ST. JUDE inspire

WINTER 2020

Cure of *a lifetime*

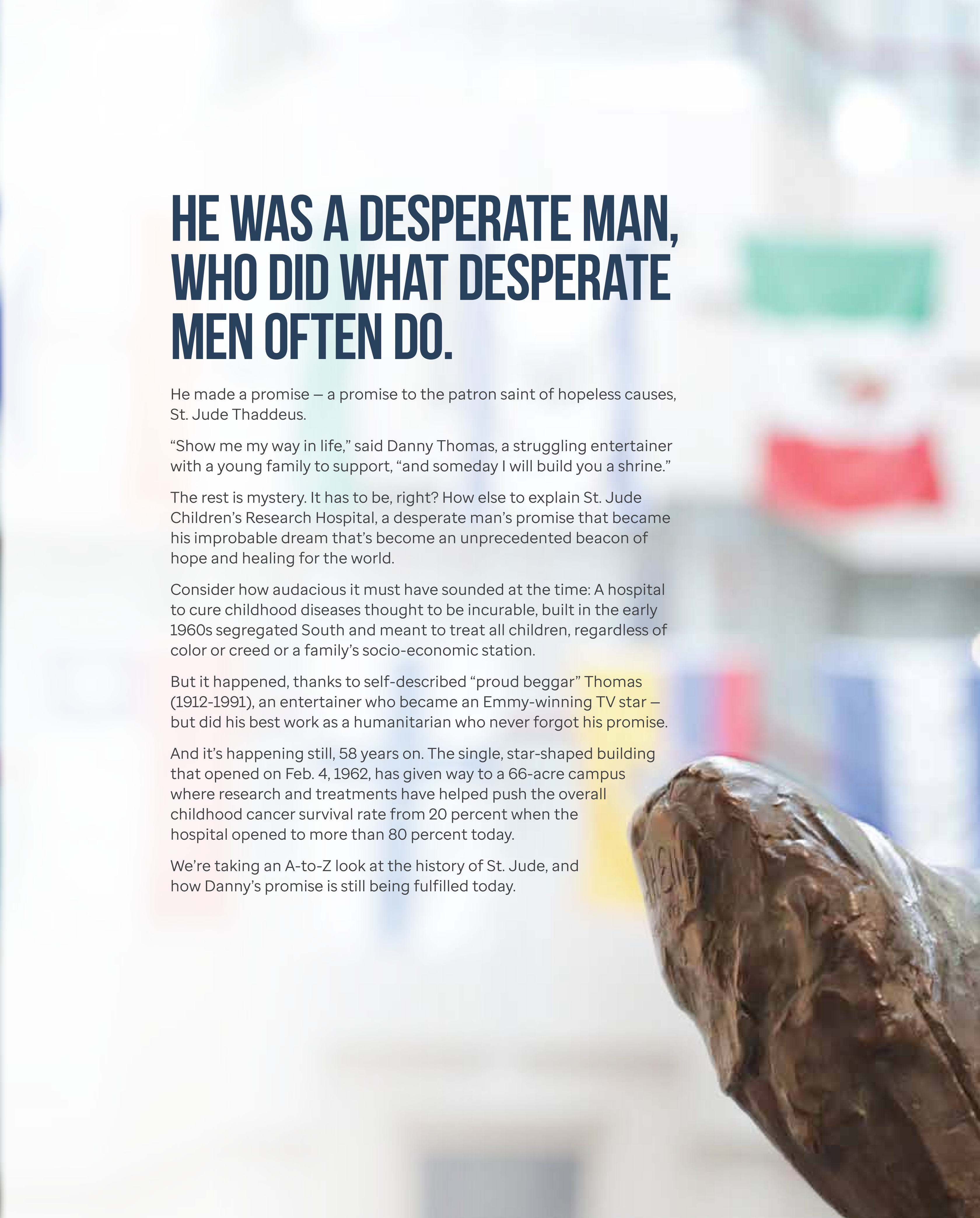
Researcher's gene therapy breakthrough punctuates end of a full life

Like Home
20 years of memories at Target House

Be Safe
proper sunscreen for little ones

Puppy Love
pet project: 4-legged therapy

On Key
the power of music at St. Jude



HE WAS A DESPERATE MAN, WHO DID WHAT DESPERATE MEN OFTEN DO.

He made a promise – a promise to the patron saint of hopeless causes, St. Jude Thaddeus.

"Show me my way in life," said Danny Thomas, a struggling entertainer with a young family to support, "and someday I will build you a shrine."

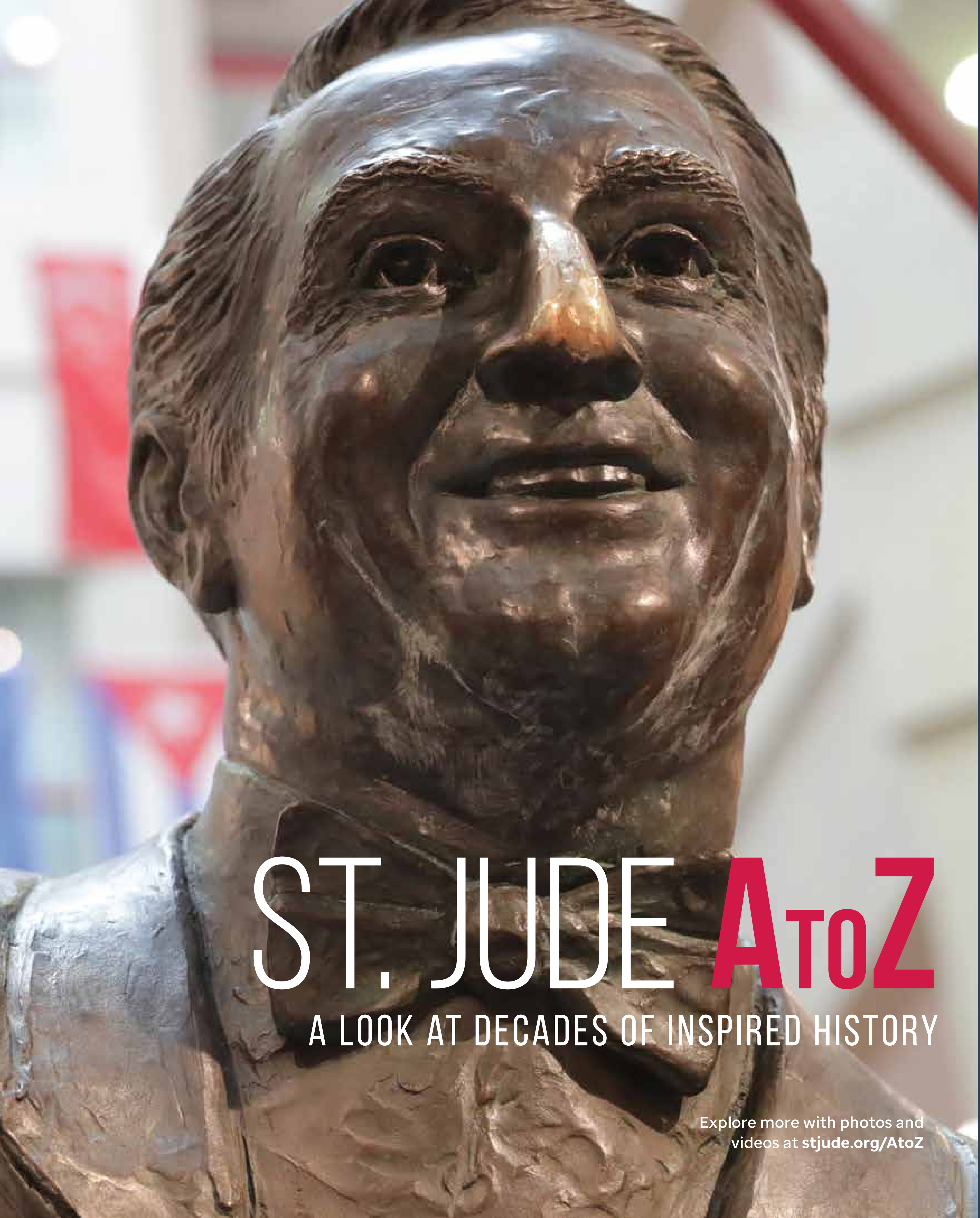
The rest is mystery. It has to be, right? How else to explain St. Jude Children's Research Hospital, a desperate man's promise that became his improbable dream that's become an unprecedented beacon of hope and healing for the world.

Consider how audacious it must have sounded at the time: A hospital to cure childhood diseases thought to be incurable, built in the early 1960s segregated South and meant to treat all children, regardless of color or creed or a family's socio-economic station.

But it happened, thanks to self-described "proud beggar" Thomas (1912-1991), an entertainer who became an Emmy-winning TV star – but did his best work as a humanitarian who never forgot his promise.

And it's happening still, 58 years on. The single, star-shaped building that opened on Feb. 4, 1962, has given way to a 66-acre campus where research and treatments have helped push the overall childhood cancer survival rate from 20 percent when the hospital opened to more than 80 percent today.

We're taking an A-to-Z look at the history of St. Jude, and how Danny's promise is still being fulfilled today.



ST. JUDE AtoZ

A LOOK AT DECADES OF INSPIRED HISTORY

Explore more with photos and
videos at **stjude.org/AtoZ**

Amos Jacobs, "my true legal name," as the man better known as Danny Thomas wrote in his autobiography, *Make Room for Danny.*

B

Billion. It will cost more than $1 billion to operate St. Jude this year.

C

No, not cancer, but the real Big C - **children,** our reason for being.

D

Donors, like 8-year-old Caroline, whose $1.40 donation came with a note that said "little things go a long way."

Elvis Presley. The King was famous for giving away cars to complete strangers, but in 1964 he donated a yacht to St. Jude, which sold it – for $60,000 to $75,000, according to various reports – to fund more research and treatment.

F

Friends. The Thomas family has always called on fellow celebrities to aid the cause – from such Danny pals as Frank Sinatra, Lucille Ball and Sammy Davis Jr. in the early years, to Jennifer Aniston, Michael Strahan, Sofia Vergara and other friends of Marlo and Tony Thomas.

Global. St. Jude is collaborating with the World Health Organization toward the goal of curing at least 60 percent of children with six of the most common types of cancer by 2030.

H

Hope. It takes more than medicine – St. Jude tells families that hope is "essential to life" and "can directly influence the well-being of pediatric patients."

I

Ira's request. For many years, a man named Ira Jackson donated a portion of his Social Security check – his only source of income – to St. Jude. Terminally ill, he made a plea for someone to "take Ira's place." Nearly 900 people responded, raising more than $150,000.

Jude Thaddeus – St. Jude, patron saint of hopeless causes. A 10-foot-tall, white marble statue of St. Jude was unveiled during dedication ceremonies in 1962.

K

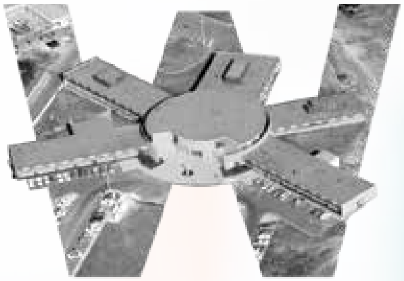
Kay Kafe, a unique communal gathering space for meals, where chefs are cherished for their ingenuity and caring – such as calling a patient's grandmother to get the recipe for her beloved mac-and-cheese.

L

Lebanese – Danny's heritage, and a great source of personal pride. In 1957, 100 representatives of the Arab-American community formed the American Lebanese Syrian Associated Charities (ALSAC) to fund the place of his dreams.

Marathon. St. Jude Memphis Marathon Weekend, the largest single-day fundraiser for the hospital, with more than 28,000 participants, raising over $12 million in 2019.

Williams, Paul. The African-American architect of the original building donated his design for Danny's vision of a truly integrated St. Jude.



V

Volunteers. More than 1 million volunteers help orchestrate and run 31,000 fundraising events supporting St. Jude around the country each year.

Unprecedented. St. Jude firsts are legion – from developing the first immunologic method to diagnose solid tumors in children (1965) to being first to adapt a computer-based, 3D radiation therapy technique for pediatric brain tumor treatment (1995).

U

N

"No child should die in the dawn of life." Danny's simple declaration of an undeniable truth.

X

Xylophone, and other instruments patients can play in the therapeutic and spirits-lifting St. Jude Music Therapy program.

Y is for **"Yucky,"** as seen in the ABCs of Cancer patient art display, which lets patients use art to express themselves: *Needles are yucky and scary. Throwing up is yucky. Taking medicine is super yucky. Cancer is mean and yucky.*

Y

T

The Thomas next generation – Tony, Terre and Marlo have elevated and expanded their father's vision. The siblings launched the annual holiday St. Jude *Thanks and Giving®* campaign, raising more than $1 billion over 15 years.

Samuel Stritch, Cardinal in the Roman Catholic Church. He mentored Thomas and steered him toward Memphis – where Stritch had served as a young priest – as a site for St. Jude.

S

P

Pinkel, Dr. Donald. The first medical director of St. Jude "introduced the word 'cure' to cancer," said Dr. James Downing, current President and CEO of St. Jude.

Owen, Randy. The *Alabama* lead singer was recruited by Danny Thomas to rally the country music community around our mission. He founded Country Cares for St. Jude Kids®, which has raised more than $850 million.

Zero – the number of bills families receive from St. Jude for treatment, travel, housing and food.

Racial inequality – a social cancer in need of a cure when St. Jude opened in the segregated South of the early 1960s, and so Danny insisted it would treat children of all races.

Quotes – *"It took a rabble-rousing, hook-nosed comedian to get your attention, but it took your heart, and your loving minds, and your generous souls, to make this fabulous dream come true."*

Q

– Danny at the 1962 dedication.

I had the honor of hosting Dr. Brian Sorrentino on stage at our annual employee training meeting almost three years ago to discuss his groundbreaking work in gene therapy.

It was an unforgettable session because Brian revealed his remarkable team had unraveled the mysteries of a cruel disease most of us know as bubble boy disease. Brian didn’t use the word “cure” that day but, as we know now, he could have.

Tragically, Brian, a childhood cancer survivor, died of a secondary cancer before the world would learn what his team had accomplished. We take a revealing look into that work in this edition of *Inspire*.

Brian’s legacy is that beautiful little boy you see on the cover, and many more children like him, because this special man never gave up – even as he was gravely ill himself.

As much as anyone, Brian’s story imbues the St. Jude narrative of never quitting on a sick child no matter the odds.

At that training session in 2017, I asked Brian to recount his “St. Jude moment.” That’s a common question because this special mission so often exposes us to raw, emotional moments that never fade.

He described “bookend” moments: First, being a new employee surrounded by boxes of unpacked lab equipment and thinking of the challenge ahead. And then in some detail Brian described that second moment, a visceral scene that will never leave me.

It’s a moment described magnificently in our cover story. No spoiler alert here but it’s essential I make this point: that powerful moment would not have occurred without the financial support of donors – generous people like you – who, year after year, funded the work of Brian and his team.

So take pride in this: it’s your St. Jude moment, too.

Richard C. Shadyac Jr.
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St. Jude Children’s® Research Hospital
Finding cures. Saving children.
ALSAC • DANNY THOMAS, FOUNDER

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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**

GREETINGS FROM ST. JUDE

Imagine a hospital and research center you'd choose to visit, without an appointment, without any reason except, of course, the best reason of all – because the place saved your daughter's life. For one Alabama family, that place is St. Jude Children's Research Hospital, which treated their little girl Khushi for neuroblastoma.

"We always love to come here," said Chirag, Khushi's dad. "We just randomly come."

They'll pick a day and pile into the car for the drive to Memphis – 215 miles, as the time flies. What's three-and-a-half hours each way, after all, in return for a child's second chance at a lifetime?

Scan the QR code with your smartphone or visit **stjude.org/khushi** to read more about Khushi.

WORLD'S MOST POWERFUL NUCLEAR MAGNETIC RESONANCE SPECTROMETER ARRIVES AT ST. JUDE

ST. JUDE CHILDREN'S RESEARCH HOSPITAL HAS ACQUIRED THE MOST POWERFUL SUPERCONDUCTING MAGNET IN THE WORLD — PART OF A NEW TOOL THAT WILL HELP RESEARCHERS SEE FARTHER INTO CELLS THAN EVER BEFORE.

BY THOMAS CHARLIER

DANGLING FROM A CRANE like a giant fishing lure, the world's most powerful superconducting magnet heralded a new era of scientific possibilities as it slowly descended into an underground shaft at St. Jude Children's Research Hospital.

A key part of the first Ascend 1.1-GHz Nuclear Magnetic Resonance Spectrometer (NMR), the largest and most powerful device of its kind, the magnet will help researchers see farther into cells than ever before. The NMR will allow St. Jude researchers to study proteins, DNA and RNA as part of an effort to understand cancer and other catastrophic childhood diseases at the molecular and atomic levels.

The new spectrometer is the centerpiece of the expansion of the St. Jude Structural Biology Department, which will use it to conduct research that, up to now, has been impossible.

"This 1.1-GHz system provides unprecedented capabilities and opportunities for us to answer challenging biological questions," said Charalampos "Babis" Kalodimos, Ph.D., department chair. "It will be our most important tool to perform research in the area of dynamic molecular machines that are otherwise not amenable to other technologies."

The capabilities of the new tool also will help St. Jude attract world-class scientists and researchers, Kalodimos said.

James R. Downing, M.D., St. Jude President and CEO, said the addition of the NMR could lead to major breakthroughs in identifying the causes of diseases and possible cures.

"In our fight against pediatric cancer and other catastrophic childhood diseases, it is imperative that we learn as much as possible about the basic relationships within cells and how those relationships affect the growth and also treatment of the disease," Downing said. "Investments in state-of-the-art technology like this NMR spectrometer allow us to make scientific progress faster."

Your donations to St. Jude give researchers the freedom to focus on the most promising pathways to understanding, treating and curing childhood cancer. ***stjude.org/donate***

LEGACY OF A CURE

BY THOMAS CHARLIER

Colleagues chuckled when Dr. Brian Sorrentino, a tall, distinguished researcher known for his intensity and hard work, began wearing teddy bear-themed neckties and giddily greeting children who came in for checkups. He long ago had quit practicing medicine, after all, and normally worked in the lab.

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

One of the first clear answers came on a summer day in 2017 when a baby from Peru was brought in for his 9-month exam. Treated some seven months earlier, the boy appeared to be thriving. Not only had he tripled in size, but his little body was churning out immune cells that allowed him to crawl and explore like a normal baby, without the sterile confinement usually required for kids born with the disorder known as bubble boy disease.

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

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

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

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

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

“WENT AT LIFE WITH EVERYTHING HE HAD”

Brian Sorrentino lived fast, considering all he managed to squeeze into his 60 years. It seems only natural that he loved fast cars, a passion that drove indelible and defining memories of him. St. Jude President and CEO James R. Downing, M.D., remembers visiting a racetrack near Memphis where Sorrentino and another hospital employee were testing their sports cars. Downing rode with both. The first driver was “smooth as silk” on the track, Downing recalls. Sorrentino was not.

“He was all over the track — he’s bouncing through the corners, his back end is fishtailing out. He’s hollering and screaming and having a blast.”

Later, the two drivers compared times. “The smooth-as-silk was faster,” Downing said, “but Brian had a lot more fun. That was Brian — Brian just went at life with everything he had.”

Sorrentino grew up mostly in the Hudson River Valley, an hour north of New York City. His older brother and only sibling, Brent, imparted in Brian his other main passion — music, taking him to see concerts at Madison Square Garden. Brian grew into such a Grateful Dead fan that after he became a father, listening to the group became a bedtime ritual with his kids.

Gael, a patient who came to St. Jude from Peru, was one of the early cases of success for using gene therapy to treat SCID-X1. Sorrentino recalled marveling at the boy. “I held him and I said to myself, ‘I can’t believe we did this.’”

Early on, Sorrentino was intent on following his radiologist father into medicine. That career choice likely was cemented by an ordeal that began when he was 17. He called his father to say he had found a lump on his chest near his neck. “Get on your bike and ride to my office,” was the response.

He was diagnosed with Hodgkin lymphoma, a cancer of the lymphatic system, part of the body’s immune defenses. Even in the mid-1970s, the disease was highly curable, but treatment involved chemotherapy mixed with massive doses of radiation to the chest.

Sorrentino completed treatment at a Bronx hospital and later went to medical school, then worked at the National Institutes of Health, where colleagues remember a researcher who was as humble and kind as he was brilliant and persistent. At NIH, Sorrentino trained under Arthur Nienhuis, M.D., a hematologist and branch chief who in 1993 became the fourth President and CEO of St. Jude.

“He was thoughtful, careful in planning and he had a wonderful way of bringing people together,” Nienhuis said of the researcher he brought to St. Jude in 1994.

TARGETING BUBBLE BOY DISEASE

The disorder commonly called bubble boy disease has a scientific appellation that reads like a code: SCID-X1, for X-linked Severe Combined Immunodeficiency. Occurring perhaps once in every 200,000 live births (15 to 20 babies annually in the U.S.), it’s an exclusively male disorder caused by a defective gene that renders babies unable to produce T-cells, B-cells and natural-killer cells — the pillars of the immune system. Without treatment, babies usually die from infection in their first year.

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

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

A major problem, however, is that, much like a ball on a casino roulette wheel, there’s no way to predict where the virus will land on the cell genome. Early trials in France and elsewhere were halted after several patients

“

HE WAS AT THE PEAK OF HIS CAREER. HIS CLINICAL TRIAL WAS UNDERWAY… HE HAD EVERYTHING TO LIVE FOR.

developed leukemia because the virus they used activated adjacent cancer-causing genes.

“That put a stop to all gene therapy, literally a hiatus for the entire field,” Downing said. “Everyone in the field sort of thought, ‘Well, this is not a problem we can overcome.’”

But at St. Jude, which was developing an ambitious gene therapy program, Sorrentino and his team set out to prove otherwise.

He employed a hollowed-out form of the slow-incubating virus that causes AIDS, which has the added advantage of being efficient in infecting stem cells. To eliminate the risk of triggering cancer, Sorrentino put insulators on the virus to keep it from activating other genes. The final component of the therapy, refined by the University of California San Francisco Benioff Children’s Hospital, employed low doses of chemotherapy to clear space in the bone marrow.

TRIUMPH AND TRAGEDY

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

“He was just so much fun to talk to…a marvelous man,” said Suzanne Sorrentino. She also notes her new husband’s passion for St. Jude, how it was elevated by his own childhood cancer experience. “He had a lot of empathy for the families and the children here because he had lived it, too.”

Omarion, born with a rare genetic disorder called X-linked Severe Combined Immunodeficiency, or bubble boy disease, explores playground equipment after his immune system was reconstituted through gene therapy developed at St. Jude.

But Sorrentino's cancer-treatment history had been surfacing in bad ways, as well. The after-effects of the radiation caused thyroid problems and forced him to have an aortic valve replaced. Later, a pacemaker was installed to regulate his radiation-damaged heart.

The SCID-X1 clinical trial, however, was going well, much better than previous therapies, with patients safely developing functional immune systems within three months, said Ewelina Mamcarz, M.D., a St. Jude bone marrow specialist and lead author of the study. "I think what made the difference on this trial was the combination therapy," she said, referring to the use of a chemo drug with the modified virus as a transport vehicle.

One of the biggest challenges had been enrolling enough patients, given the rarity of the disease. Half came from other countries, including the Peruvian boy named Gael.

Sorrentino seemed especially elated to get out of his lab and see the kids. "I've never seen him as happy as with the patients," Mamcarz said.

But less than a month after Gael's exam, Sorrentino was diagnosed with lung cancer — the final, tragic sequel to that medical drama of his own. The news came as a shock because he had assumed the breathing problems he experienced that summer signaled more heart trouble.

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

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

"Brian was just crushed by the diagnosis because he was at the peak of his career. His clinical trial was underway, children's lives were being saved...," Suzanne said. "He had everything to live for."

In a bitter irony, Sorrentino sought to enroll in a clinical trial for his disease even as he led one for SCID-X1. But his weakened heart disqualified him.

As a physician, he knew his condition was terminal. "Then it kind of just became a race against time to see how much could he get done before the disease took its toll on him," Suzanne said.

The diagnosis, indeed, gave new urgency to Sorrentino's work. He continued to work at the hospital until he was too weak, and then monitored the project from home. Sometimes, his colleagues came to his house, working for a few hours, ordering pizza, then working more.

A BITTERSWEET LEGACY

A week before Sorrentino's death in November 2018, Mamcarz drove to his home, opened her laptop and showed him the data and the transcript of the paper on the SCID-X1 trial that would be submitted to the prestigious *New England Journal of Medicine*. By then he was so sick that he kept pain medicine nearby. But looking at the paper — seeing proof that his gene therapy worked — comforted him. The two doctors high-fived each other and shrieked with joy.

"After seeing the data, he said that was the best pain medicine that he could get," Mamcarz said.

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

▲ *Following successful gene therapy treatment for bubble boy disease, Omarion was able to escape sterile confinement and play outside with Ewelina Mamcarz, M.D., a St. Jude bone marrow specialist who was lead author of a study of the therapy.*

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

In April 2019, six months after Sorrentino's death, the *New England Journal of Medicine* published the SCID-X1 study, which reported that the first eight patients treated either had fully reconstituted immune systems, or were progressing toward it.

Since then, four additional patients have been treated — with the same success. Kids who otherwise would have no immune protection can hug their parents, attend birthday parties and go on vacations. "Truly, the results continue to be outstanding," Mamcarz said.

In another honor that Sorrentino didn't live to see, *Smithsonian* magazine bestowed its American Ingenuity Award in Life Sciences on two members of his SCID-X1 team — Mamcarz and Stephen Gottschalk, M.D., chair of the Department of Bone Marrow Transplantation & Cellular Therapy at St. Jude.

Brent Sorrentino, however, said his humble brother was less interested in awards and recognition than he was in other measures of success.

"There are a dozen and counting kids alive today because of my brother," he said.

Brian knew the radiation effects might rob 20 years from his life, his brother said. But the treatment had given him 40 years, too, and he used that time to bequeath decades of life to kids born with SCID-X1. "Brian said, to him, that's a good trade."

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

Hear from Dr. Sorrentino's wife Suzanne, and St. Jude President and CEO James R. Downing, M.D., on Brian's love for cars, sports and more at **stjude.org/sorrentino**

St. Jude patient **Tony**, blood cancer pictured with his dad

Your gift can make a lifesaving impact

when you support the mission of St. Jude Children's Research Hospital®. Giving a gift of stock or from your donor-advised fund (DAF) or IRA will help St. Jude accelerate progress and improve treatment for children battling cancer and other life-threatening diseases. Treatments invented at St. Jude have helped push the overall childhood cancer survival rate from 20% when we opened to more than 80% today. With your support, we won't stop until no child dies from cancer.

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PERFECT HARMONY

ST. JUDE MUSIC THERAPIST AMY LOVE STRIKES A HEALING CHORD WITH PATIENTS

By David Williams

For Amy Love, music is medicine and more. As a music therapist at St. Jude Children's Research Hospital, she said it's more than a necessary part of treatment. It's a learning tool, a coping mechanism, a creative outlet and a sure-fire way to spark that sweetest of sounds – children laughing, playing, having fun.

"There is no reason that music shouldn't be a large part of somebody's hospital experience," Love said, "because it really captures who we are as people." And so, as one of two full-time music therapists at St. Jude, Love is a troubadour among the more traditional medical staff, serving the same purpose – helping young patients with catastrophic illnesses get better.

The music therapy program, which Love has seen grow from "a small cart of some small instruments to our own music therapy clinical space," can help young children with developmental, social and motor skills. Older patients might learn how to play an instrument and write songs – a way of articulating the doubts and fears that come with cancer.

Music therapy, Love said, can also be a means of "celebrating big accomplishments and making the hard days better." It can build self-confidence at a time when the patient hardly recognizes the face in the mirror.

Music as learning tool. Music as coping mechanism. Music as creative outlet.

For Love, music's benefits are in perfect harmony with the needs of patients. "Music can be such a healing thing in the hospital," she said. "There is no better setting to have music."

Hear from Amy Love and learn more about the St. Jude music therapy program at **stjude.org/musictherapy**

the Songbird

BY DAVID WILLIAMS

“By singing, I’m showing everybody that my deafness doesn’t hold me back.”

“this high F up here?” she says. “That’s where I stop being able to hear. I just hear clacking.” Legally deaf from childhood treatment for neuroblastoma, Tiara Herr can’t hear high notes, fire alarms, phones ringing or birds singing – yet she plays piano, and writes and sings original songs. She performs in musical theater, most recently a revival of “South Pacific.” She even gives voice lessons, drawing on a love of science sparked by St. Jude Children’s Research Hospital to teach singing as a “full-body experience.”

“So when I listen to music, and there’s all this high stuff, I don’t experience that. But what I can experience is really cool. I’ll be playing, and I can lay my head on the piano and I can feel the vibrations coming through my bones.”

‘Lost in music’

The little girl in the frilly dress would run through the hallways of St. Jude, singing at the top of her lungs.

“I would sing in every part of the hospital,” Tiara says now, sitting at the piano in her rustic Oregon home, some 20 years and 2,000 miles removed from St. Jude in Memphis. “They probably knew I was coming because they could hear this little kid singing these cute songs.”

Nothing could silence her. Not the tumors, which would eventually number 40. Not the treatment, which included dozens of surgeries, chemotherapy, radiation therapy and a bone marrow transplant.

“I try to remember the little girl running through the hallways,” she says. She didn’t seem like she had a care in the world, but in reality she was fighting for her life every second of every day. “I need to do a lot of reflection to remember that that girl is still in me.”

Oh, she’s still there.

She’s at the piano now, not just playing but expressing, not just hearing but experiencing. She’s talking about the science of her art, and how feeling the notes she plays “really tells me whether that music is going to be effective at conveying what I’m feeling in that moment.”

Her playing, like her singing, has power and force – she favors dissonant chords, which she jokes are “awesome and angsty.” It’s an apt soundtrack for someone who defied death more than once as a child, and who copes as an adult with chronic pain, anxiety and depression.

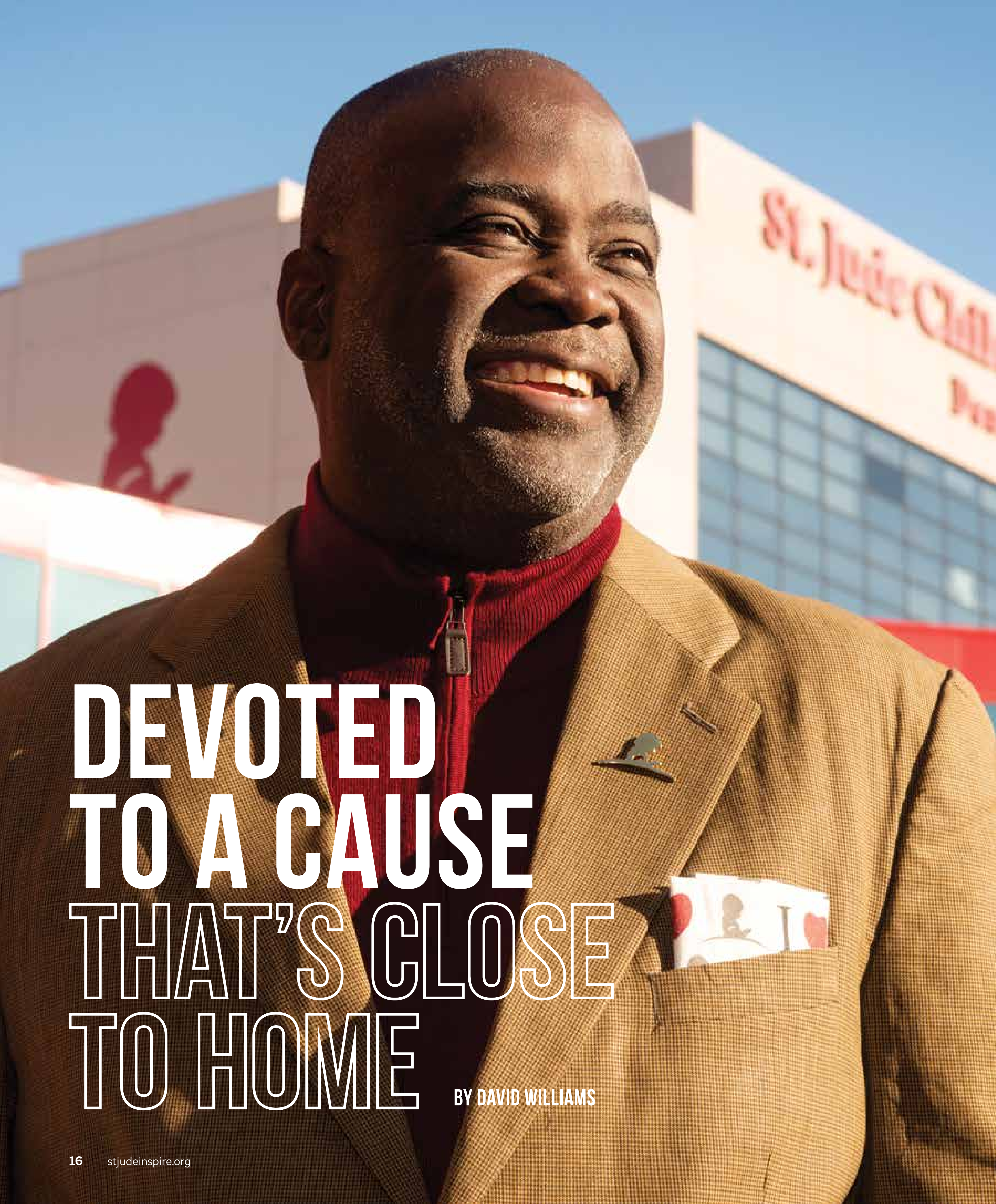
Music helps. It always has.

“Music is so expressive,” says Tiara, 27. “By singing, I’m showing everybody that my deafness doesn’t hold me back. That all this trauma that I have from being a childhood cancer survivor doesn’t hold me back. Because I can get lost in music and forget that ever happened to me.”

“I try to play or sing as much music as I can, because that is the one thing that is guaranteed to lift me up.”

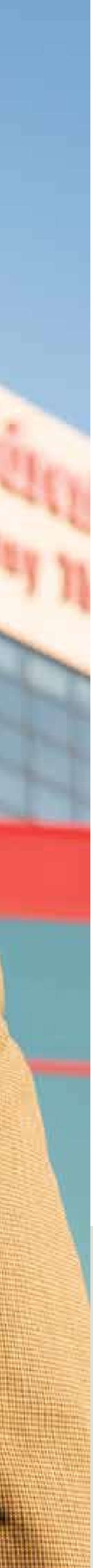
Because what the little girl knew in her heart, the woman feels in her bones: When you can’t hear a bird’s song, be your own songbird.

To hear Tiara and her music scan or visit stjude.org/tiara



DEVOTED TO A CAUSE THAT'S CLOSE TO HOME

BY DAVID WILLIAMS



He was born in Memphis in 1969, the year after Dr. Martin Luther King Jr. was assassinated in the city. He grew up in the Foote Homes public housing project, hearing his mother's stories of tanks rolling through the streets in the wake of Dr. King's death.

"A lot of the men who participated in the sanitation workers' strike, they lived in the projects with us," Jason Farmer said. "So it was just one of those teachable moments. Because we would see the men come home. I would see them get hosed off outside, not understanding why they came home so dirty every day."

A teachable moment, not from a book but from life. And Farmer learned it well, growing up to become a leading light of African-American support for a Memphis institution founded on the ideals of inclusion and equality – St. Jude Children's Research Hospital.

"When you talk about space and time," he said, "Dr. King was assassinated here in 1968, and St. Jude was in its infancy… And a lot of people just don't really know how critical of a role St. Jude played in helping that healing process, after the assassination of Dr. King. Sometimes it makes you wonder where we would be if St. Jude wasn't here."

Farmer was honored recently with a Daily Point of Light Award from Points of Light, a global nonprofit organization founded by President George H.W. Bush, who in his 1989 inaugural address evoked the vision of "a thousand points of light," calling for the nation to serve those in need.

That spirit of service burns bright in Farmer, most notably through St. Jude Spirit of the Dream, an annual Black History Month event celebrating the achievements of African Americans who embody the lifesaving work of St. Jude and its founder, Danny Thomas. Farmer helped establish the event, playing an influencer role that encouraged others to get involved, and serves as its vice chairman.

Farmer has also been a St. Jude donor and supporter all of his adult life, from his days in the Marine Corps, to twice running in the St. Jude Memphis Half Marathon. He's also volunteered at the WGC-FedEx St. Jude Invitational, the annual Memphis PGA TOUR event benefiting St. Jude.

"It's a noble mission," Farmer said, invoking Thomas' belief that no child should die in the dawn of life. "It's a doable mission."

But this is more than a story of a generous Memphian supporting a worthy institution. Farmer's bond is personal with St. Jude, which opened in 1962 as the first fully integrated children's hospital in the South. There weren't just African-American patients being treated in the same rooms as white patients, but African-American researchers, doctors and nurses working alongside white colleagues.

And in the years following Dr. King's assassination, one of the first African-American physicians at St. Jude, Dr. Rudolph Jackson, helped develop a program to provide nutritional assistance and address common health problems in low-income households.

The program served as a prototype for WIC, the federal initiative for women, infants and children, and thousands of local families were enrolled – including the Farmers, who lived about two miles from St. Jude.

Later in life, his family would turn to St. Jude again, when a young relative was diagnosed with lymphoma and successfully treated there.

Feeling "greatly indebted" to St. Jude, Farmer said giving back has always come naturally to his family.

"It doesn't even really feel like volunteering," he said. "It's just what we're supposed to do.

> "…a lot of people just don't really know how critical of a role St. Jude played in helping that healing process, after the assassination of Dr. King."

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

The tao of Colin:

FIVE THINGS MY SON TAUGHT US ABOUT LIFE

BY TAMIKO TOLAND

My son Colin was a remarkable boy, charming and funny, with the full promise of any toddler before cancer diverted his life's story. After his diagnosis with a brain tumor, we truly came to appreciate and admire his grit, determination and the brilliant spirit that pulled him forward despite fundamental and seemingly insurmountable challenges.

Yes, cancer ended his life, but not before he made his mark on this world and taught us five important lessons that make me grateful every day that I got to be his mom.

1 Never Give Up On Your Dreams

Colin's dream started at St. Jude Children's Research Hospital, when he announced during treatment that he wanted to become a police officer, even if he would be the first to do so with a brain tumor. The Ithaca (NY) Police Department welcomed him with open arms. During his press interviews at his very large and public swearing-in ceremony, he said something to the cluster of reporters that became the central tenet of his police career: "Never give up on your dreams."

2 Never Give Up On Yourself

From Colin's initial diagnosis on, he constantly worked with therapists to get stronger, more agile and communicate better. Despite challenges from his initial diagnosis and later setbacks, Colin never stopped trying and never let go of his commitment to improving. Perhaps because of this, in Colin's worldview, everybody had the capacity to be better.

3 Enjoy The Small Moments

Colin appreciated small moments and the things that made him feel connected to the world around him. It was as simple as sitting outside on a nice day with the cats milling about and having friends stop by to say hello. When life speeds by, it is all too easy for these opportunities to flutter to the ground, but Colin still reminds us to take the time for the pleasures of the mundane.

4 Laughter Is the Best Medicine

Colin was a perennial jokester who loved to make people laugh.

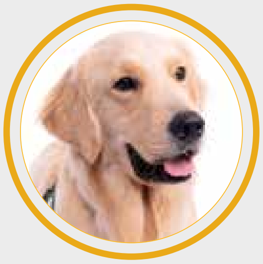
There is little we can control in life and we will always encounter difficulties. However, humor is a wonderful antidote to that chaos. We saw time and again how Colin could change the mood in a room and that his levity improved everything.

5 Love Persists

What legacy does a child leave? Many people have fretted about their footprints disappearing from the Earth, worrying that they have not left a mark that will stand the test of time. There is no permanence in a constantly changing universe, but Colin had a precocious confidence in his place within it.

Colin touched many hearts in a short lifetime. The love he gave and inspired is still here, indelibly imprinted onto all those souls. We were extremely fortunate that, in his "career" with the police, he became a community figure and many people followed his story and cheered him on. Now, they carry a piece of his spirit with them.

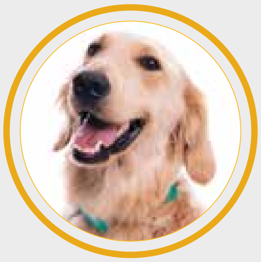
All bodies give out at some point, whether through accident, illness, old age or other cause. We leave behind what we shared with others. Love is the most durable resource, one that persists beyond the grave. It is the thing that makes life worth living and that makes loss more bearable because it fills the spaces left otherwise empty.



Puggle

Birthday:
11-22-17

Breed:
Golden Retriever



Huckleberry

Birthday:
12-10-17

Breed:
Goldendoodle

Follow Puggle and Huckleberry on Instagram **@stjudepaws**

PUGGLE & HUCKLEBERRY

NEWEST ST. JUDE EMPLOYEES OFFER FURRY COMFORT

BY BETSY TAYLOR

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

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

Take the case of 12-year-old Devon, who is at St. Jude undergoing treatment for neuroblastoma. He misses his dog, King, back home, but seeing Puggle makes things better.

"When Puggle entered the room, you saw Devon's world light up, and he became a little more open and engaging, and he wanted to get up out of bed," said St. Jude Child Life Specialist Brittany Reed, who serves as Puggle's handler.

Shandra Taylor, who works with Huckleberry, said the dogs have tangible effects, such as helping patients get through imaging scans without anesthesia. They're also good at encouraging patients to move around after surgery, a crucial part of recovery. "It's so much more than just a social visit. There's something really magical about the presence of a dog," Taylor said.

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

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

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

BY TIFFANY SMITH-FLEISCHMAN

Q & A: TOP TECH EXPERTS WHO FOSTER INNOVATION AT ALSAC

How does a charity that started six decades ago keep in stride with the times? By turning to the experts – in this case, the technology experts. *St. Jude Inspire* caught up with two such people to find out how they're helping foster innovation at ALSAC, the fundraising and awareness organization for St. Jude Children's Research Hospital.

Sarah Gavin • Expedia Group
Vice President, Global Communications

photo credit: Expedia Group

Her connection to St. Jude:

In 2012, Sarah planned an event with Expedia that merged meaningful travel, mommy bloggers and St. Jude. The beach party-themed event at Target House, a patient housing facility for St. Jude, allowed St. Jude moms to mingle with moms who blog, forging connections between the two groups. "I've been hooked ever since," she said.

She's particularly proud of:

Bringing travel and technology to St. Jude through the creation of a 360-degree virtual reality room.

"We had four different patients come in and we had asked them about their dream travel experiences," she said. Armed with that information, Expedia developed live experiences for the patients, taking them to the places they most wanted to see.

One girl told them how much she loved horses, so an Expedia employee — who was a childhood cancer survivor herself — traveled to Argentina to capture the live, interactive experience of wild horses for this patient.

"To hear from this little girl who loves horses, and to bring the experience of wild horses from Argentina… It was just such an honor to be able to do that," Gavin said.

Leaders in other industries should advise ALSAC/St. Jude because:

Sharing across industries enriches all of the organizations involved and the people working within them, Gavin said.

"People go into the experience with the idea that they are going to give. And it's amazing how much you get from it."

His connection to St. Jude:

Three years ago, a network of technology experts in Seattle hosted members of ALSAC for a technology summit. They asked Jeff, who was working at Amazon at the time, to help out.

"I did a half-day workshop about working backward, about being customer-centric," Gelfuso said. And in that short time, he had the opportunity to understand what the ALSAC team was trying to do. He loved "seeing this amazing team working behind the scenes."

From that exchange of ideas, Gelfuso was asked to join ALSAC's Digital Innovation Advisory Council, saying, "I was hooked."

He's particularly proud of:

Helping ALSAC adopt an internal accelerator to develop innovative solutions in a short period of time. He said it was rewarding to see the work pay off.

"Within an established business, it can be hard to transform," Gelfuso said. "I love seeing what they are doing to transform ALSAC, to become a digital-first philanthropic organization of the future."

Leaders in other industries should advise ALSAC/St. Jude because:

"Doing very small things that I take for granted, then teaching or sharing that with ALSAC and the innovation team, has just helped them in ways that blow me away," he said. "I think I've been able to make an impact on the organization, and that's really rewarding. … And they're genuinely just great people, and it's hard not to want to be a part of that."

Jeff Gelfuso • Facebook
Executive Director – Product Design, User Experience, Systems and Tools

LET'S CROSS THAT BRIDGE NOW: HAVING 'WHAT IF' CONVERSATIONS WITH PATIENTS AND FAMILIES

By Justin N. Baker, M.D.

Chief of the St. Jude Division of Quality of Life and Palliative Care, and director of the Hematology/Oncology Fellowship Program

No patient or family wants to get bad news, and no doctor wants to give it. Human instinct tells us to avoid unhappy conversations — so we tell patients, "Let's cross that bridge when we get to it." This can be a natural default that puts off talking about potential negative outcomes in the hope that maybe we'll never have to talk about them at all. Delaying such conversations may ultimately do our patients, their families and ourselves a disservice. When we don't talk about what worries our patients and their families, we leave those worries to rest heavily on their minds. This can weigh them down when they could instead be working through their fears and preparing for what the future might hold.

As a pediatric oncologist specializing in quality of life and palliative care, leaning in to difficult moments is part of my job. But many doctors don't have the same training. Navigating conversations to manage uncertainty is a tricky part of providing patient-centered cancer care. I've seen this as I work with our St. Jude patients and families. For example, the father of one of our patients recently emailed our team to say, "When our son got sick, we were so helpless, and when he relapsed, we were helpless all over again. It was you, and people like you, who patiently helped us understand what it was that we needed to do... Your work is hard work, but it is good work, and we are so grateful that you do it."

To help doctors have "what if" conversations, I recently teamed up with former St. Jude fellow Jennifer Snaman, M.D., and her colleagues at Dana-Farber Cancer Institute, to create a framework for these interactions. Published in *Pediatric Blood and Cancer,* this framework may help empower doctors to address the fears of patients and their families and provide information that patients and families need to understand what may happen.

"While worrying about the here and now, patients and their families can also be occupied with worries about the future, grappling with the prognosis and how to prepare for what might happen," Snaman explains.

In my experience, some of the most common concerns patients and families going through cancer treatment ask me about are:

What if the cancer comes back?

What if the treatment doesn't work?

What if the side effects of treatment turn out to be life-threatening?

Patients and their families want improved communication with their doctor around prognosis. Without clear communication, misunderstandings can creep in, exemplified by research showing most parents of children with advanced cancer and most adolescent and young adult cancer patients expect better disease outcomes than their oncologists. This means that when negative outcomes start to happen, patients and their families can feel blindsided and unprepared for what they now face.

Central to our framework is having “what if” conversations during times of clinical stability or even when delivering positive or “good” news. Even when doctors deliver difficult news clearly and compassionately, the stress of such situations may prevent patients and families from understanding.

Creating opportunities to have “what if” conversations regularly and during more positive interactions may help reinforce and strengthen the doctor-patient relationship and provide opportunities for patients and families to truly grapple with their thoughts and feelings.

“Determining when to involve pediatric or adolescent patients directly in ‘what if’ conversations should take into account the patient’s wishes, with the understanding that communication preferences may shift over time,” Snaman says. “It may also be helpful to involve psychosocial clinicians, other members of the care team or specialists in palliative care in such conversations.” It is also important to normalize these conversations, ensuring patients and families that there is nothing about their current situation that makes us more worried. This can allow space and time for other concerns to be raised.

While many doctors may harbor concerns around talking about prognosis or unpredictable outcomes, these conversations may make patients and their families feel more secure when negative situations unfold. Doctors don’t need to have the answers ready for all the questions or concerns that might come up during these conversations. Sometimes, holding and owning uncertainty is all that we can do. In other circumstances, oncologists can collaborate with other interdisciplinary providers to address specific concerns.

We believe our framework will help doctors achieve their goals for helping patients and families improve their understanding of the prognosis, explore concerns and examine their preferences for care.

A FRAMEWORK FOR ‘WHAT IF’ CONVERSATIONS

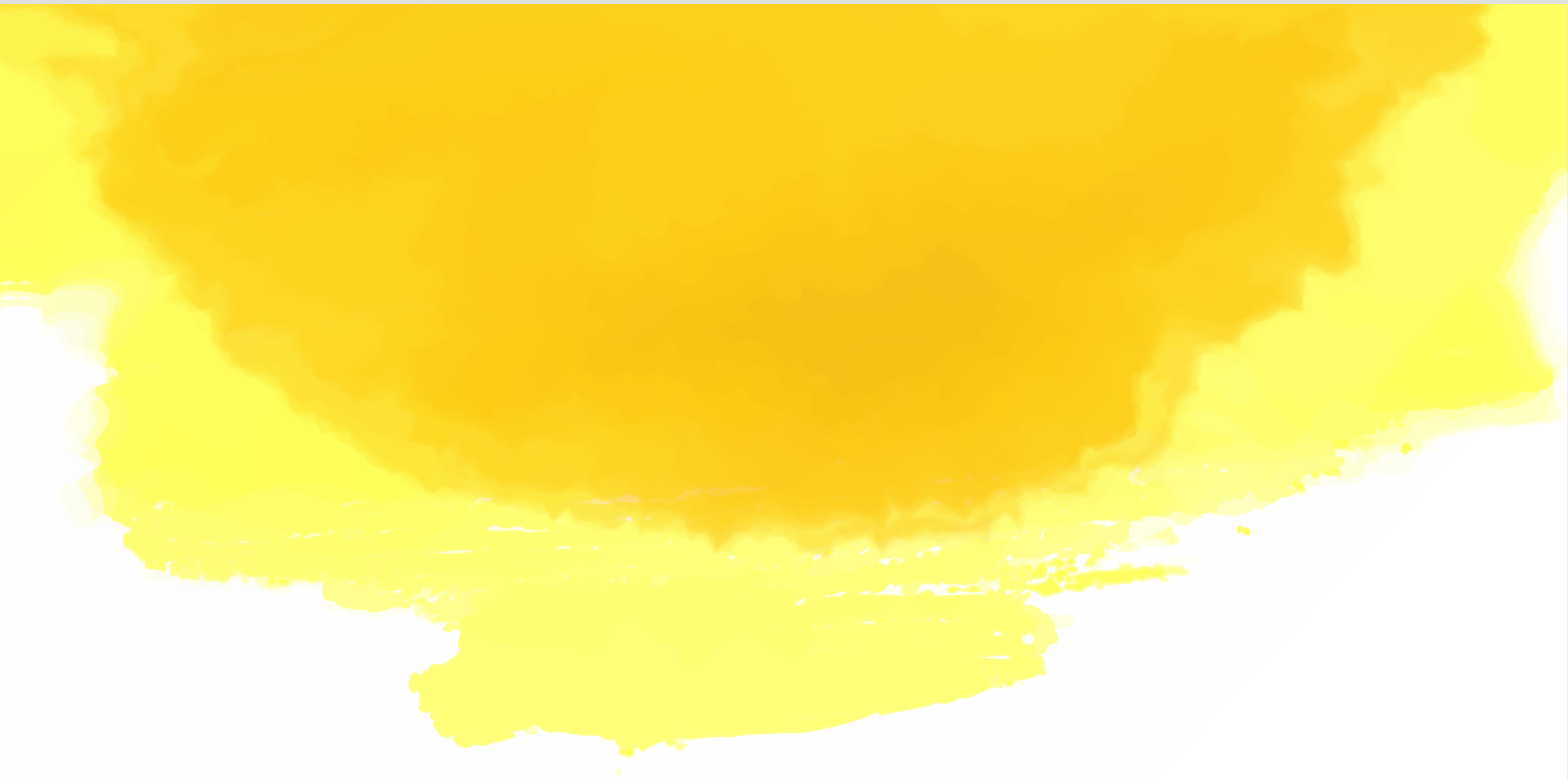
- Introduce and normalize “what if”
- Ask permission to explore “what if”
- **If yes:** figure out what is worrying them
- **If no:** respond empathetically, offer opportunities to talk in the future

- Listen and attend to initial emotions
- Clarify whether additional information would be helpful
- If information is needed: deliver in an honest manner
- Consider introducing ideas about goals and preferences

- Read, name and respond to emotional cues
- Normalize and reassure
- Hold and own uncertainty
- Explore sources of support or strength

- Reassess at regular intervals
- Reaffirm commitment to mutual honesty and respect
- Summarize and plan next steps
- Reassure and return to current situation
- Consider recalling previous “what if” conversations in the setting of changes in a child’s illness trajectory

This article originally published on the St. Jude Progress blog.



WHAT I'M TELLING MY PATIENTS AND FAMILIES ABOUT SUNSCREEN

By Teresa Wright, M.D.

Consulting physician in Surgery at
St. Jude Children's Research Hospital

A recent study published in the *Journal of the American Medical Association* found some chemicals in sunscreens can be absorbed into the bloodstream.

Four chemicals that block ultraviolet rays – avobenzone, oxybenazone, octocrylene and ecamsule – were detectable in the bloodstream in amounts that warrant further investigation. Frankly, it isn't clear if this presents a safety issue, and more study is needed. The study also concluded that sunscreen should continue to be used.

But this study involved adults. So what should parents do for their children?

Because children spend more time playing outdoors, a significant amount of lifetime sun exposure occurs before the age of 18. There is overwhelming evidence that chronic sun exposure and sunburns (particularly in childhood) increase an individual's lifetime risk of all forms of skin cancer, including melanoma (the deadliest form of skin cancer).

TWO TYPES OF SUNSCREEN

There are two ways you can protect your skin from ultraviolet rays. One type of sunscreen is a physical blocker – think of zinc oxide and titanium oxide – that sit on the surface of the skin and block UV rays. The other, called a chemical blocker, allows UV-blocking chemicals to work while being absorbed into the skin.

Although we knew that chemical sunscreen ingredients could be absorbed into the skin, this recent study showed that they can be detected in the bloodstream – which has raised the question of safety. In general, I tell parents to choose sunscreen products that contain physical blocking agents – zinc oxide and/or titanium oxide – and avoid the products containing the chemical ingredients.

WHAT SHOULD I LOOK FOR IN A SUNSCREEN?

Look for a product with an SPF (sun protection factor) of at least 30. Products marketed for children will often have an SPF of at least 50. Look for a product with "broad spectrum" coverage, meaning it protects against both ultraviolet A and B rays from the sun. For younger children and children with very sensitive skin, it's best to select products containing physical blockers. Also, look for products that are sweat and/or water resistant.

HOW SHOULD I APPLY SUNSCREEN?

For maximum protection, sunscreen must be used correctly. Do not skimp! It should be applied generously at least 15 minutes before going outdoors. It takes approximately one ounce (six teaspoons) of sunscreen to adequately cover an adult of average size. Sunscreen should be reapplied at least every two hours, but more often when swimming and sweating.

CAN I APPLY SUNSCREEN TO MY BABY?

Infants under the age of 6 months should be kept out of direct sunlight as much as possible. Sunscreens containing physical blockers can be applied to small areas of exposed skin, such as the face or back of the hands. Products that come in a stick are especially easy to apply to delicate areas, such as the nose, cheeks and ears.

ARE SPRAY SUNSCREENS SAFE?

Recently, there have been concerns regarding the safety of spray sunscreens due to the possibility of inhaling the product during application. Until the FDA has conducted a more thorough investigation, many organizations are recommending avoiding the use of spray sunscreens on children. If you have nothing else available or decide to continue using these products, please do not spray the product directly on your child's skin. Instead, spray it into your hand, well away from the child's face, and rub it onto the skin.

WHAT ELSE CAN I DO TO PROTECT MY CHILD?

More than one million new cases of skin cancer are diagnosed each year in the United States, and roughly one in five Americans will develop some form of skin cancer during their lifetime. In 2019, the American Cancer Society estimates there will be nearly 95,500 new cases of melanoma.

If you don't have the physical blocker type of sunscreen handy, that doesn't mean you should not use sunscreen at all. Protecting your skin from sun exposure is more important.

Remember to set a good example by protecting yourself. Many of us grew up in a time when sunburn was simply accepted as part of spending time outdoors. Now that we have better information about the harmful effects of excessive sun exposure, we should make every effort to protect ourselves and our children as much as possible.

Teresa Wright is Division Chief of Pediatric Dermatology at Le Bonheur Children's Hospital. She is a consulting physician in Surgery at St. Jude Children's Research Hospital and a member of the St. Jude Pediatric and Adolescent Melanoma Referral Clinic medical team.

How Do I Protect My Child from Excessive Sun Exposure?

Proper sun protection has several components:

1

Avoid deliberate sun bathing and indoor tanning.

2

Seek shade whenever possible (especially between 10 a.m. and 4 p.m.).

3

Wear protective gear, including clothing, a wide brimmed hat and UV protective sunglasses.

4

Use broad spectrum sunscreen regularly and correctly.

This article originally published on the St. Jude Progress blog. To read more from doctors and researchers, visit **stjude.org/progress**.

A PATHWAY TO HOPE AND INDEPENDENCE

A COUPLE WITH AN AFFINITY FOR CARNIVAL CRUISE LINE DONATES TO ST. JUDE IN HONOR OF EMPLOYEES WHO HAVE HELPED THEIR SON

By Thomas Charlier

D.J. Powell walks along the Pathway to Hope during a recent visit to St. Jude. As frequent cruisers, the Powell family appreciates the special attention that Carnival Cruise Line provides for D.J., who is autistic. The Powells show their appreciation for Carnival and its employees by purchasing bricks in honor of Carnival employees.

David and Linda Powell have no personal ties to St. Jude Children's Research Hospital, but they've managed to build quite a legacy on the Memphis campus.

And they did it brick by brick.

Over the past seven years, the Mississippi couple has purchased 10 inscribed bricks on the Pathway to Hope, raising over $13,000 for St. Jude while adding to the sidewalk coursing through the grounds.

What makes their connection to St. Jude truly notable, though, is how it began. The relationship quite literally was born at sea.

Since the 1980s, the Powells have traveled much of the world on Carnival Cruise Line. Their devotion to Carnival only deepened as they saw the special attention ship crews provided for their autistic son, D.J.

Because Carnival is a major St. Jude partner – having committed $33 million to the mission since 2010 – the Powells decided to donate to St. Jude to thank the company.

Now 28, D.J. has been on 83 cruises totaling 533 days, meaning he's spent about a year and a half on Carnival ships. "They treat him like a celebrity. You'd think he owned it when he gets on board," Linda said.

The Carnival crews provide a safe, comfortable environment in which D.J. can enjoy a measure of independence. His confidence grew as he learned to use his room keys, for instance, and how to maintain a schedule.

"Every day, autism reminds D.J. what he can't do," Linda said. "Cruising Carnival reminds him what he can do."

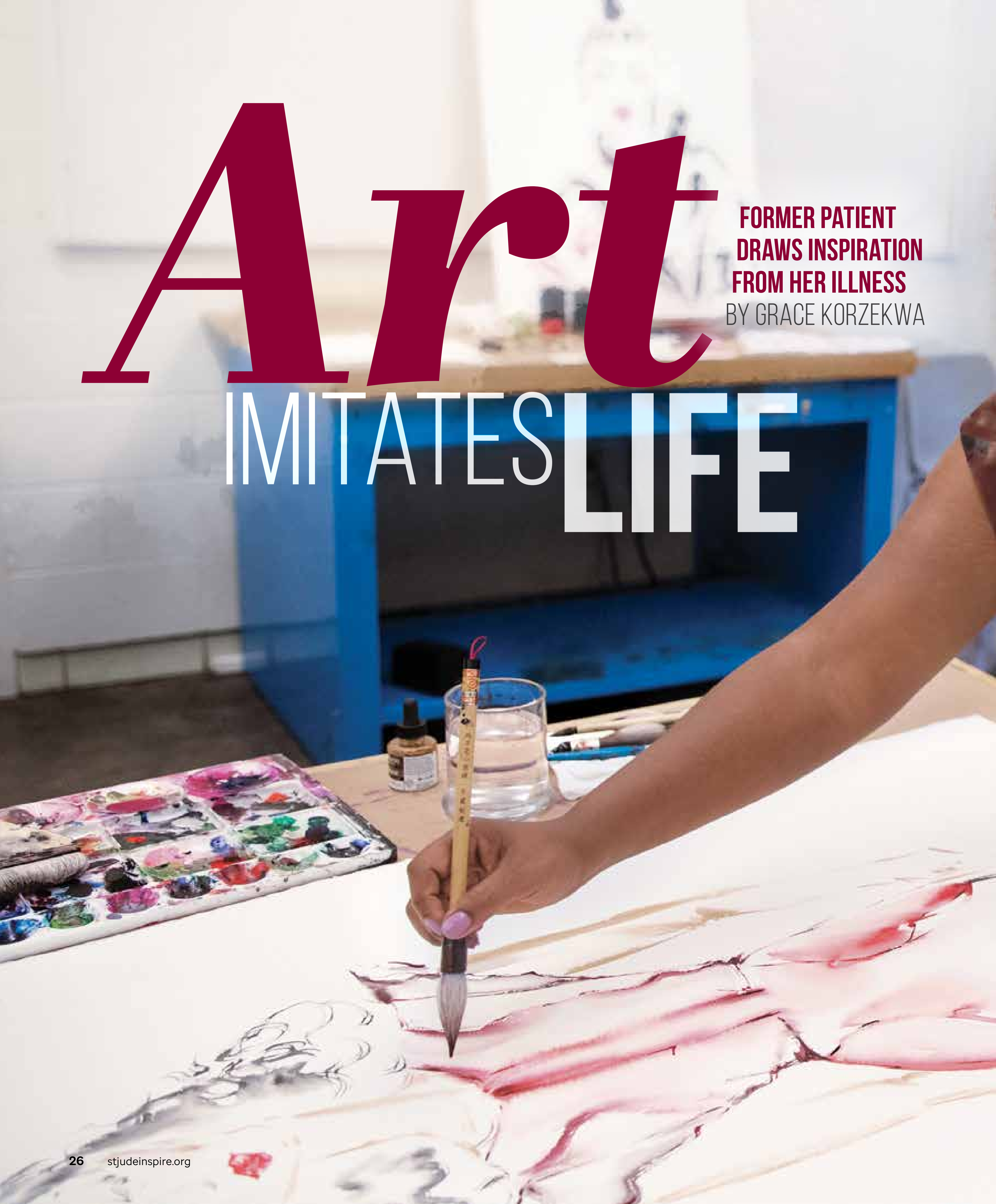
Already aware of St. Jude and its work, the Powells saw reminders of it on Carnival ships, where guests can "Groove for St. Jude" and buy specialty items benefiting the research.

The Powells saw the Pathway to Hope as a fitting venue for their support. Composed of more than 14,000 bricks purchased by donors, it has generated $17.4 million for St. Jude since 2007.

During a recent ceremony at St. Jude, Linda presented a brick to Pierre Camilleri, hotel director on the Carnival *Mardi Gras*, honoring him for his help with D.J.

It was well received. "That man had tears in his eyes when he walked up there to get his brick," Linda said.

Fill each step of the journey with hope. Engrave and dedicate a brick on our campus pathway. ***stjude.org/brick***



Art IMITATES LIFE

FORMER PATIENT DRAWS INSPIRATION FROM HER ILLNESS

BY GRACE KORZEKWA

Kris Keys will show you who she is through her designs and illustrations. And her mom Gwen will tell you how hard Kris worked to get there.

"Kris does not brag on herself," said Gwen. "But that's just her. She puts her heart and soul into her paintings. I just look at her videos and see those paintings come to life."

Kris was born in the 1980s with a low blood count. Her family physician described her blood cells as looking "crazy." Gwen became a fierce advocate for Kris. Enter St. Jude Children's Research Hospital, fortunately located in the Keys' hometown. Most often known for researching and treating childhood cancer, St. Jude also began treating blood disorders from its very founding in 1962. A physician identified the rare blood disorder affecting Kris as hereditary elliptocytosis.

The genetic disorder wouldn't always be debilitating, but there were several health crises ahead for Kris. Her St. Jude care team taught her family how to watch for the signs.

While Kris was in treatment, St. Jude nurses introduced her to art. Gwen encouraged her to pursue her passions. Instead of shrinking from the world, Kris eventually traveled it, learning as much as she could, even as she was managing a chronic illness.

After high school, Kris told her mom she wanted to do an internship in New York City. Gwen told her there was no way, but Kris had already accepted. "This kid was like, 'It's gonna happen.' And I'm just sitting at home, dollar signs swirling around my head, trying to figure out how I'm going to help this kid get to this point."

Turns out, Gwen didn't need to worry much. Kris found a place to stay through someone at the Keys' church. "I learned

Fashion designer, artist and former St. Jude patient Kris Keys paints her way around the world doing live fashion illustrations commissioned by both major brands and individuals.

something about faith from her," said her mom. "Because she was so confident that this was going to happen. And it did."

When Gwen got a chance to visit Kris in New York, she had hardly ever been out of Tennessee. "It was like I was the 2-year-old and she was leading me around. I got to experience some places I would never ever go. It was just this child's confidence and faith that said, 'It's gonna happen, Mom.' And I said, 'OK, Kris.'"

And then, New York wasn't enough. Kris was accepted to a design program in London.

Kris made it to London to take foundation classes, then began courses at the London College of Fashion learning the basics of garment construction and how to tell a story through clothing.

Now, Kris is a full-time fashion designer and illustrator. She designed a womenswear collection called Hematology, using the very cells that run through her body as inspiration.

"I worried about her a little bit but year after year I was able to let it go," Gwen recalled. "I knew she was able to take care of herself, and she would call me when she needed advice."

Gwen left the country for the very first time to visit Kris in Europe.

When back at home, she watched from afar, closely but not too closely, allowing Kris to find her way. "I felt like I was on the trips with her every step of the way. I learned stuff that I probably didn't learn in Geography."

Kris continues to make art all over the globe.

And her mom is still her biggest advocate.

Scan to learn more about Kris Keys and watch her art in motion. **stjude.org/kriskeys**

gift guide

Give a gift that gives back from the St. Jude Gift Shop.

1.

Red Leather Mini-Journal

Fill this 192-page, lined-paper, refillable notebook with all your thoughts and support the lifesaving mission of St. Jude Children's Research Hospital. *#1139RED00* **$20**

2.

Lapel pins

Show your support for St. Jude with these magnetic lapel pins. Available in silver, gold or red. *#2911SLV00, #2911RED00, #2911GLD00* **$5 each**

3.

Buffalo St. Jude Hoodie

Bundle up in buffalo print with this warm and cozy St. Jude hoodie. *#9102GRY* **$48**

4.

Patient Art Mesh Technical Trucker Hat

Show off your love for the mission of St. Jude with this mesh sublimated design performance hat that features St. Jude patient artwork. *#582700000* **$19.99**

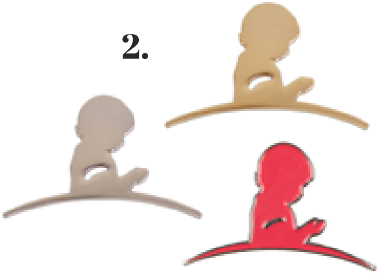
5.

Grateful Mug

Remember to start each day with a grateful heart, and a cup of coffee with this 18 oz. mug. *#202400000* **$16**

1.

2.



3.

4.

5.

stjude.org/giftshopinspire

Celebrating 20 years of Target House

BY BETSY TAYLOR

Target House offers a free home away from home for children receiving treatment at St. Jude. With the help of its vendors and celebrity partners, Target has provided comfort for families and millions in support to St. Jude.

Maria remembers her son Carlos was 6 years old that chilly day in 1997 when she bundled him up and brought him to the construction site in Memphis. He donned a red hardhat, stood with the other children and helped shovel dirt for the groundbreaking of Target House.

The family had been living in a rental home in a nearby suburb while Carlos was treated for acute lymphoblastic leukemia at St. Jude. Even then, so far from their home in El Salvador, they'd felt surrounded by love. But this ceremony, remembers Maria, represented something wonderful.

"Just knowing other families would have a true home base. It felt exciting."

Carlos got to keep the shovel — and he still has it at his grandmother's house in El Salvador, a keepsake of a day filled with promise.

Anna, Missouri, acute myeloid leukemia

Sweet 16 at St. Jude

Anna and her mom, Jane, were getting a jump on plans for Anna's 16th birthday when the pediatrician called. Anna's labs were back, and it wasn't anemia making her tired.

Jane remembers the doctor saying, "I've got terrible news. Anna has leukemia, and there's no question. You need to get home and pack a bag because you're going to Memphis."

Anna and her mom arrived at St. Jude in October 2017, and Anna began chemotherapy. The family settled into Target House.

For Anna's 16th birthday, Jane marshaled a team of moms to help her pull off a party in the newly-renovated dining room at Target House. There were paper lanterns hung from the ceiling, a giant cookie cake and friends who drove five hours through rain to be with Anna. "The day couldn't have been better," said Anna.

Leah, Guyana, acute lymphoblastic leukemia

Traditions old and new

Leah and her family are far from their home in South America while she undergoes treatment for acute lymphoblastic leukemia, but their kitchen at Target House smells like home. Her mom, Anita, makes family favorites, such as curry chicken and eggplant roti. Leah always wants to help. "Mom gives her a piece of the dough so she can play with it while she cooks," said her dad, Leon. Keeping tradition is important, but celebrating new traditions at Target House has also been a gift. The family decorated their door for Halloween, and the kids loved the buildup to the holiday. "It was quite an experience," said Leon. "They loved it and enjoyed it all."

"Treatment is better having everyone together," said Anita. "Yes, they are so far away from home, but having everyone here makes it easier for not only the family, but for the patient, and that's a blessing."

TAKING THE CAKE

Cakes are the exclamation mark at the end of a good meal and practically synonymous with celebration. For Carly, 21, of South Dakota, making and enjoying food has special meaning. In 2018, treatment for acute myeloid leukemia took away Carly's taste for food and ability to stand long enough to prepare it. Today, this former chef reclaims her love of cooking, dish by joyously prepared dish.

CARLY'S CELEBRATION CAKE: ITALIAN LEMON CAKE WITH BOILED ICING

CAKE
2 cups all-purpose flour
1½ tsp baking powder
½ tsp baking soda
1 tsp salt
10 tbsp butter (room temp)
1¼ cups white sugar
3 eggs
1 tsp vanilla extract
⅔ cup milk
3 tbsp lemon zest
⅓ cup fresh lemon juice

FILLING
8 oz. mascarpone (room temp)
½ cup whipping cream cold
¼ cup powdered sugar
1 tsp vanilla extract
3 tbsp lemon zest

ICING
1½ cups sugar
⅔ cup water
3 lemons, juiced and zested
3 egg whites
pinch of salt
2 tsp limoncello

TO MAKE THE CAKE, preheat oven to 350° F. Butter and flour two 8-inch round pans. Sift together the flour, baking powder, baking soda and salt. Mix fresh lemon juice and milk in a small bowl and set aside. Pulse sugar and zest of a lemon in a food processor until zest is incorporated. Cream butter and sugar in a stand mixer using a paddle attachment. Add vanilla and eggs one at a time, mixing until incorporated before adding the next. Scrape the bowl down. Add flour and milk mixtures to the butter in alternating batches. Once well-mixed, divide evenly between two pans. Bake for 30-35 minutes.

TO MAKE THE FILLING, gently combine lemon zest, mascarpone, vanilla and powdered sugar. Whip the cream on high until stiff. Gently fold whipped cream into mascarpone mixture (in thirds) until thoroughly incorporated.

TO MAKE THE ICING, combine sugar and water in a saucepan over medium high heat. Simmer until syrup reaches the soft ball stage. Beat eggs (at room temp) and pinch of salt until they form soft peaks. Combine lemon juice, limoncello and lemon zest. Remove syrup from heat and add the lemon mixture. In a slow stream, pour the boiled syrup into the egg whites while beating at medium high speed. Continue to beat egg whites until stand mixer bowl is cool to the touch.

TO FINISH, spread the filling onto one cake, then stack the remaining layer on top. Pipe the icing onto the top layer and finish by lightly torching.

*Visit **stjude.org/carly** to see Carly prepare her Italian lemon cake and three other favorite dishes. Learn tips and watch Carly share stories from her life.*

St. Jude patient **Tam**,
brain cancer

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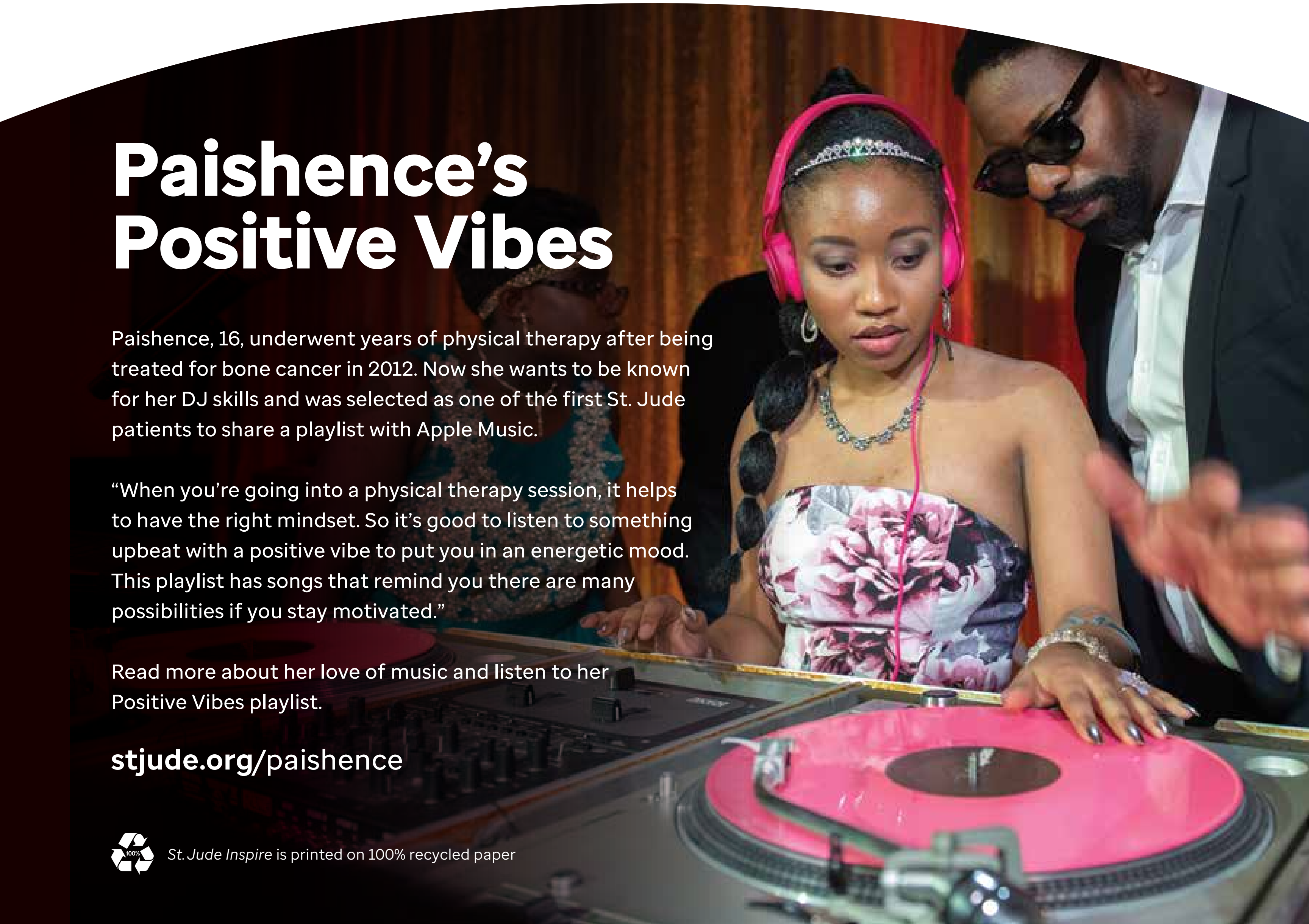

Paishence's Positive Vibes

Paishence, 16, underwent years of physical therapy after being treated for bone cancer in 2012. Now she wants to be known for her DJ skills and was selected as one of the first St. Jude patients to share a playlist with Apple Music.

"When you're going into a physical therapy session, it helps to have the right mindset. So it's good to listen to something upbeat with a positive vibe to put you in an energetic mood. This playlist has songs that remind you there are many possibilities if you stay motivated."

Read more about her love of music and listen to her Positive Vibes playlist.

stjude.org/paishence

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