# 

## Life doesn't frighten me'

Adam Cruthirds' next goal: raise \$1 million for the hospital that saved his life

**Global Goals** 

fighting childhood cancer worldwide

Obesity

ST. JUDE

a new foe after treatment **Darius Rucker** 

raising his voice to give back

**Gene Therapy** 

donors see promise for other cures







met the young man you see on the cover soon after he arrived at St. Jude Children's Research Hospital. Inspiring seems like such an inadequate word to describe Adam but it's fitting in so many ways.

Inspiring because he persevered, despite the fact he couldn't take normal chemo and doctors had to devise an alternative treatment for him.

Inspiring because he appeared with me at a press event to promote the 2014 St. Jude Memphis Marathon and, to my utter shock, announced he'd run the half marathon the following year. Never mind being treated for acute lymphoblastic leukemia or his disintegrating hips.

Inspiring because he crossed that finish line and so many others – literal and metaphorical – since we met.

Inspiring because as other kids his age are singularly focused on college, Adam, 21, isn't just pushing toward a college degree. He's about to fulfill a promise to raise \$1 million for St. Jude Children's Research Hospital which saved his life.

This is the kind of special person you'll meet in the inaugural edition of *St. Jude Inspire* and in each subsequent edition. And once you get to know Adam and Nick and Aubrey through the pages that follow, there'll be no doubt why we chose the magazine's name. But it could just as easily be named *Heroes* for the St. Jude doctors, researchers and medical professionals you'll hear from, directly, in their own voices. Their cutting edge work will be an important focus of every edition.

You'll also be introduced to some other very inspirational people – heroes themselves – whose donations of time, money and emotional support make the mission of St. Jude Children's Research Hospital so – and here's that word, again – inspiring.

St. Jude Inspire is for and about each of you.

pul

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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** 





DARIUS RUCKER TALKS ABOUT MOM'S ADVICE AND HOW ST. JUDE PATIENTS INSPIRE HIM

BY DAVID WILLIAMS PHOTOGRAPHY BY KATIE KAUSS AND KEITH GRINER

# DARIUS RUCKER'S RISE AS A COUNTRY MUSIC STAR OVER THE LAST DECADE HAS BEEN ABOUT MUCH MORE THAN HIT SONGS AND SOLD-OUT SHOWS. HE'S ALSO BECOME ONE OF COUNTRY'S MOST GIVING PERFORMERS, SUPPORTING ST. JUDE CHILDREN'S RESEARCH HOSPITAL WITH HIS TIME AND TALENTS.

His Darius and Friends benefit concert in Nashville has raised more than \$2 million. He's also made multiple visits to the hospital, joined the monthly donor acquisition program "This Shirt Saves Lives" and in 2014 recorded the song "Possibilities," which was inspired by patient Brennan and co-written by the boy's father.

St. Jude Inspire talked to Darius about why he supports St. Jude and what inspires him most about the young patients he's met.

#### You've supported St. Jude for more than a decade now. What's been most meaningful for you?

**DR:** The kids I get to meet and hang out with and become friends with, and I've known for a time now. To see them year after year, doing better, doing great. I always say, once I visited St. Jude, I wanted to do something, and I've been doing something ever since.

#### Do you remember how your first visit to St. Jude came about?

**DR:** I had just started in country music. I had finished a Hootie (& the Blowfish) tour and I was a baby act on a Brad Paisley-Dierks Bentley tour. I was the first act. I was hanging out with Dierks and Brad, and Dierks said he was going to St. Jude. He asked if I wanted to go. I said, 'Yeah, I'd love to go.' And we went, and I was moved.

#### Were you familiar with St. Jude before visiting?

**DR:** Totally. I knew about the hospital. Danny Thomas was one of my grandmother's favorite actors, so I knew about the hospital and all the great things (St. Jude founder) Danny Thomas and (his daughter) Marlo Thomas were doing. I knew about it, but you know, I didn't know what I could do until I went. I was like, well, I'll figure out something.

#### You're a giving person, in your life and career. What are the roots of your philanthropy?

**DR:** My mom raised me that way. We didn't have much, we were poor growing up. She was a nurse, and trying to raise these kids. We didn't have much, but she always instilled in us that if we could help somebody, we should.

#### When you visit St. Jude, are you struck by how strong the patients seem, despite what they're facing?

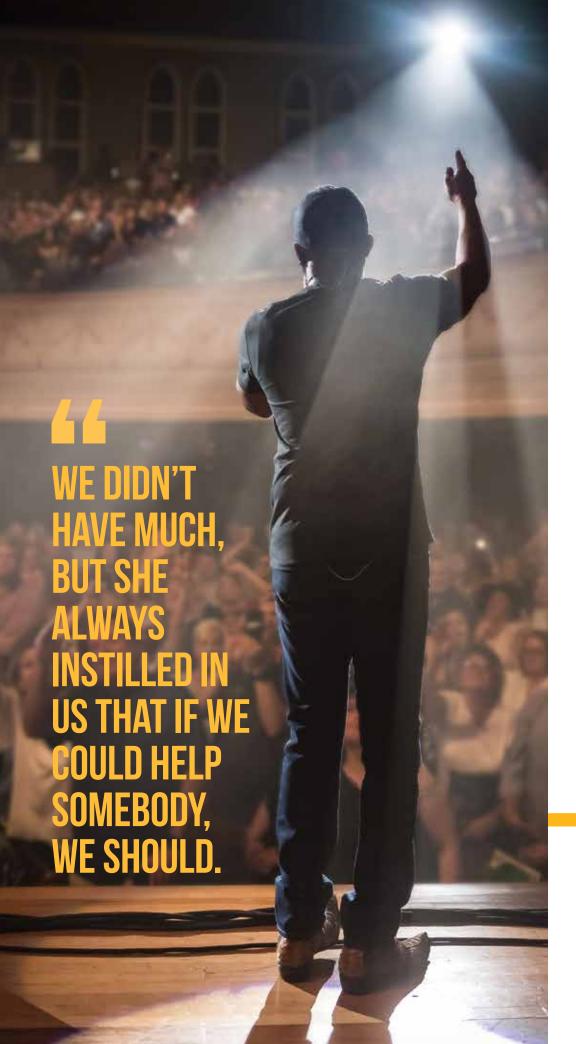
**DR:** You just said it, man. They're so strong. At the hospital, and even outside of the hospital, when you meet these kids, that's the one thing you really take away. They're so strong.

You talk to the doctors and the parents, and you find out what's wrong with them. Then you're laughing and talking with this kid. And I'm saying to myself, 'Could I be this strong if I was in the same situation? Could I be laughing and talking right now?'

That gives me such a hope for them, and gives me such a happiness to be helping St. Jude letting these kids be this happy.

#### How do you explain St. Jude to people who aren't familiar with the hospital, its methods and mission?

**DR:** When I talk about St. Jude, the two things I stress that are just amazing to me, is first how a parent never gets a bill (from St. Jude). And when I explain it to people, I go, 'They don't not just get a medical bill.



They don't get a bill for their travel. They don't get a bill for food. They don't get a bill for lodging.' The other thing I tell people is, every time St. Jude comes up with something that works, they don't hoard it. They tell the world, this is what we're doing, this is working. I get chills just talking about it. I think that's amazing.

#### Your *Darius and Friends* benefit concert has been a great success. How's that feel?

**DR:** It's such an amazing thing. We don't announce who's going to be there until two weeks out or something. And we sell out in minutes, every time.

We were at the Wildhorse Saloon. Then we moved to the Ryman, and we're talking about we may have to move to someplace even bigger than that. And it's just awesome to have an event like that that we know we can do every year.

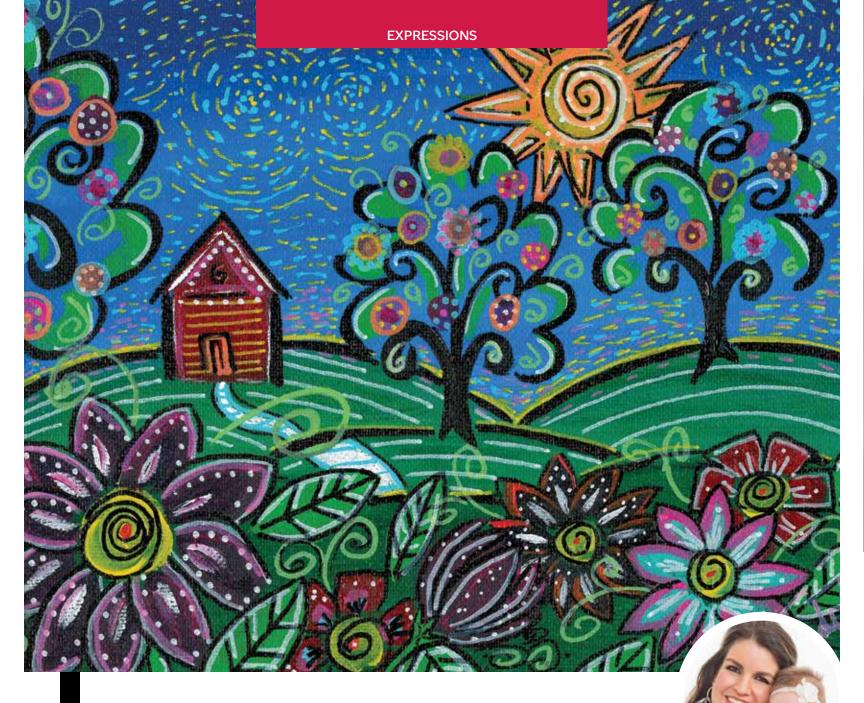
And the thing, to me, that makes it even better is, we sell out before we even announce who's coming. Then all these big names come. Everybody we've ever asked has said yes.

#### Those are magic words, aren't they? St. Jude.

**DR:** That's such a great way to say it. It's a magic word.



Scan the QR code with your smartphone or visit **stjude.org/dariusvideo** to watch a video of Darius Rucker performing "Possibilities," with help from St. Jude patients.



ART PLAYS A BIG ROLE IN THE PATIENT EXPERIENCE

Art therapy is often used to reduce stress or anxiety, explore complex feelings, manage side effects, and improve quality of life for patients. Patient art is also used by ALSAC, the fundraising and awareness organization for St. Jude, to raise awareness and support. The artist behind this whimsical painting, Tayde

Cruz Dodds, is a three-time St. Jude survivor and an employee of ALSAC. She has the unique role of working with patients on artwork used in fundraising efforts.

"I love art and I hope patients can find a new passion in addition to it being therapeutic for them," Tayde says. "Art can just give them a different perspective of life, even for a moment. Older patient artists love to learn that their skills can help St. Jude, and seeing their creations on different marketing materials, decorations and walls brings a huge smile to their faces and mine too."

Pictured above: St. Jude survivor Tayde Cruz Dodds and her daughter



### A GLOBAL CHALLENGE

## NEW ST. JUDE-LED STUDY SHEDS LIGHT ON THE SCOPE OF CHILDHOOD CANCER WORLDWIDE

#### BY THOMAS CHARLIER

Despite impressive progress in treatment over the past half-century, childhood cancer still poses a major global health scourge in terms of the lives it cuts short and the lasting disabilities it causes, St. Jude Children's Research Hospital investigators said in a groundbreaking study.

Traditional analyses of pediatric cancers focused on the number of cases and deaths, with both figures ranging in the hundreds of thousands annually. But the new study, using a different metric, estimated that in 2017 children worldwide lost a total of 11.5 million years to disability or death from cancer, with low- and middle-income countries in Asia, Africa and Central and South America impacted most severely.

With the measure known as disability-adjusted life years – the sum of the years of lives lost and years lived with disability – health officials now can more accurately compare the burden of pediatric cancer with such other diseases as tuberculosis and HIV infection, researchers

say. That knowledge could help in establishing policy priorities.

The study was led by Dr. Lisa Force of the St. Jude Department of Global Pediatric Medicine, who was first and corresponding author, and Dr. Nickhill Bhakta, of the same department. It appears online in Lancet Oncology.

"By looking at a different metric, disabilityadjusted life years, we can now show for the first time that the burden of disease due to childhood cancer is significant and underappreciated in both the cancer and child health communities," Bhakta said.

Last year, St. Jude joined with the Institute for Health Metrics and Evaluation at the University of Washington to come up with better estimates of the childhood cancer burden. The institute, with collaborators in some 150 countries, provides estimates for 359 diseases and injuries worldwide in what is known as the Global Burden of Disease study.

The St. Jude analysis builds on data collected in the 2017 global burden study. It found that of the 11.5 million disability-adjusted life years lost, 97.3 percent resulted from cancer deaths at young ages.

The report comes more than a year after St. Jude launched a \$100 million initiative to bring cancer care within reach of more of the world's children. It also follows the announcement last September of a five-year collaboration between St. Jude and the World Health Organization to raise survival rates worldwide to 60 percent for six of the most common pediatric cancers.

The global challenges of treating childhood cancer can be not only medical but cultural, Daniel Mckenzie, executive director of Kidzcan Children's Cancer Relief in Zimbabwe, said during a 2018 visit to St. Jude. Addressing members of ALSAC, the fundraising and awareness organization for St. Jude, he said the majority of people in his country live in



Total number of years children worldwide lost to disability or death



Percentage of life years lost resulting from cancer deaths at young ages.



Percentage of worldwide pediatric cancers occuring in low- and middleincome countries

# The global challenges of treating childhood cancer can be not only medical but cultural

rural areas and are less likely to be served by traditional medical facilities.

Mckenzie said his two visits to St. Jude and ALSAC have been "like coming to receive an energy boost," because of what he's learned. "It's what you're teaching us that we're taking back," he said. "You might not know the name of the child, or be able even to pronounce the name of the village where the child comes from, but what you're doing here has an impact on that child."

St. Jude, founded in 1962, has led the way in raising the survival rate for childhood cancer from 20 percent to more than 80 percent in the U.S.

But more than 90 percent of pediatric cancers occur in low- and middle-income countries, where access to care often is limited and many kids go undiagnosed.

Other authors of the study include Dr. Christina Fitzmaurice, of the University of Washington, along with more than 130 members of the Global Burden of Disease 2017 Childhood Cancer Collaboration.

Studies like this are made possible by generous supporters like you. **stjude.org/donate** 

# COLLABORATION IS THE KEY TO FIGHTING CHILDHOOD CANCER WORLDWIDE

#### By Carlos Rodriguez-Galindo, M.D.

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

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

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

#### THE BURDEN OF CHILDHOOD CANCER

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

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

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

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



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

#### LAUNCHING OUR MOONSHOT

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

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

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

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

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

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

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

#### **COLLABORATION IS KEY**

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

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

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

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

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

# 

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

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

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

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

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

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

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

# THE HPV VACCINE CAN PREVENT MORE THAN 31,000 CANCER CASES A YEAR. THIS IS WHY I CARE SO MUCH.

#### By Robin Mutz, MPPM, BSN, RNC, NEA-BC

Chief nurse executive and senior vice president at St. Jude

One of my dear friends recently passed away because of treatment-related complications of stage 4 cervical cancer. When her husband called me with the news, I knew what that meant. Every year in the United States, the human papillomavirus (HPV) causes 33,700 cancers in men and women. The HPV vaccine can prevent most of the cancers (about 31,200) from ever developing. Here are five things to know about HPV and cancer.

1

The Centers for
Disease Control
and Prevention
(CDC) recommends
the HPV vaccine for
boys and girls.

2

HPV vaccination
can be started
as early as age
9, but is typically
initiated at the
adolescent checkup with other
immunizations.

3

Vaccination is also recommended for girls aged 13 through 26 years and boys aged 13 through 21 years who have not yet been fully vaccinated.

4

More than 31,000
cases of cancer could
be prevented with HPV
vaccination each year.
Getting vaccinated
early protects children
long before they're
exposed to HPV.

5

While the HPV vaccine

works best with adolescents, the FDA recently expanded its approval for use in males and females aged 27-45 who haven't received the vaccine.

My dear friend never had the opportunity to receive the vaccine. When her son went to his physician to get the HPV vaccine, his doctor told him the vaccine was only for girls. There is so much misinformation about HPV and the vaccine. As health care providers, we are obligated to educate our communities, health care providers, third party payors and legislators. Everyone should have the opportunity of many more reunion weekends, not have life halted from something that is preventable.

### **OBESITY: THE SIDE EFFECT OF** THERAPY WE DON'T CONSIDER

#### By Emily Browne, DNP, RN, CPNP

Director of the Transition Oncology Program

besity is one of the consequences of treating childhood cancers like acute lymphoblastic lymphoma (ALL). Which raised a question

What do you do when your treatment works, but then causes another health concern? Our study, published in CANCER, probes the causes of this outcome and ways to address it.

#### TREATING OBESITY IN CHILDREN WITH CANCER

Our research revealed that children with ALL begin to gain weight early on during remission induction treatments. Obesity may contribute to a variety of health problems, including high blood pressure, decrease in bone health, heart disease, diabetes, higher rate of infection and other complications. Patients' height development was also adversely affected.

#### WHY WERE PATIENTS BECOMING OBESE?

Medications like glucocorticoids, a steroid medication used to fight inflammation and immune system problems and important in ALL therapy, will increase appetite and promote fat production. Couple that with the side effects of chemotherapy: nausea, fatigue and chronic pain - you're also less likely to eat healthy meals and much less likely to engage in proper exercise.

In addition, because of the state of the patients, parents and guardians tend to be more permissive in what their children eat. Many times, it's difficult to simply get a patient undergoing chemotherapy to eat anything.

#### **INTERVENE WITH PATIENT AND FAMILY EARLY**

Our data suggest that early intervention is key. This

means starting a dialogue with the patient and their family during remission induction treatment.

"We want to create a multidisciplinary approach in working with patients and their parents, including meeting the family where they are and finding when they want to or are ready to make some changes," corresponding author Hiroto Inaba, M.D., Ph.D. said. "But the changes have to be realistic. They're only as effective as the patient's ability to maintain them."

When treatment begins, we intervene with a multidisciplinary team of oncologists, nurses, dieticians, physical therapists, psychologists and endocrinologists to put together a plan to decrease likelihood of weight gain during treatment.

More study is needed to address the height consequences of therapy. We recommend patients showing sign of short stature get evaluated for growth hormone deficiency.



... the changes have to be realistic. They're only as effective as the patient's ability to maintain them.

We are hoping that new treatment options can decrease the intensity of chemotherapy, but we continue to collaborate with multiple departments to help ensure our patients have good quality of life in survivorship.





## KIDS RULE THIS HOUSE

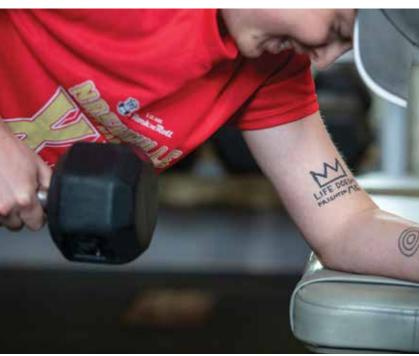
Chip and Joanna Gaines came to St. Jude for a garden-themed party hosted by our long-time partner Target, and revealed a new playhouse at Target House built especially for the kids of St. Jude. It was the latest show of support for St. Jude from the Gaineses, who rose to fame on the HGTV series Fixer Upper and are the founders of homeand-lifestyle brand Magnolia. In 2017, Chip and Joanna teamed up with Target to renovate the dining room at Target House, the long-term lodging facility for St. Jude patients and families. The couple has helped raise more than \$1.7 million for the kids of St. Jude.



View more photos at **stjude.org/playhouse**.









# ADAM'S AIM

FORMER PATIENT HAS A MILLION REASONS TO PUSH HIMSELF ACROSS THE FINISH LINE

BY THOMAS CHARLIER • PHOTOGRAPHY BY MIKE BROWN



s a brisk morning ripens into a glorious day, Adam Cruthirds gulps down a handful of medicine and supplements and soon is jogging toward Downtown Memphis, his steady gait giving no hint that his hips have been rebuilt and his body is still reeling from more than 1,000 chemotherapy doses.

Block by block, Adam pushes ahead, accompanied by three supporters. Not usually one to hold back, he nonetheless heeds the advice of his running coach.

"There's no reason to push – we can't

overdo it," Lisa Sanchez-Sullivan had told him. "You know when it doesn't feel right."

Three miles into the run the group does come to a halt, if only momentarily. Within sight of St. Jude Children's Research Hospital, they pose for a selfie and turn around for the return leg.

St. Jude is what this run is all about, anyway. Adam is training as a St. Jude Hero, raising money through a slew of running and cycling events, all leading up to his biggest fitness test to date: the St. Jude Memphis Marathon® in December.

TOP LEFT: With the help of his caregivers at St. Jude, Adam has embarked on a training program in preparation for the St. Jude Memphis Marathon®.

BOTTOM LEFT: "Life Doesn't Frighten Me" is tattooed on his arm, from the poem written by Maya Angelou. The other tattoo features three circles, each one representing a close friend who passed away at St. Jude.

ABOVE: Adam prepares for a bicycle ride with supporters during his continuing campaign to raise money for St. Jude. For the 21-year-old Adam, the events represent a special type of endurance — both physical and mental. They're part of a marathon effort, if you will, to collect dollars to symbolically repay the hospital that saved his life.

Toward that end, he's raised more than money. He's raised an army – Adam's Army, as it is known. In just four years, this international group of supporters has generated more than \$800,000 in donations to St. Jude.

Adam's goal now is to push that total to \$1 million. Whether he achieves it by the end of this year — his preference — or by the time he's 26 and is officially considered cured, he's sure of the outcome.

"It will happen," he says.

#### AN OVERWHELMING DISEASE

Cancer is nobody's idea of a day at the beach, but Adam, with metaphorical flourish, has a way of describing it like that. Except in his telling there's a "little tsunami" involved.

Life before the disease, he says, is like sitting in the sand, enjoying the sunshine and the view of the ocean. All of the sudden cancer, in the form of a large, powerful wave, engulfs its victims and sweeps them out into the sea, far from their past lives, and tosses them around in dangerous currents.

"And then, after everything, it kind of just lays you back on the beach to a different life, a life that you didn't really know existed," he says.

Adam can speak to the turbulent tides and upheavals attending a cancer ordeal. His began in late July 2014, when he was just 16 and in the middle of what he would later call the best summer of his life. He had trekked to Germany with a youth group, taken a beach vacation with his big sister. He hiked in North Carolina and rafted a whitewater river.

Mysteriously, however, he began experiencing intermittent hand pain, throbbing and excruciating. Although family and friends initially suspected arthritis, Adam received a diagnosis of acute lymphoblastic leukemia.

2 /2 / Months of Charles of Chemo later.

with childhood cancer, the transformation was abrupt and traumatic. One day he was eating pizza and watching the sun sink over the Mississippi River with a friend. The next, he was in the ICU of St. Jude getting chemotherapy as doctors fretted about his astronomical white blood cell count.

As is so often the case

ALL, the most common childhood cancer, also is among the most survivable. Since St. Jude opened in 1962, the survival rate for the disease has soared from 4 percent to 94 percent for patients treated at St. Jude. Still, treatment is a long, rough process often involving some 30 months of chemotherapy.

Adam's course was especially difficult. Early on during treatment, he suffered pancreatitis. Doctors realized he was allergic to one of the main chemotherapy drugs,

Adam and his family are joined by members of his St. Jude care team for his "No More Chemo Party." The much-anticipated celebrations mark the end of chemotherapy treatment for patients at the hospital.



requiring a radical departure from the established protocol for treating ALL.

Though it would help save Adam's life, the replacement drug wreaked havoc on his immune system. An air bubble formed in his chest, and later, his esophagus became partially blocked. For eight months, he wore a mask to fend off infections.

Despite the precautions, virus after virus infected him, and eventually he suffered septic shock. Of all the side effects, or "party favors," as his mom, Connie, ruefully calls them, the most disturbing was a week-long bout with delirium.

"One thing after another kept happening," Connie says.

#### 'HE KNEW EVERYTHING HE WAS MISSING'

In many respects, Adam's cancer experience showed that being an older patient has its peculiar downsides. Young children who are afflicted haven't established a sense of normalcy that can be shattered by the disease. They don't know what they're missing.

Adam was planning to complete the St. Jude Ride, but flooding along the Mississippi River forced the official fundraising event to be canceled. Despite the setback, fellow cyclists rallied together to ride with Adam in support of his trek to \$1 million.

That wasn't the case for Adam. Like any teenager, he had tasted the fun and adventure life can offer, only to have it brutally taken away.

HE SAW YOUNGER ST. JUDE PATIENTS, KIDS FOR WHOM HE HAD FELT A KIND OF RESPONSIBILITY "After his diagnosis, he became an angry, trapped teenager," Connie says. "He knew everything he was missing."

The bitterness consuming Adam, however, wasn't just about what was happening to him. He saw younger St. Jude patients, kids for whom he had felt a kind of responsibility, suffer and sometimes die.

Among them was a feisty 9-yearold named Carson with whom

he had grown especially close. She needled Adam relentlessly, making a running joke of calling him a "disappointment" to St. Jude because he was, in her assessment, insufficiently brave and positive. She

gave him a collection of attractive handmade straps for his face mask, emphasizing to him the importance of looking nice even when he didn't feel well. When Carson passed away in 2015, Adam served as a pallbearer at her funeral.

Less than a year into his treatment, Adam and his mom knew something had to change. Even if the cancer didn't kill him, the toxic side effects of anger, anxiety and sadness would.

#### DRIVEN TO PAY BACK

Adam traces his fundraising efforts in part to needing to fill time during the tedium and discomfort of treatment. "It was kind of like therapy."

He also was following the example of others, including Carson, who had pledged her piggy bank to St. Jude.

Adam learned that the alternative chemo regimen had helped push his total treatment costs to more than \$3 million, although, like all other St. Jude patient families, his family never got a bill from the hospital.

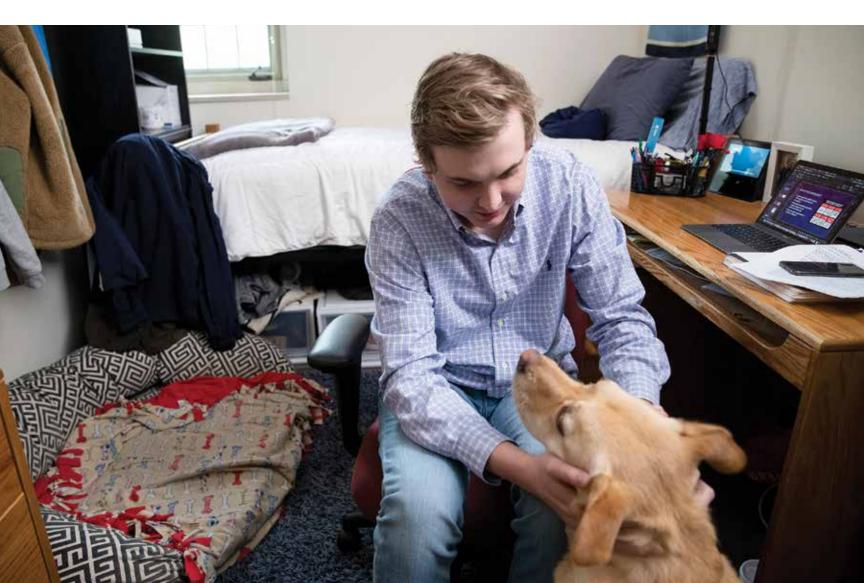
"People invested in me, so I've got to give back," he says.

He studied fundraising methodology and formed Adam's Army in 2015, its initial goal set at raising \$100,000. Member teams took part in the St. Jude Walk/Run, as well as the St. Jude Ride and Marathon, that year.

But as Adam prepared for the half marathon during the St. Jude Memphis Marathon Weekend in December 2015, another "party favor" from his treatment emerged. Doctors confirmed that his hips had been ravaged by avascular necrosis, an affliction that eats away the bone.

Trailed by a wheelchair, and under close monitoring by St. Jude medical staff, Adam completed the half marathon anyway. He crossed the finish line linked arm-in-arm with supporters. "Everybody was bawling. I can't tell you how many people are on the team because they witnessed it," Connie says.

Adam, shown in his dorm room with his dog Louie, juggled final exams while training for the St. Jude Rock 'N' Roll Nashville Half Marathon.



Shortly after the race, Adam underwent surgery to reconstruct his hips. He completed his leukemia treatment in spring of 2017, and remains in remission.

In an effort to help other patients, he's been open about the physical and emotional problems that still resurface occasionally. His main priority, however, is generating dollars for St. Jude.

After Adam's Army quickly surpassed the initial fundraising goal, the target moved continually higher.

# "THE FIRST THING I LEARNED ABOUT FUNDRAISING IS WHEN YOU HIT ONE GOAL YOU JUST MOVE IT UP TO THE NEXT ONE."

Since treatment ended, Adam has struggled somewhat to figure out who he is. For two-and-a-half years, he was the kid with cancer, the one who took chemo every other day.

A tattoo on his left arm reflects the strong, confident young man who has emerged. Taken from a Maya Angelou poem, it reads, "Life Doesn't Frighten Me."

For all the challenges that remain, Adam insists he's found a measure of peace in knowing that his calling is to give back, to serve others.

That's why he's jogging down a street in Memphis.

And that's why, with each passing moment, that big cancer wave that pummeled him so harshly recedes farther and farther away, leaving him in the sun, with a whole new life ahead.





■ TOP: Adam's mom Connie (right), has been a central figure in his fundraising efforts from the start. She is pictured with Clark Butcher, owner of Victory Bicycle Studio in Memphis, who helped rally cyclists to support Adam on his ride. Adam said of those who turned out: "It's just crazy that they don't know me and they still come out and support, but it means a lot."

BOTTOM: The more than 1,000 chemotherapy doses Adam endured during treatment took a toll on his joints and hormone levels. As a result, he must take more than 20 supplements and other pills daily.



Visit **stjude.org/marathon** to learn more, support a





### TAKING THE STAGE

A dancer's every step is part of a journey, and Aubrey's took her to the stage of Memphis' historic Orpheum Theatre. The occasion was a photo shoot arranged by St. Jude Children's Research Hospital, which was with Aubrey on every step of another journey — her successful treatment for a rare cancerous brain tumor, medulloblastoma.

Before her illness, dance was everything to Aubrey. From her first lessons at age 3, she fell in love. She later joined a competitive team, practiced 10 hours a week and eagerly learned new types of dance. Ballet, tap and musical theater – she loved it all.

The camera captured her return to the stage, a moment that was at once ethereal and symbolic. "Aubrey is brave and beautiful," said her mom, Melinda. "Seeing her on stage felt like coming home, it felt like life getting back to normal."

Read more of Aubrey's story at **stjude.org/aubrey**.

# DONORS SEE PROMISE IN GENE THERAPY RESEARCH AT ST. JUDE

#### BY THOMAS CHARLIER

rom his early work designing eighttrack tape players for cars, Tom Sheehan knows how technologies tend to come and go. But there's one field of medical science that he believes has almost limitless potential.

"I think the whole genetic-cell research thing is the next wave of the future for finding all kinds of cures," says Tom, who retired as chief operating officer at the company formerly known as Delco Electronics Corp.

Drawing from their backgrounds in technology, Tom and his wife Judy, a former X-ray technician, developed a keen interest in gene therapy research during their many years of financial support of St. Jude Children's Research Hospital. The Sheehans recently made a large gift of stock to the hospital, earmarking the earnings for gene therapy. "To us, it's the right field to be supporting," he says.

Gene therapy, which introduces genetic material to compensate for abnormal genes in cells, recently has produced promising results in the quest at St. Jude to conquer catastrophic childhood diseases. To donors and patient families alike, the advances have been especially heartening.

Earlier this year, St. Jude researchers announced they had developed a cure for infants born with X-linked severe combined immunodeficiency – an oftenfatal disorder commonly known as "bubble boy disease," which leaves kids unable to fight even the most common infections and illnesses.

The cure developed by St. Jude involves therapy that uses an altered virus to

transport and insert a correct copy of a gene into the genome of patients' blood stem cells. Following treatment, children begin producing fully functioning immune cells.

The Sheehans, who previously made donations toward the Pediatric Cancer Genome Project involving St. Jude, were elated by the gene-therapy advances. "It shows the technology is working," Tom says.

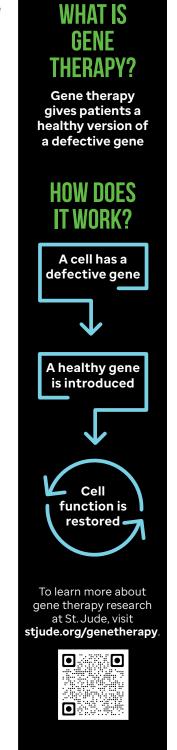
Like the Sheehans, St. Jude donors Steve and Sally Lamb have made major contributions toward gene therapy work at St. Jude because they see the potential for the research to cure cancer and other diseases.

"We've felt, based on our research – not that we're scientists by any stretch – that the answer lies somewhere in gene therapy. We think that there's a good chance that cures are going to be found and people are going to be saved because of the work being done in the gene therapy area," says Steve, 59, who lives in the Boston area and is chief financial officer for a life insurance-distribution firm.

There also is a personal component to the Lambs' decision to make a three-year, \$150,000 commitment to gene therapy studies at St. Jude. Steve and Sally each have seen several family members diagnosed with cancer, some of them succumbing to the disease.

"About the only thing worse than an adult getting cancer is a child getting cancer," Steve says. "That's what got us to St. Jude."

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



# BY THOMAS CHARLIER CACCOLOR CONTROL CO

born tinkerer who stays plugged in to the latest technology, Denton Olson saw electronics retailer Best Buy as the best fit in terms of places he could work

while attending college. Besides, he says, "I like many of the things the company stands for."

One of the things Best Buy stands for – in a very big way – is the place that saved Denton's life.

Since 2013, Best Buy has raised more than \$80 million for St. Jude Children's Research Hospital, where Denton received treatment for acute lymphoblastic leukemia as a child. The retailer is an annual partner in St. Jude *Thanks and Giving*®, a star-studded year-end campaign that encourages consumers to donate while they shop and support the lifesaving mission of St. Jude.

Denton was not quite 3 when he was diagnosed with ALL, the most common form of childhood cancer. He remembers being pulled around in the signature red wagons during treatment, and he also remembers the catheter through which his chemotherapy was administered. But most vividly of all, he recalls the kindness of doctors and nurses who truly seemed to love their jobs.

66

I always said that if I ever could donate to something...
St. Jude would be the one I would choose because they saved my life.

Now 23, Denton works at Best Buy while he pursues a mechanical engineering degree at the University of Missouri. From his years shopping at Best Buy, Denton knew of the company's support for St. Jude.

"However, I didn't really realize how indepth their contribution was until I started working there and seeing the amount of revenue they were able to bring in for the hospital," he said. "I definitely appreciate that. I always said that if I ever could donate to something... St. Jude would be the one I would choose because they saved my life."

Denton's story is one of the many reasons why Best Buy has supported St. Jude for the last six holiday seasons. "What makes Best Buy so special is that we are a company with a big heart," said Ray Sliva, Best Buy's senior vice president of retail operations. "We want to help more young people like Denton Olson live happy and healthy lives."

Denton still returns to St. Jude for postcancer health screenings as part of the St. Jude LIFE study. Today he is an "incredibly caring and kind person," as well as a proficient coworker, said his Best Buy teammate Christian Crawford, who also shares an apartment with Denton and Denton's wife.

"We have a motto at Best Buy – 'Have fun while being the best' – and I think he really exemplifies that," Crawford said.

#### Just me and my beanie let the story begin Chemo was taking my hair like a blow in the wind

Nick faced cancer and lived to tell about it — survivor songs full of rhyme and raw emotion, a soundtrack to a teenager's journey through darkness to light.

# NICK'S SONG

He raps about facemasks and sanitizers, fear and recovery. He raps about the beanie that once covered his bald head, but now he wears only "when it's cold / not when I'm hurting."

And he raps about the place that saved his life after a diagnosis of acute lymphoblastic leukemia: St. Jude Children's Research Hospital.

Words he wrote in a journal called "Nick's Story" flew from the page and became full-fledged songs.

"Beanie" is a song about losing your hair — and your sense of self. It's a song about wanting to vanish:

#### Hide me from the people, please Hide me from myself, please

It's also about getting your life back:

Now the story continues and my life is heading up No more sanitizers, face visors and separate cups

Once shy, now Nick sings his survivor songs to the world. He sings to give thanks to the place that saved – and changed – his life.

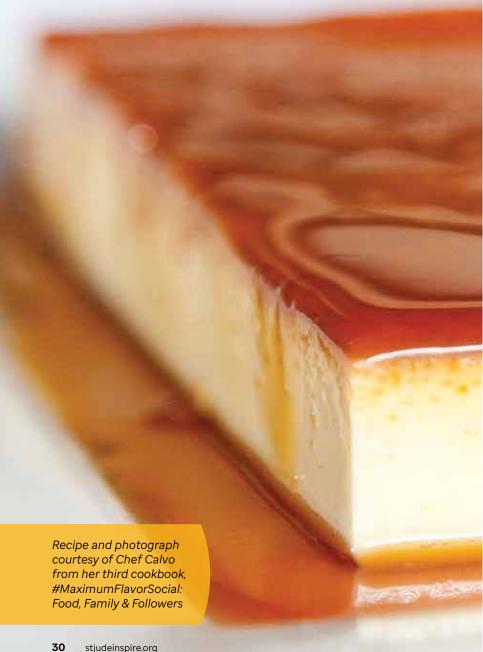


Scan to read Nick's full story or visit stjude.org/nick.





# Ataste of HOME





When Chef Adrianne Calvo makes her special feast every year for the families of St. Jude Children's Research Hospital, it's sure to include flan. "Flan is a staple in every

Cuban family get-together," she says. "In my family we judge a great flan by how creamy it is. It can't be too sweet or have holes. It's an exciting moment when we get a perfect flan."

#### **CUBAN FLAN**

#### **INGREDIENTS**

1 whole egg 5 egg yolks 1 (12 oz) can evaporated milk 1 (14 oz) can sweetened condensed milk 1 tsp pure vanilla extract

#### **METHOD**

Pinch of salt

Make your favorite caramel recipe in a saucepan, then pour into the bottom of a casserole dish. As you prepare the custard, the caramel will cool. > In a separate bowl, using a whisk, beat the 1 whole egg and 5 egg yolks together. Add the evaporated milk and sweetened condensed milk to the eggs and mix together. Add the vanilla extract and the pinch of salt. **Pour the custard** mixture into the casserole dish over the hardened caramel. Place your flan on a baking pan and fill with hot water to about halfway up the sides. **Bake** in a pre-heated 350-degree oven for 45 minutes. Turn off the oven and let set for another 15 minutes. Remove from the oven and the water bath and let cool. Run a butter knife around the outside edge of the flan. Place a plate large enough to handle the liquid caramel over the flan and invert. > Chill the flan for at least an hour before serving. Serves 8.

> To learn more about Chef Calvo, visit stjude.org/chefcalvo.



# guide

This season, check off your holiday shopping list with a gift that gives back from the St. Jude Gift Shop.



#### DRUZY BEAD MULTICOLORED GOLD BRACELET This colorful bead bracelet stretches to fit most

wrists. Includes goldtone St. Jude circle charm and tassel. **\$36** Item #7088



#### NUTCRACKER

This wooden nutcracker is the perfect holiday decoration.
Mouth opens with back lever.
15"H **\$16** Item #3567



#### BALLERINA & NUTCRACKER 4" ORNAMENT Bring the

magical tale of the Nutcracker to your tree this year. Adorned with ribbon. \$16 Item #4211



#### WAGON 3" ORNAMENT 1

Give your tree playful charm with this adorable glass ornament. Engraved St. Jude logo charm. **\$10** Item #4203



#### GENUINE LEATHER RED SHOULDER BAG

This sleek red 100% leather bag is perfect for work or a night out. 10½"H x 12½"W x 5"D. **\$84** Item #6512

CABLE KNIT CHENILLE AND SHERPA GREY THROW BLANKET

A stylish layer of warmth neutral enough to fit any decor. 50" x 60". 100% micro-chenille polyester with 100% polyester plush Sherpa lining. Includes zippered vinyl pouch. \$55 Item #4685

FREE SHIPPING on orders over \$100 stjude.org/giftshopinspire





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

At only 5 months old, tests revealed Miguel had retinoblastoma, a type of eye cancer. He was referred to St. Jude Children's Research Hospital®, where his treatment included a combination of chemotherapy, laser treatment and cryotherapy. Today, Miguel is cancer-free and the playful little boy has vision in both eyes. "I don't know what we would have done without St. Jude," his mom, Liliana, said. Families never receive a bill from St. Jude for treatment, travel, housing or food — because all a family should worry about is helping their child live.

Give today at **stjude.org** | **800-4STJUDE** 





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