit to St. Jude.

But in 2017, on the 14th birthday of his youngest son, Phillips, Benton found himself at St. Jude once again.

The hallways were reminiscent of days gone by, when he had visited his father and his colleagues at work. This time, though, Benton and his wife, Leigh, were accompanying their son, who had been referred to St. Jude as a patient.

"I really wished that my dad had been there," Benton said, choking up. "That was the day I think we missed him the most."

Hallways of hope

Decades earlier, Dr. Pratt and his wife, Sarah, moved from Richmond, Virginia, to Memphis with three young daughters in tow. It was January 1965, and he was a pediatrician with a keen interest in childhood cancers who accepted a job offer from Dr. Donald Pinkel, the first medical director of St. Jude Children's Research Hospital. What the Pratts believed would be a two-year stint expanded, along with the size of their family. Benton and his brother were born in Memphis.

St. Jude was a second home to the Pratts. Sarah was part of the Wives Club and worked with new doctors' wives and families to help them get acclimated to the city and sometimes the United States. The Wives Club morphed into the St. Jude Women's Club, which today includes women employees of the hospital as well as spouses of employees. Today, Sarah Pratt is an active member of the Ladies of St. Jude, a club that provides support to the hospital.

Dr. Pratt didn't live to see the birth of his grandson Phillips, who would walk through the hospital doors years after his grandfather's retirement.

At St. Jude, Phillips was diagnosed with a rare liver cancer, fibrolamellar hepatocellular carcinoma. He needed a liver transplant. While neither of his parents were matches, one of his cousins was a perfect match and readily donated the left lobe of her liver. He received the transplant in December 2017.

His recovery wasn't always easy. Phillips remembers feeling frustrated while in intensive care as he craved to quench his thirst. Being on a ventilator prevented him from having liquids or ice. He longed to see his older brother, Charles, who was a senior in high school. He missed his family and friends. Phillips needed more surgeries, one lasting 12 hours, to remove hundreds of tumors. He required a feeding tube and countless rounds of chemotherapy.

His journey was intermingled with good times, too. The Make-A-Wish Foundation granted his wish for a week-long trip to Tokyo with his parents and brother. He celebrated his eighth-grade graduation and on his 16th birthday, he was surprised with his dream car, a blue MINI Cooper.

Moving forward

Now, Phillips is full of energy and has a zest for life. This summer, he proclaimed, "I just want to move forward with my life and take the next step." One day, to the astonishment of his parents, he came home and told them he had a summer job.

Still under the watchful eyes of his doctors, Phillips explained, "St. Jude really takes care of you so well and it's really one-of-a-kind. All of the staff is so caring." He particularly enjoys keeping his nurse Loren abreast of the latest developments in his life.

"St. Jude is such a welcoming place, they have treated us like family," his mom said.

St. Jude has been family to the Pratts for a long time. The hallways of the past were filled with happiness for the Pratt children, while Dr. Pratt labored to give St. Jude patients hope.

Today, the hallways are filled with happiness and hope for the Pratt grandchildren. They've been Phillips' biggest cheerleaders, encouraging him and keeping him in good spirits throughout his journey.

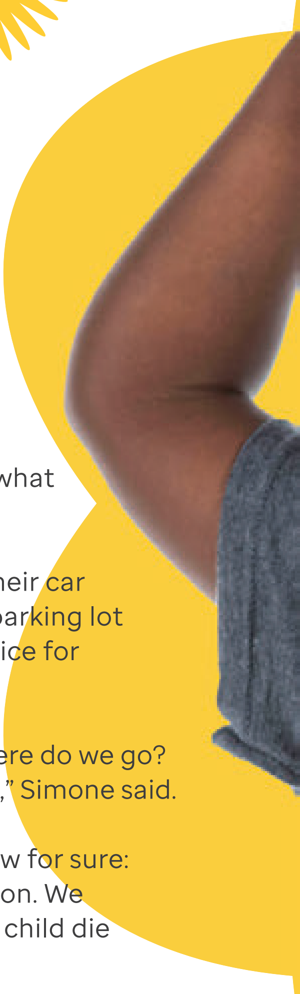
Phillips is an upcoming senior in high school. And, following in his grandfather's legacy, he has his sights set on becoming a physician.

COVER STORY

From Doubt to Success

Azalea's parents found the beginning of great things at St. Jude

When Simone and Ricardo's daughter was diagnosed with cancer in Jamaica, the odds seemed insurmountable. Then a call from St. Jude changed it all.



By Ruma Kumar · ALSAC

They dreamed of her and knew her name long before she was theirs. Azalea Genesis: the beginning of great things. And she was. From the September day she was born to Simone and Ricardo in Kingston, Jamaica, Azalea was a happy, magnetic force with an arresting smile that stretched wide, crinkling her nose and eyes. Sometimes, her mother was nervous to take Azalea out. She was just too endearing.

"This child knew no strangers. She just made friends and charmed people wherever she went," Simone said.

"I was worried someone would take her from me."

But when Azalea was 2, it wasn't a charmed stranger who tried to take Simone's daughter.

It was cancer.

Bathing her daughter one evening, Simone noticed an odd growth, barely the size of a kidney bean, and took Azalea to the doctor. The pediatrician said it wasn't serious and sent them home with steroid creams. The fleshy nodule only grew bigger. Puzzled, the pediatrician suggested the family see a surgeon who could remove it. A clean cut and everything would be fine, they'd thought. But when the surgeon looked at it she blurted out a word that sounded like an absurd jumble of letters: rhabdomyosarcoma. Simone had the doctor write it down. She returned home clutching the paper and confusion.

When she thinks back to this time, Simone recalls the journey of Azalea's diagnosis, treatment and care in four phases: Doubt. Hope. Faith. And success.

Doubt came on hard, confounding and dark.

Biopsy results in January 2016 confirmed Azalea had rhabdomyosarcoma, a soft tissue cancer, one of the most common types in children, but rare in the way it grew in Azalea's body. Treatment in Jamaica would not be easy, the oncologist told them. The three chemotherapy medications she needed would be expensive and sometimes not available, delaying necessary therapy. One of them would have to leave their job and care for Azalea full time, taking her to the hospital every three weeks. They'd need to try to shore up more money than they'd make in a year to cover the costs of treatment.

"I was in a state of complete darkness," Ricardo said. "I could not see a path to go forward. I'm the man of the house, have to be strong for my family, but at that moment I was diminished because I literally couldn't see what to do."

Stunned, they sat in their car holding hands in the parking lot of the oncologist's office for nearly two hours.

"What can we do? Where do we go? The doubt really set in," Simone said.

"But one thing we knew for sure: Death was not an option. We would not let our only child die without a fight."

A month before they'd found themselves deep in doubt in that parking lot, Simone remembers watching ads for St. Jude Children's Research Hospital on TV, part of the ad blitz during the annual St. Jude Thanks & Giving® campaign. "This place is in the business of saving children's lives and my child needed help."

With the rhabdomyosarcoma diagnosis now official, Azalea's oncologist in Jamaica submitted a referral to St. Jude. St. Jude was quick to respond: "How soon can you get here?" Simone heard them ask on the phone.

Doubt ebbed, allowing flecks of hope to fill its place.

A week later, they were on a plane to Memphis. It was winter and a case manager in D Clinic said to bring

warm layers and favorite toys to help Azalea feel more comfortable.

"How cold?" Simone asked. "Like a freezer," she heard the man say. Simone gathered what she could: long sleeved shirts and thin cotton sweaters they'd wear one on top of the other because fleece and wool are hard to come by in tropical Jamaica. She packed favorite snacks like banana chips. Before they left, Ricardo alerted their mortgage company to prepare the deed in case they'd need to sell their home and also secured the titles to both their cars. Their savings near-depleted already from Azalea's doctors' visits and surgery in Kingston, the couple was willing to liquidate everything they had to save their daughter's life.

They arrived in Memphis in the dead of night after a 12-hour, circuitous flight. Simone remembers sleeping surprisingly well at Tri Delta Place, the on-campus housing facility. In the morning, on the walk to the clinic in the Chili's Care Center, they marveled at being able to see their breath in the crisp January air. They sent puffs of white into the heavens along with silent prayers.

Weaving through the maze of halls, Simone and Ricardo didn't know what to expect. What would

treatment involve? What would it cost? How realistic were Azalea's chances of recovery?

Once they reached D Clinic, sitting with doctors, they heard two things that floored them. First, that they'd never receive a bill from St. Jude. Not a cent. Not for anything. Doctors' visits, medicine, procedures and surgeries, food and housing and travel cost: All of it was covered thanks in large part to generous donations from private citizens and large corporations alike.

And if that wasn't enough, they heard this too: "What your daughter has, we can fix it."

Azalea's care would require a 42-week regimen of chemotherapy and perhaps radiation, doctors braced Simone and Ricardo, but they'd come to the right place.

Simone was overwhelmed. It was a dizzying time because she was also two months pregnant by now, trying so hard to save her firstborn as she grew another in her womb. But sitting there listening to the doctors at St. Jude, Simone felt as if prayers she'd been too wary to say aloud had been answered.

Being at St. Jude, hope took root, and now, so did faith.

"St. Jude gave us everything I thought we'd lose: my family, my child, my marriage, my hope," Ricardo said.

By the spring, Azalea was responding well to chemotherapy, but the doctors wanted to try something new, something other than radiation to augment her treatment. They wanted to try a groundbreaking surgery with Azalea Genesis, the girl who was named for the beginning of great things. She'd be a pioneer for a surgery that would remove the tumor and replace it with tissue and skin from her mouth. It had recently been done in Canada, but never in America. Azalea would be the first candidate for such a procedure and if it worked the way doctors hoped it would, she'd pave the way for this treatment option in other children with rhabdomyosarcoma, too.

Azalea got the surgery in mid-June. It took five hours. Simone paced the halls and forgot to eat. The doctors emerged from the operating room assuring her it had gone well, even though it had taken twice as long as they'd expected. Azalea would be sore but she was expected to heal, make a full recovery and wrap up chemotherapy by the end of the year.

They were right. Azalea did heal beautifully. Within weeks she zipped along the hallways to her clinic checkups. Nurses were used to seeing her arrive well before Simone, who was by now heavily pregnant and barely a month from giving birth to another daughter, Hadley.

When her baby sister was born, Azalea treated her like a new doll, Simone said. She stroked Hadley's cheek and head, balanced her gingerly in her lap, cooing. And on the days she was too weak with chemotherapy to do anything, she curled up beside her baby sister for comfort.

They are still close, Hadley and Azalea. These days, Azalea is a healthy, happy 7-year-old. Her life is blessedly normal, uneventful. She is learning new languages in school and is teaching Hadley, who is 4, how to announce her name in French. She is learning to add and subtract three-digit numbers. She paints and draws obsessively, and aced a recent penmanship assignment, curling her cursive letters just so. She is spending a week taking first term exams at school. These school tests pale in comparison to those she faced when she was 2 years old, battling cancer, but she's tackling them with the same grace and determination she developed naturally over her time at St. Jude.

She prefers dancing to walking, twirling and jumping and spinning in her home. She dreams of being a contestant on America's Got Talent.

"I'm going to dance my way to the top," she tells her parents.

◂ *Photo was taken prior to the COVID-19 pandemic.*

EL SEED'S HOPEFUL ART FINDS A HOME AT ST. JUDE

His artwork, incorporating Arabic calligraphy to create a message of hope, is showcased in the newly renovated Danny Thomas/ ALSAC Pavilion

By David Williams · ALSAC

A map of the world shows St. Jude Children's Research Hospital is thousands and thousands of miles from the home of international artist eL Seed.

The heart suggests otherwise.

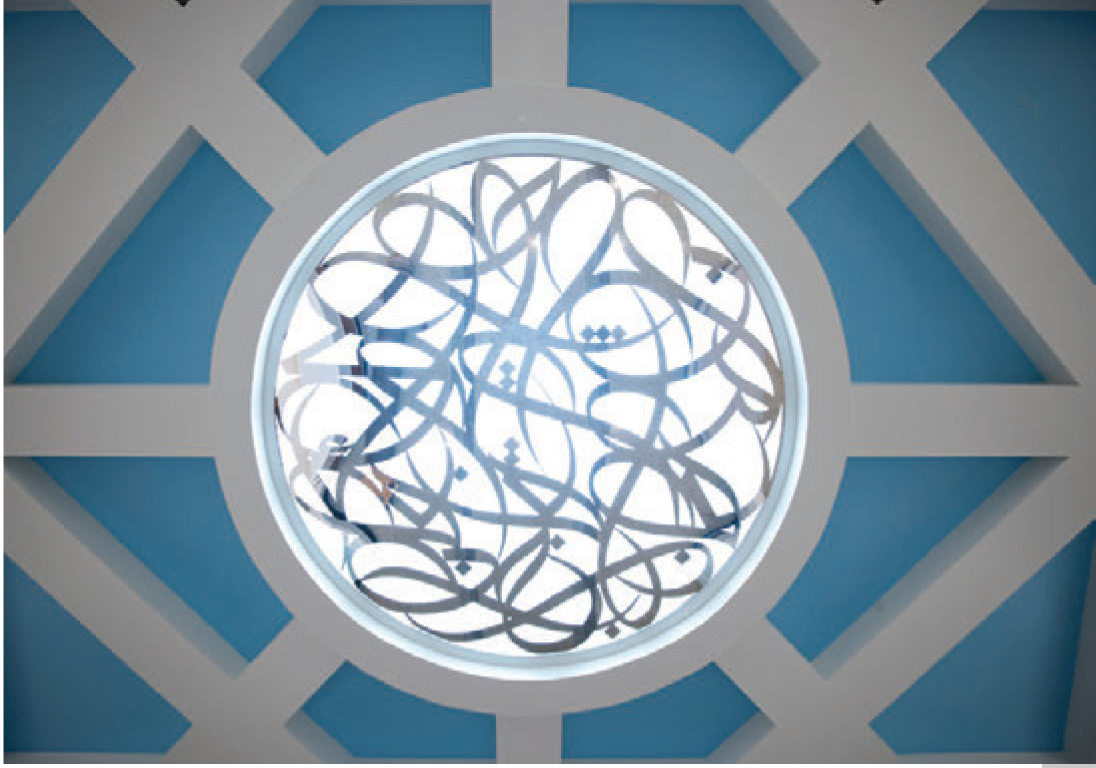
Working mainly with Arabic calligraphy to create art that speaks of peace and unity, this French-born son of Tunisian immigrants says he feels a powerful symmetry with St. Jude in Memphis — from its founding by Danny Thomas, an American-born son of Lebanese immigrants, to its care of sick children from all over the world regardless of race or creed, to its belief in the healing qualities of art.

"I've traveled the world with my work and I see that all the time it creates an emotion — most of the time the right one," he said. "And this shows actually there's no boundaries or barriers between our humanity. Somebody that could be in China or in Brazil could feel the same emotion toward something. I think this is the humanist part of my art that is linked to the mission of St. Jude."

The pandemic has, so far, prohibited eL Seed from visiting St. Jude, but his work now has a home there. His original art installation, featuring a quote from Lebanese-American writer and artist Kahlil Gibran, is showcased in the newly renovated Danny Thomas/ALSAC Pavilion on the St. Jude campus.

The quote, expressed in Arabic calligraphy, reads:

I am alive like you, and I am standing beside you. Close your eyes and look around, you will see me in front of you.



"For me, it's a message of hope and solidarity," eL Seed said. "You're stating to somebody that you're beside him, and you're standing in front of him. That's the spirit, and the idea, behind this piece of art."

It's a moving piece of art – literally. Installed in the skylight of The Pavilion, the artwork reflects onto the floor when the sun shines through. And if you can't read Arabic script, the artist says, no matter.

"I always say that there is a universal beauty that doesn't need to be translated," eL Seed said. "I think Arabic script, in a way, reaches your soul."

eL Seed was born in Paris, and learned to read and write standard Arabic as part of a teenage quest to become more in touch with his heritage. "My father moved from Tunisia to France so I am a part of two cultures," he said.

He was surprised, when learning about St. Jude, to find a kindred spirit in its founder. Danny Thomas' heritage was a source of great personal pride, and the organization he created in 1957 to raise money to build St. Jude – American Lebanese Syrian Associated Charities (ALSAC) – was made up of 100 representatives of the Arab American community.

Thomas and his fellow members of ALSAC were united by their ancestry, their audacious dream of a hospital to treat patients of all colors and creeds without cost to their families, and a desire to thank America for the freedoms it had bestowed on them.

The St. Jude origin story held a powerful resonance for the 39-year-old eL Seed, a recipient of the UNESCO-Sharjah Prize for Arab Culture, which recognizes those whose work and achievements help spread a greater knowledge of Arab art and culture.

"Being the son of an immigrant, and leaving your mark and being an inspiration for a generation to come, that's what I found amazing about him," eL Seed said of Danny Thomas. "I look at his journey and I think how I can see a reflection and how I can be inspired by him."

eL Seed's immersion into St. Jude included a virtual tour, which highlighted not only aspects of treatment and research but also the role that art plays in St. Jude's holistic approach to healing.

He saw the colorful murals that cover the walls, and "visited" the ABCs of Cancer patient art display, in which patients use art to express themselves as they cope with catastrophic diseases.

He also learned more about the global scope of St. Jude, sharing its research discoveries and reaching out to some of the world's sickest children in low- and middle-income countries where survival rates lag behind those in the U.S.

For eL Seed, it was a case of seeing the same values he strives to promote, reflected back from thousands and thousands of miles away, at St. Jude in Memphis.

"I don't discriminate in any way. I try to highlight communities that sometimes don't have a light on them. I try to be a tool for social change," he said. "I try to be useful with my art, and not making art just to beautify spaces, but also try to make art to create the change. I would say that what I'm trying to do is, in a way, aligning with the mission of St. Jude."

Now that his artwork has a place on the St. Jude campus, he vows to do more for the cause – call it a post-pandemic promise.

"I would love to promise to come visit, and to stay not just one afternoon but stay a few days, and see if we can create an art piece with some of the kids of St. Jude," eL Seed said. "It would be, I think, amazing."

ST. JUDE

PERSPECTIVES

Imani Brown:

‘I dare you’ to create a better world for kids with cancer

Imani Brown is a childhood cancer survivor, treated elsewhere, who remembers her mom’s phone calls with insurance companies and how she struggled under the weight of those bills. Danny Thomas’ dream of a place where children could be treated regardless of race, religion or ability to pay inspires Imani to work for the San Francisco office of ALSAC, the fundraising and awareness organization for St. Jude Children’s Research Hospital. And so does her mom’s strength throughout her life: as a defiant little girl during the Civil Rights era, as the parent of a child with cancer and as a cancer patient herself. In memory of her mom, Imani shares her story.

I’d like to introduce you to Dr. Barbara Diane Mahone Brown. Born in 1944, a force to be reckoned with. Proud and strong. This was my mother.

Barbara Mahone grew up in the segregated South in Tuskegee, Alabama.

What seems crazy to me is her life in the segregated South is just one generation away from mine. What's also crazy to me is my mom used to dare my Aunt Paula to drink out of the white people's water fountain, something that could have gotten them in a lot of trouble or possibly killed. Not the smartest game of Truth or Dare.

Let's fast forward from the 1940s to the early 1960s and another act of daring. Danny Thomas was founding St. Jude Children's Research Hospital, a specialty hospital he built intentionally in Memphis, in the segregated South. At a time when most medical facilities had separate bathrooms, nurses and entrances, St. Jude blazed a trail. Everyone would be welcome, and they'd all be coming through the same entrance.

In addition, Thomas looked at what were thought to be incurable diseases and decided, God willing, they would cure them.

Fast forward to the 1980s. The world is now in color and Dr. Barbara Diane Mahone Brown gives birth to me.

Now fast forward to the year 2000, just 45 days before my high school graduation, when I was diagnosed with a brainstem glioma and told I had six months to live. The tumor was in my pons and was inoperable.

The right side of my body went numb, I had headaches, double vision, difficulty swallowing. Things were not looking good. They told my parents, *She's going to be dead in a couple of days. You need to make plans*. They told my father, *There is no hope*.

Here's my mother, all grown up, who fought with bill collectors and insurance companies to get all of my hospital bills paid while she also fought for my life.

My father told me she prayed and prayed the tumor would come out of my head and go into hers instead.

I survived my battle with cancer. However, 15 years later, as cruel fate would have it, my mother was diagnosed with multiple glioblastoma brain tumors, and it was just six weeks from her diagnosis to her death. I witnessed her very last breath. It was the worst thing that ever happened to me and some days it's hard to know how to move forward.

Two years later I got a job at ALSAC. I work there so no family has to go through what my mother went through as she was fighting for my life, because all she should have been focusing on was helping her child live. Because I want to give back with this borrowed time that I'm living on.

I'm not a doctor. I'm not a researcher, but this is what I can do to keep moving the fight forward to cross that bridge into the unknown future.

So I say to you: Believe that you can do things they tell you you cannot do. Dream a dream that seems a little too big for this world. Be determined to make change. And always move forward. Bring light into these dark times.

I dare you.

Debbie Coolman:

St. Jude Saved My Life – Twice

Debbie Coolman, now 50, looks back on what it has meant to have St. Jude as part of her life.

For an entire year beginning when I was 13, I felt excruciating pain. Numerous tests couldn't pinpoint the cause, and my doctor in Ohio theorized it was growing pains.

At a second visit, he said it must be arthritis and I would need to learn to live with the pain.

My parents could see my suffering. They switched to a different doctor, which led to a referral to St. Jude Children's Research Hospital in 1984, where tests determined I had stage IV Hodgkin lymphoma, and it had spread to my bones.

I had been on painkillers, but after my first dose of chemotherapy at St. Jude, the pain disappeared. Two years of chemotherapy and six weeks of radiation therapy at St. Jude made sure the Hodgkin lymphoma was gone for good.

In 2008, St. Jude invited me back for the St. Jude LIFE study, which investigates the long-term effects of cancer treatment as a way to improve the health of survivors and create better treatments.

They found breast cancer in a scan I wouldn't have had the opportunity to have done in my hometown. That's why I tell people St. Jude saved my life not once, but twice.

Griffin's mom, Jennifer:

4,700 Miles To Hope

When an American military couple stationed in Germany learned on Veterans Day their son Griffin had cancer, they had hours to figure out what to do next. This is their story, as told by Griffin's mom, Jennifer.

As an Air Force family stationed abroad, we joke we collected each of our three children on a different continent: Vivien was born in Texas, Benjamin in Germany, and Griffin, our youngest, in South Korea.

In Korea, there's a tradition called doljanchi that's celebrated on the child's first birthday. Part of the custom involves placing some common items in front of the birthday child and whatever they grab first is said to reveal something about their future.

We did a doljanchi for Griffin and he picked up a toy stethoscope. Did that foretell good health, I wondered, or that he'll be a doctor? I think I can now say that, while not experiencing good health, our little boy is in an intense and lengthy medical apprenticeship… as a pediatric cancer patient whose treatment will last nearly three years.

By late 2019, we had moved our family from Korea back to Germany, and this is where Griffin was found to have acute lymphoblastic leukemia. The local hospital said he absolutely had to start chemotherapy within 48 hours, and we had to decide where that would happen because preparations had to be made.

We had to figure something out fast. Unfortunately there was little cellphone service and no WiFi in the hospital, so we were literally hanging out a window frantically Googling, looking for options. Our biggest thing was, we wanted to get back to the United States. Even after eight years abroad, that's our home at the end of the day. When bad things happen, you want to go home.

Twelve hours after diagnosis, Griffin and I were on a plane, bound for St. Jude Children's Research Hospital, where he had been accepted as a patient. He was receiving blood products right up until the moment we left the German hospital. As soon as the last drip of platelets went in, they disconnected the IV and we went straight to the airport for a 10-hour flight that got us part of the way to Tennessee.

My husband and I were both sure we were going to the best place in the world for Griffin. For so long, though, we'd been in military communities, where you just step in and make friends immediately, and our kids had playmates constantly in close proximity. It turns out, at St. Jude, we are surrounded by all these people who instantly understand our struggles – just like in the military. We found a new community at St. Jude. An amazing one.

Griffin, unfortunately, still had leukemia in his bone marrow after the first phase of chemotherapy and therefore a greater chance of relapse. But St. Jude has a plan in place for this, and part of it involved immunotherapy that was administered 24/7 for two cycles of 28 days via a pump carried in a backpack. At first, Griffin — who is a VERY determined little boy and who has earned the family nickname Trash Panda for his cleverness in wreaking havoc — refused the backpack. Then my husband had the idea to turn it into a "proton pack" using egg crates, a plastic water bottle and some creativity. Griffin loved it, and we got that immunotherapy into our little Trash Panda.

There is much more treatment still ahead. But I've always been an optimist. And I think we must be the luckiest unlucky people in the world. Because we have so much support, and so much hope.

St. Jude patient
Tayde
pictured with her daughter

St. Jude Walk/Run

stjude.org/walkrun

September is almost here, which means it's time to lace up for the St. Jude Walk/Run! Join supporters from across the nation for a family-friendly fundraiser supporting the lifesaving mission of St. Jude. Whether you walk, run or participate virtually—your efforts help ensure that St. Jude will always be there for families facing childhood cancer and life-threatening diseases.

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Finding cures. Saving children.
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ST. JUDE CHILDREN'S RESEARCH HOSPITAL TO INVEST $11.5 BILLION TARGETING CHILDHOOD CATASTROPHIC DISEASES GLOBALLY

Photo was taken prior to the COVID-19 pandemic.

St. Jude Children's Research Hospital is launching the largest strategic expansion in its nearly 60-year history, investing more than $11.5 billion over six years to accelerate research and treatment for children around the globe with catastrophic diseases.

Included in the new, six-year plan adopted in March by the St. Jude Board of Governors is $1.9 billion in capital spending. Among the construction projects: a proposed, $500 million outpatient clinic and doctors' office; and a new $110 million patient family housing facility.

Most of the $11.5 billion plan would be funded by donors and require no debt.

"We're committing substantial resources to broaden scientific understanding, raise survival rates, improve quality of life, and connect researchers worldwide in the quest to find cures and save children with cancer and other deadly diseases,“ said James R. Downing, M.D., St. Jude president and CEO.

This newest roadmap builds on the prior six-year St. Jude strategic plan, which at the time was the largest for the institution and resulted in $7 billion in investment. During that period, St. Jude accepted 20 percent more new cancer patients; increased faculty by 30 percent and staff by 23 percent; and embarked on several large-scale construction projects, including the soon-to-open $412 million Advanced Research Center.

This expansion plan is possible because of generous supporters like you. **stjude.org/donate**

And, significantly, it also began building the global infrastructure required to provide access to quality care to children in low- and middle-income countries through accelerated international outreach efforts.

This newest six-year plan focuses on the expansion of patient care and clinical and laboratory-based research related to pediatric catastrophic diseases, including work in cancer, blood disorders, neurological and infectious diseases. It adds 1,400 employees, 70 of them faculty positions.

THE PLAN HIGHLIGHTS

A $3.7 BILLION INVESTMENT WILL EXPAND CANCER-FOCUSED RESEARCH AND RELATED CLINICAL CARE.

“As we move forward with this strategic plan, our mission—to advance cures and means of prevention for pediatric catastrophic diseases through research and treatment—remains at the forefront of everything we do,“ Downing said. “The mission serves as our compass, and the plan serves as our guide for the journey ahead.“

Among key areas of focus:

- Cancers with the Lowest Survival Rates: The cure rate for childhood cancer has increased from 20 percent overall when St. Jude was founded in 1962 to more than 80 percent today due in large part to the research and treatment conducted at St. Jude. But researchers have yet to unlock the secrets of several difficult-to-treat pediatric cancers that most often are fatal, notably brain cancers. Under the new plan, St. Jude will increase investment into uncovering why cancers arise, spread and resist treatment. This includes hiring more researchers dedicated to advancing insights across the spectrum of pediatric cancer—leukemia, solid tumors and brain tumors—and cancer subtypes.
- The number of patients on St. Jude–led protocols may grow as much as 30 percent. Those numbers are achieved through a small increase in patients admitted, and through an increase in multi-institutional studies. St. Jude already leads trials on medulloblastoma, for example, at 16 other institutions in four countries. Similarly, it has conducted trials on ALL in collaboration with the China Childhood Cancer Consortium.
- Quality of Life: With survival rates for childhood cancer steadily rising, researchers increasingly have focused on advances that also improve the quality of life for patients. St. Jude has led the way in developing less-toxic treatments that reduce the risk of devastating and long-lasting side effects from chemotherapy and radiation, but there’s still tremendous progress to be made. As part of its research, St. Jude has amassed critical historical data by following more than 5,000 patients who have survived at least five years.

ST. JUDE WILL MORE THAN TRIPLE ITS GLOBAL INVESTMENT TO IMPROVE SURVIVAL RATES AROUND THE WORLD.

In 2016, St. Jude expanded its global efforts through the development of St. Jude Global and the St. Jude Global Alliance. The goal was to mobilize caregivers, foundations and governments to work collaboratively toward developing the workforce, healthcare systems and research expertise required to address the growing worldwide childhood cancer burden. In 2018, St. Jude expanded its efforts through a $15 million collaboration with the World Health Organization called the Global Childhood Cancer Initiative. The goal of the effort was to raise survival rates in low- and middle-income countries for children with six of the most common forms of childhood cancer from 20 percent to 60 percent by 2030.

This new plan builds on the work by tripling St. Jude's investment — committing more than $470 million over the six-year period. Major efforts under this expansion include:

- Development of a multimillion-dollar Pediatric Cancer Global Drug Access Program — in collaboration with WHO, other

Photo was taken prior to the COVID-19 pandemic.

U.N. agencies and international organizations – to distribute an uninterrupted supply of anti-cancer drugs for childhood cancer treatment in low- and middle-income countries.

- Expansion of educational programs to train the workforce needed to treat childhood cancer worldwide.
- Creation of seven international operational hubs staffed by St. Jude workers to effectively manage the St. Jude Global Alliance, a network of more than 140 institutions across 50-plus countries.

MORE THAN $1 BILLION WILL BE INVESTED TO EXPAND RESEARCH IN NONMALIGNANT DISEASES.

The $1.1-billion investment will expand and accelerate research into sickle cell disease and other blood disorders; create a new laboratory-based research program in infectious diseases that affect children worldwide; and establish a new research and clinical program to better understand and treat pediatric neurological diseases.

Responsibility to fund the historic expansion falls to American Lebanese Syrian Associated Charities (ALSAC), the fundraising and awareness organization for St. Jude. Under a unique operating model in place since Danny Thomas founded St. Jude, it's able to focus exclusively on treatment and research because ALSAC, also founded by Thomas and headquartered on the same Memphis campus, works with millions of donors to raise the money to make the mission possible.

Private fundraising conducted by ALSAC is the organization's lifeline because pediatric cancer research typically receives a disproportionately low share of government research dollars. Of the approximately $6 billion distributed annually by the National Cancer Institute, for example, only an estimated 4 percent targets pediatric cancers.

As a result, it is projected that 87 percent of funds to sustain and grow St. Jude over the next six years will come from public donations and investment income.

ALSAC partners with more than 11 million active donors who give to fund most of the $1 billion-plus cost to operate St. Jude annually as well as fund its capital projects.

In the previous phase, for example, donors funded the cost of a new $412 million Advanced Research Center set to open this spring. It will provide 625,000 square feet of badly needed space for gene editing, metabolomics, epigenetics, genomics, structural biology and one of the most advanced microscopes in the world, as well as labs for research in neurological diseases, infectious diseases, immunology, developmental neurobiology, and cellular and molecular biology.

"We are making our biggest (financial) commitment ever – during a pandemic – because our donors have demonstrated their commitment to us," said Richard C. Shadyac, Jr., President and CEO of ALSAC. "It's an incredible display of loyalty and purpose, and the power of people coming together to help the most vulnerable in our society: sick children."

The St. Jude model is unique in other ways as well, namely that it

> *"It's an incredible display of loyalty and purpose, and the power of people coming together to help the most vulnerable in our society: sick children."*
>
> **Richard C. Shadyac, Jr., President and CEO of ALSAC**

never bills patients for treatment, travel, housing or food. That's often a huge financial commitment borne by donors: Treatments for pediatric cancer can last up to three years or more and cost on average $425,000, including housing, travel and food. But there are also instances where the cost of care exceeds $1 million.

That operating model is a hallmark of Thomas' belief about equal access to medical care, rooted in what he saw growing up poor in a Toledo, Ohio, neighborhood.

From its inception, the St. Jude donor base has reflected Danny Thomas' approach to include as many people as possible in the mission to end childhood cancer. As he crisscrossed the country raising money to open St. Jude, he was repeatedly quoted saying he'd prefer a million donors who gave $1 to one who gave $1 million.

Last year, the average donation was approximately $43.

"We're in a position to say yes to these kind of bold expansion plans from St. Jude for a simple reason: the generosity of so many supporters," Shadyac said.

A FATHER'S LOVE OF GIVING LIVES ON IN THE SON

By Betsy Taylor · ALSAC

Kevin Dong wants you to see his dad – really see him. Because his dad's life and death motivate his passion for St. Jude Children's Research Hospital.

Picture the telecommunications lineman, wearing his work overalls, clocking in when it's still dark out, climbing up telephone poles or crawling deep underground through dank, unlit tunnels. Taking his lunch wherever he could, even if that meant the work van. A second-generation Chinese immigrant knitting together the city of New York through its telecommunications lines.

Then came 9/11.

His dad volunteered for a work assignment at Ground Zero that lasted three months and involved trudging through toxic debris doing telecommunications clean up.

Then in December 2014, three days before Christmas, after nearly 40 years as a lineman and a couple of years into his retirement, the 64-year-old was diagnosed with stage IV pancreatic cancer.

He died one month later.

Kevin, an operations analyst at New York-based JetBlue Airways, sometimes shares his dad's story with people at St. Jude events because it helps answer the why question: Why do you volunteer?

For years, he's given his time to several nonprofits because he loves to network, but when he went to his first St. Jude event just after his dad died, he felt an instant, deep connection to the mission – and a way to give back that felt personal.

"My dad had 64 good years before being diagnosed with cancer," said Kevin. "These kids are just starting out."

He helped out

One day in early January 2015, Kevin's dad stopped busting his chops about all of his volunteer work.

That's how Kevin knew for sure his dad didn't have long.

"When he was sick and in pain, there were times that I just didn't want to leave his side," said Kevin. "At his apartment on hospice care, I would stay there for five hours straight after work, and…my dad would say, 'How's your volunteer goal? I know you're still working on that.'"

And he would urge Kevin to leave the apartment, stop worrying about taking care of him and keep his promise to help people.

"That was really heart-wrenching for me because he used to always be such a jokester about it," said Kevin.

You see, Kevin was always volunteering for nonprofits, happy to do good and fulfill his volunteer hours at JetBlue. The company incentivizes volunteerism and community involvement by letting its crewmembers redeem their volunteer hours for airfare vouchers that are donated to the nonprofits of the crewmembers' choice.

Kevin's time was often booked with dinner events or galas, and his dad, the blue collar, no-fuss guy that he was, used to "bust chops," pretending to be annoyed by all that volunteering and gussying up.

But he did it with a wink. If he messed with you, that meant he cared about you.

When Kevin's dad died, it was as if a candle had been snuffed, and the world lost its meaning for a moment for Kevin and his sister.

At his dad's wake and in the weeks afterward, people from his dad's neighborhood in Chinatown shared stories of his kindnesses, such as helping out elderly people with small tasks, lending a hand to the mom

KEVIN KNOWS THAT FOR HIS FRIENDS, THE MOST VALUABLE THING THEY CAN GIVE IS THEIR TIME.

and pop businesses near his apartment, and stopping to play basketball with the neighborhood kids.

Kevin still chokes up when he talks about it because he had no idea.

As he listened to these stories, Kevin realized his dad spent his entire life helping others – as a telecommunications lineman, as a volunteer at Ground Zero, by running errands for a family in Brooklyn and through daily thoughtful acts in his community. He had also been in the local National Guard during the Vietnam War.

"He wasn't really flashy, but he was just known for being selfless in his own way," said Kevin. "A lot of what he did for the community, there are no accolades. But you know, I don't want him to be forgotten because in Chinatown, he helped out."

Super volunteer

In 2016, a friend invited Kevin to volunteer at his first St. Jude fundraising event.

He worked beside a long-time St. Jude volunteer named Eddie Ramos and found a kindred spirit. "He stayed until the very end and helped me pack everything," said Eddie.

The next weekend, Kevin photographed a St. Jude golf event. A couple weeks later, he took pictures for a happy hour held by the Friends of St. Jude New York committee, a group of young professionals united to help St. Jude.

"They said, 'Hey, you're a young professional. They're young professionals. You might as well join their committee because you're already here at all the events,'" said Kevin. "That's how it kind of organically happened that I joined the committee."

Today, he's an integral part of several St. Jude fundraising events in New York.

Kevin can't pick a favorite event, but he says the annual St. Jude Walk/Run comes close because people of all generations and backgrounds come, from the rich Wall Street types to the blue collar folks like his dad, and everyone in between, all in support of St. Jude.

A strong St. Jude is a diverse St. Jude, Kevin believes.

New voices

One day last spring, Kevin's close friend Xenia Zayas, more popularly known as Chef Zee on YouTube, told Kevin she wanted to do something to help St Jude. She had seen his social media posts and felt inspired.

Xenia and her fiancé had built her Chef Zee YouTube channel and now had more than 144,000 followers who tuned in for her "Grandma Certified" cooking. She incorporates her background of Cuban and Dominican food and makes it easy for people without fancy ingredients to make simple, home-cooked meals.

"Her food creates an experience," said Kevin. "It's very heartwarming. She has a personal story to all her dishes. I don't want to gush too much, but yeah, she's great."

Last year, she taught a virtual audience of St. Jude supporters how to make Peruvian chicken. "It's a unique blend of Hispanic and Asian spices that work in perfect harmony to create a chicken that's juicy and tasty," said Xenia.

Kevin knows that for his friends in New York, many of whom are second and third generation immigrants, the most valuable thing they can give is their time.

"She was willing to get involved and engaged," said Kevin, of his fellow Syracuse University alum. "I was very moved by that."

Carrying the torch

Kevin thinks about his dad who, although bone tired from work, still made time for pick-up games with the neighborhood kids.

The man who slogged for three months through debris at Ground Zero to remove destroyed telecommunications lines and replace them with new ones. Who knows what he saw because he never talked about it.

Who knows how much it damaged him.

The man who worked for 40 years to help provide the best life possible for his two kids so they would grow up to be not only successful, but good.

Each child deserves the chance to live an amazing, long and meaningful life.

This is why Kevin shows up.

EVERY MINUTE COUNTS

James Ingold watched a family go from panic to hope in one minute. Now the Illinois CPA asks others to make an investment in one child's most important minute at St. Jude.

James Ingold remembers sitting next to a family on their first day at St. Jude Children's Research Hospital and seeing them go "from 100 percent panic and concern to comfort and hope in one minute" as the woman who worked the admissions desk explained the St. Jude no-bill policy.

He was there with a close family friend whose son had begun treatment for cancer in 2004, the year James went from being a casual St. Jude supporter to a man with skin in the game.

Since then, he and his wife, Martha, have helped raise almost $1.2 million for St. Jude, in part from a regular email the CPA sends to his fellow "investors."

If you think about how much it costs to run St. Jude for a single day, it's a daunting number. So the Illinois accountant encourages his supporters to think about donating to St. Jude in increments of several seconds or one minute – he tabulates the numbers for them.

"You wouldn't believe the checks I started getting for those weird amounts: $117, $334, $1,249," said James. "An investment in one child's most important minute. And it really worked."

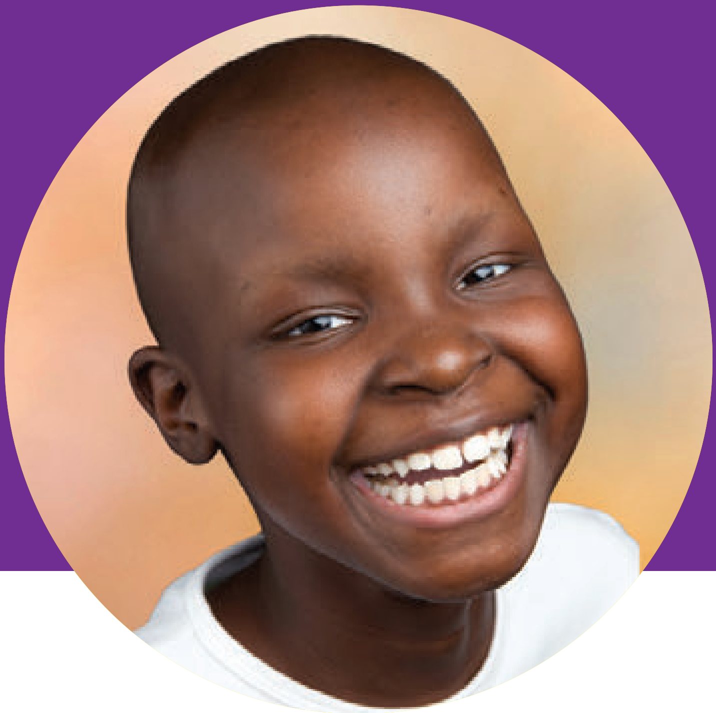
James has helped run the St. Jude Bloomington Telethon in Illinois since 2004 and today chairs that event. He's also a member of the St. Jude Midwest Leadership Board of Directors.

James and Martha were never able to have children of their own, a matter of some heartache when they were younger, but today they feel they have thousands of children to love and protect: all the kids of St. Jude.

A Curious Mind

St. Jude saved Jessica Sims' life 17 years ago. The chemical engineering graduate has been on a quest to know why ever since.

By Betsy Taylor · ALSAC



Jessica Sims, diagnosed with stage IV cancer at 7 years old, speaks thoughtfully, laughs easily, and talks casually about matters of great complexity.

Take, for instance, the way she describes her early interest in science, where she learned about Gregor Mendel who, through his work on pea plants, discovered the fundamental laws of inheritance. During this time, said Jessica, "I learned that the odds of you being born is one-over-some-astronomical-number. I remember thinking, 'Wow, you really are unique. There's really no one else like you.'"

Today, at 24, a cancer survivor and recent chemical engineering graduate, she understands more than her peers that we have a finite time on Earth, and it's not to be wasted.

Yet, far from being a downer, she's like a shot of can-do optimism.

"If you say that, can you tell them I'm the only shot that doesn't hurt?" said Jessica.

Fair enough.

Through a combination of surgery, radiation therapy and chemotherapy over the course of several months, she was treated at St. Jude Children's Research Hospital.

"Why am I still here?" she wants to know. "Why are any of us here?"

This desire to know. These big questions. They've made her a seeker, a scientist. They've propelled her through her life.

Missing one full year

Two weeks into second grade, Jessica's mom noticed something she hadn't seen before — a bump the size of a baseball on Jessica's thigh.

After X-rays and an MRI came a diagnosis of stage IV alveolar rhabdomyosarcoma, a cancer of the muscles. "Actually, I think my parents talked around the word [cancer]," said Jessica. They used the word "surgery," and that was bad enough.

"I cried because I was very scared," said Jessica. "What 7-year-old wants to hear they have to have surgery?"

She remembers going back to school that day with "bandages on me from where they drew my blood, and I think I just got my homework and went home."

It would be more than a year before Jessica set foot back into a traditional classroom.

Missing an entire school year. She cites this as the worst thing about having cancer.

Jessica conducts research during a medical internship at Louisiana State University in Shreveport. She graduated from LSU with a degree in chemical engineering.

An extraordinary childhood

Jessica has memorized dozens of mathematical formulas in her time. She knows the periodic table by heart. She's kept journals and binders full of study notes. She can remember the butterfly pillow with red wings and blue spots she packed on the night before her parents drove her to St. Jude.

But she says the harder aspects of her St. Jude experience are tough to recollect, "a blur."

She relies on her parents' memories to fill in the blanks.

"She was very sick," said her dad, Tony. "When we first got to St. Jude, they gave her a 14 percent chance of survival for five years. That was really devastating to us."

He and Jessica's mom, Brenda, held back their fear and pain as much as they could – so Jessica wouldn't see it.

"When she started taking her chemo, I was coming back up there with them for a week's visit and my wife called me and told me, 'She's going to look a little bit different, so don't let her see you fall apart,'" said Tony. "I didn't know how different she was going to look. I never experienced anything like that before. She had lost just about all of her hair."

"I've been a firefighter for 37 years," said Tony. "Just some of the things that I saw her go through, I don't know if I would have been as brave as she was. And I have to really be honest with you about it: She was really a brave little person."

Jessica has only a few vague memories of the rougher times. For her, the primary takeaway of her time at St. Jude – underlined, annotated and starred as the main idea – was love.

She remembers the first person she spoke to at St. Jude was a nurse with "the sweetest voice ever. She was honestly so sweet." Tony and Brenda remember that woman, too, as the one who helped them through.

"She was just trying to cheer us on to not give up," said Tony. "And so I'm glad we listened to her because we were really in a tailspin."

That nurse set the tone.

"When you start treatment there, it's like you have a new family," said Jessica. "They want to make sure that you're comfortable and things are going well. And when bad news comes up, they're worried, too."

Still, her most vivid memories are of genuinely good times.

"I remember when they actually rolled out a huge pad of bubble wrap, and they told us to have at it. I remember I took my IV and I rolled right over it," said Jessica. "It was so much fun."

She looked forward to Tuesdays when dogs came to visit the kids through the Doggy Daze program, and on Halloween, she said, "They would deck out every clinic, every floor, with a theme. We would walk around the hospital and they would fill our bags with candy."

Jessica says the miracle of St. Jude is not just the science or the cures, but the way they gave her a childhood that was better and more remarkable than she might have had otherwise.

Jessica attends an LSU football game before COVID-19.

"I started telling people that even though my childhood was surrounded by unusual circumstances, I had an extraordinary childhood," said Jessica. "You can say I traded an ordinary childhood for an extraordinary childhood."

Faith and science intertwined

Jessica may have missed more than a year of school, but she never stopped learning.

"She was always asking questions when the doctors came in and she always had a big conversation about what they did or why they did it," said Tony. "And they would always be generous and explain it to her."

And she never stopped making connections.

Jessica's time at St. Jude deepened her faith in God "because I'm described as a miracle, a walking miracle," said Jessica.

She pondered that a lot as a little girl.

Her dad saw her gravitate to science and math in middle school, so he encouraged her in that direction. "Chemistry for me was so complicated but interesting at the same time," Jessica said, "because you just think, 'Wow, look at all that's happening in a single reaction.' And for me actually, it was also very faith-affirming because it was so complicated.

"When I look at anything science-related, I always think, 'It takes years for someone to master a complete understanding of this, maybe even a lifetime.' And then to think that God did this in seconds to a few days is just mind-blowing to me."

Science for Jessica has been a place to put all her big questions to the test: Where does life come from? Why are we here? How does this happen?

Her parents have questions, too. How did they get to this wonderful place after such hardship?

"We still take it one day at a time even though she's 24 years old," said Tony. "We just take it one day at a time."

Stronger for it

Chemical engineering jobs have been scarce because of COVID-19, but Jessica isn't worried. She's ridden out uncertainty before and come out stronger for it.

For now, she's had time to help her sister's fledgling wholesale real estate business, learn new songs on the piano, read her Bible and bond with her 2-year-old niece.

"We're working to build a relationship with her, you know?" said Jessica "And make sure she knows me and my mom and my dad. And just letting her know she has a loving family that surrounds her."

You see, Jessica invests in people. The same way her dad invested in her, urging her to explore her interests in math and science even though it was hard. And even though there weren't many other Black girls doing the same thing.

The same way her mom invested in her by taking care of her and lifting every member of her family up because of what Jessica calls "her servant heart."

She wants to be that same kind of mentor for other girls and women of color.

"We need more diversity in medicine. The same is true for engineering," said Jessica. "I want people to see, 'Hey, I did it. You can, too. You just gotta work hard for it.'"

She wants to be a role model for kids who have cancer, too.

Jessica's thigh has a slightly caved-in look where the surgeon took muscle out with the tumor.

She wishes it was less subtle so people would ask her about it. She wants to talk about St. Jude and how transformative it was.

"Because if you think about it, it's a part of me," said Jessica. "It's a contributing factor to the person I am today."

St. Jude patient
Ryleigh

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Join us on a virtual tour of St. Jude Children's Research Hospital.

Through this online experience you can visit places like the Medicine Room, the ABCs of Cancer wall, Kay Kafe and the Flags of the World display in the Danny Thomas Research Center.

Welcome to St. Jude:
tour.experience.**stjude.org**.