



**St. Jude Children's
Research Hospital**

Finding cures. Saving children.

ALSAC • DANNY THOMAS, FOUNDER

2020

ALSAC/St. Jude Annual Report



THE MISSION of St. Jude Children's Research Hospital® is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. Consistent with the vision of our founder, Danny Thomas, no child is denied treatment based on race, religion or a family's ability to pay.

ALSAC – American Lebanese Syrian Associated Charities – is the fundraising and awareness organization for St. Jude. ALSAC is dedicated solely to raising the funds and awareness necessary to operate and maintain St. Jude, now and in the future.

When 1-year-old Mikayla was diagnosed with acute myeloid leukemia, a cancer of the blood and bone marrow, her parents didn't know what to expect. "There are experiences I think in human life where we run out of tears, and that was one of them," said her dad, Juan Manuel. But Mikayla's family, like all families, never received a bill from St. Jude for treatment, travel, housing or food. Read Mikayla's story at stjude.org/mikayla



AN IVY
LEAGUE
STUDENT
IN A
CLASS
OF

HER OWN

To understand her mom's reaction when Courtney declared she wanted to go a thousand miles away for college – “this nonsense,” as Audrey now calls it, with good humor – you have to go back to the beginning.

Actually, before the beginning.

Six months into her pregnancy, a test showed Audrey's baby would be born with sickle cell disease. There was a family history: A nephew had died from complications of sickle cell at age 3. So Audrey wanted the test. She wanted to know so she could prepare, so she could give her baby every chance to thrive with a disease that can cause chronic, sometimes debilitating pain.

And Courtney has thrived, thanks to St. Jude. “I tell people I thank God, and I thank St. Jude second-most for, really, all aspects of her life,” Audrey said.

St. Jude wasn't just a healing place for Courtney. It's where she learned to read, in that difficult summer between first and second grade, as she struggled with the cognitive side effects of her disease.

It's where her personality “bloomed” – her mom's word – as the chance to participate in St. Jude

fundraising events drew out this once-timid girl who went from “being afraid of everything and everybody” to an impromptu singing performance on stage in a ballroom full of people. Or, as Courtney said, with a laugh, “and then one day somebody at ALSAC (the fundraising and awareness organization for St. Jude) handed me a microphone, and apparently they couldn't get it away ever since.”

Sickle cell disease did not define her. She wasn't about to let it confine her. As a high school senior in Memphis she was accepted at Cornell University. Think of it – an Ivy League education for a girl whose mother once worried “the child would never read.”

Now mom was worried about other things. About things of great consequence to the parent of a sickle cell patient, like geography. Cornell is in Ithaca, New York, a thousand miles from Memphis and the support system with which Courtney grew up. A thousand miles from mom, and St. Jude.

“I tried to discourage her by telling her, ‘Courtney, you know when you get sick, I'm not going to be able to blink and be sitting there holding your hand in the hospital,’” Audrey said.

And there was the weather. Winters can be harsh in Ithaca, and cold weather can trigger pain episodes in sickle cell patients. It was so cold the first time Courtney visited campus that she had to borrow a heavy coat from the girl with whom she was staying – and that was in October.

“I said, ‘Don’t you think that should be a concern, that you need a big ol’ coat in October, and you have sickle cell disease?’” Audrey said.

Nothing would dissuade Courtney. Nothing would dim her hopes. But Audrey had one more card to play – St. Jude.

So when they went to see her doctors, to talk about this nonsense of Courtney’s big college adventure, Audrey remembers thinking: “Here we go. St. Jude has always provided my solution

to every problem in my life. They’re going to sit this child down and tell her she should not be going off to this cold-weather world.”

In retrospect, mom might have seen it coming. She might have guessed the place that had cared for her daughter throughout her young life – the place that had seen her struggle and overcome – would now champion Courtney in this bold, new chapter.

The reaction at St. Jude?

Oh, my God, Courtney’s going to Cornell! Oh, we’re so proud of you! We’re going to find you a doctor up there, don’t you worry. We’re going to take care of you, you’ll be fine.

Audrey laughs, looking back.

“I’m like, wait a minute. I was depending on you all.”

The Future of Sickle Cell Disease Treatment

Today, with early diagnosis and use of recently developed treatments, the life expectancy of children with sickle cell disease has increased 98 percent

St. Jude operates one of the largest sickle cell programs in the country, treating upward of 900 patients annually.

Thanks to generous supporters like The Links, Incorporated, we’re making great strides in research and treatment here and around the globe:

▶ St. Jude also is testing an app, mHealth, that helps teens transitioning from pediatric to adult sickle cell care with everyday issues such as making appointments with an adult hematologist, reading an insurance card, learning how to fill a prescription and read a pill bottle.

▶ Advances have been made in neurocognitive screening at St. Jude to assess language, reasoning, visual-spatial skills, attention and working memory, executive functioning, verbal memory, processing speed, fine-motor dexterity, academic skills and social-emotional functioning.

▶ In collaboration with the Aminu Kano Teaching Hospital in Kano, Nigeria, St. Jude began a newborn screening and sickle cell outreach and awareness program.

▶ St. Jude leads the Sickle Cell Clinical Research and Intervention Program, which studies how sickle cell disease progresses over time, from childhood into adulthood, and how we can improve the quality of life for sickle cell disease patients while we continue to search for cures.

“My mom had been preparing me my entire life... whether I was going an hour away or 14 hours away.

– Courtney



St. Jude Children’s Research Hospital research highlights

Too little or too much DUX4 is just right



St. Jude researchers have evidence that a protein that fuels leukemia in some children can also doom the tumor cells. The protein is DUX4. Normally the DUX4 gene is expressed briefly during development. But the gene is also switched on in about 7% of children with B-cell acute lymphoblastic leukemia. The cells include a fusion gene that combines part of DUX4 and the gene IGH. Results can be explored for treatment of B-cell acute lymphoblastic leukemia.

July 2019 | *Nature Communications*

Studying single cells to understand a type of pediatric brain tumor



St. Jude scientists completed the most in-depth study of medulloblastoma subtypes. To do that, they studied single cells, helping shed light on how the cells become cancerous. The findings may help scientists create lab models of the disease and design future clinical trials. “The ability to look at these single cells propelled us 10 steps forward in understanding how the types of medulloblastoma arise, what drives them and how we can make treatments more effective,” said Paul Northcott, Ph.D., Developmental Neurobiology.

July 2019 | *Nature*

Image captures ‘streamlined essence of what life entails’



In a first, St. Jude scientists captured the atomic structure of a mechanism for unwinding DNA. Double-stranded DNA must separate before it’s copied and the cell divides. The image shows an enzyme complex bound to single-stranded DNA along with the molecules that fuel unwinding. The structure of the enzyme complex, called the MCM complex, was known. But how the process worked was a mystery.

August 2019 | *Nature Communications*

Exercise may give the brain a boost



Improving cancer survivors’ physical fitness may boost their thinking and learning skills. A St. Jude study reveals more about this link. This work relied on the St. Jude Lifetime Cohort (St. Jude LIFE) study. The scientists tested 341 childhood leukemia survivors and 288 control subjects. “Survivors are more likely to have limited ability to exercise,” said Kirsten Ness, PT, Ph.D., FAPTA. “Physical activity can have a positive effect on cognitive ability.”

October 2019 | *Cancer*



St. Jude shares the breakthroughs it makes, and every child saved at St. Jude means doctors and scientists worldwide can use that knowledge to save thousands more children.

Like a crystal ball, a blood test can predict when serious infections will strike



Children with leukemia are at high risk of infection because treatments weaken their immune systems. Detecting infections early can make a lifesaving difference.

Researchers at St. Jude showed that a new test predicted bloodstream infections up to three days before symptoms appeared. "This work gets to the heart of something families of children with cancer desperately want – to know what is coming next and to be able to do something about it," said co-senior author Joshua Wolf, Ph.D., MBBS, Infectious Diseases.

December 2019 | *JAMA Oncology*

Predicting protein phase separation



St. Jude and Washington University are studying liquid-liquid phase separation. Cells sort and separate proteins and other components through the process.

Intrinsically disordered proteins lack structure. Some of them can also drive liquid-liquid phase separation. Researchers have developed a way to predict how proteins phase separate. The answer will help scientists studying how these proteins contribute to disease.

February 2020 | *Science*

The role of oxygen in wiring the brain



Environmental factors like oxygen affect neurons in the brain. Scientists at St. Jude are studying the role oxygen plays in the maturation and migration of neurons.

They have identified a new mechanism that helps control these processes.

March 2020 | *Neuron*

Expanding ways to tame a global childhood killer



The first human study of an experimental anti-malarial drug discovered at St. Jude offers reason for hope. Malaria is caused by a parasite spread by the bite of infected mosquitoes. Despite its ability to be prevented and cured, it still kills almost 500,000 people every year. More than 60% of the deaths are young children.

April 2020 | *Lancet Infectious Diseases*

Inherited mutation can drive SHH medulloblastoma



Children treated for cancer are apt to get infections. Scientists at St. Jude, the University of Pittsburgh and Harvard Medical School sequenced antibiotic-resistant bacteria that infect kids with leukemia. What they found is bacteria adapt over time and respond to therapy, helping them survive in the body in spite of antibiotics.

May 2020 | *Proceedings of the National Academy of Sciences*

Predicting secondary cancer risk in childhood cancer survivors



Childhood cancer survivors can develop other cancers later in life. St. Jude scientists sequenced DNA from blood samples gathered through the St. Jude LIFE study.

This study brings childhood cancer survivors back to the hospital for health screenings throughout their lives. Studying the effect of cancer treatments and inherited mutations in DNA-repair genes may help predict who has a higher risk of another cancer.

June 2020 | *Journal of Clinical Oncology*

Computational tool helps illuminate hidden mutations



St. Jude researchers have developed a powerful tool to help identify cancer-causing mutations in patients' genomes.

The tool combines math and biology to find alterations in tumor cells that drive patients' cancer. The method is called cis-expression or cis-X and is publicly available on St. Jude Cloud and GitHub.

June 2020 | *Nature Genetics*



Treatments invented at St. Jude have helped **push the overall childhood cancer survival rate from 20% to more than 80%** since it opened in 1962. And we won't stop until no child dies from cancer.

St. Jude Children's Research Hospital to invest \$11.5 billion targeting childhood catastrophic diseases globally



St. Jude patient **Maelin-Kate** fanconi anemia

In 2021, St. Jude Children's Research Hospital will kick off the largest strategic expansion in its 60-year history, investing more than \$11.5 billion over six years to accelerate research and treatment for children around the globe with catastrophic diseases.

Included in the new, 6-year plan is \$1.9 billion in capital spending. Among the construction projects: a proposed, \$500 million outpatient clinic and doctors' office; and the new \$110 million Domino's Village patient family housing facility.



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

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

Here are the plan highlights:

A \$3.7 billion investment will expand cancer-focused research and related clinical care.

Among key areas of focus:

- **Cancers with the Lowest Survival Rates:** Researchers have yet to unlock the secrets of several difficult-to-treat pediatric cancers that most often are fatal, notably brain cancers. Under the new plan, St. Jude will increase investment into uncovering why cancers arise, spread and resist treatment. This includes hiring more researchers dedicated to advancing insights across the spectrum of pediatric cancer – leukemia, solid tumors and brain tumors – and cancer subtypes.
- The number of patients on St. Jude–led protocols may grow as much as 30 percent. Those numbers are achieved through a small increase in patients admitted, and through an increase in multi-institutional studies.

- **Quality of Life:** St. Jude has led the way in developing less-toxic treatments that reduce the risk of devastating and long-lasting side effects from chemotherapy and radiation, but there’s still tremendous progress to be made. As part of its research, St. Jude has amassed critical historical data by following more than 5,000 patients who have survived at least five years.

St. Jude will more than triple its global investment over the 6-year period to improve survival rates for childhood cancer around the world. Major efforts under this expansion include:

- Development of a multi-million dollar pediatric cancer global drug access program – in collaboration with WHO, other U.N. agencies and international organizations – to distribute an uninterrupted supply of anti-cancer drugs for childhood cancer treatment in low- and middle-income countries.
- Expansion of educational programs to train the workforce needed to treat childhood cancer worldwide.
- Creation of seven international operational hubs staffed by St. Jude workers to effectively manage the St. Jude Global Alliance, a union of institutions, foundations, doctors, nurses and other partners committed to improving care for children with cancer and other life-threatening diseases.

More than \$1 billion will be invested to expand research in nonmalignant diseases.

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

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

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

In 2020, the average donation to St. Jude was approximately \$43.

St. Jude patient **Eduardo**
eye cancer
pictured with his mom



St. Jude to invest \$200 million over 6 years to increase access to quality cancer medicines for children across the globe

There will be more than 400,000 new cases of childhood cancer globally this year. The majority of those cases will occur in low- and middle-income countries without resources to adequately diagnose and treat the disease.

As part of its six-year, \$11.5 billion strategic plan, St. Jude Children’s Research Hospital has announced it will invest an estimated \$200 million over six years to dramatically increase access to quality cancer medicines for children around the world and, in conjunction with the World Health Organization, create the Global Platform for Access to Childhood Cancer Medicines.

The announcement followed an intense period of research that spanned several years and builds on the dedicated work of many over decades.

In October 2021, the St. Jude Board of Governors approved the business plan for the new platform and committed an investment to fully fund its development and implementation. The success of the platform will require more discussions with stakeholders in its development, implementation, scale-up and sustainability.

But here’s how it will work:

The St. Jude/WHO global medicines access platform will launch as a two-year pilot project providing medication at no cost to 12 countries. By the end of 2027, it is expected that 50 countries will receive childhood cancer medicines through the platform.

It’s estimated 120,000 children could be impacted within the first six years.

The program will provide end-to-end support. It will consolidate global demand to shape the market; assist countries with the selection of medicines; develop treatment standards; and build information systems to ensure that effective care is being provided.

Art by St. Jude survivor **Tayde**



Shirley poses with the first contest pie – apple.

DANNY THOMAS' DREAM LEADS TO

50 YEARS OF SUPPORT

It was 1970 when Danny Thomas took the stage in St. Paul, Minnesota, before a crowd at the Epsilon Sigma Alpha international council convention.

In the audience was Shirley Krcmar, (pronounced KIRCH-mar) a mom of three boys from small-town Ohio, who sat mesmerized while Danny shared the story of his dream:

In 1962, St. Jude Children's Research Hospital opened its doors in Memphis. There, he said, doctors treated children with cancer whether their parents could afford it or not. It didn't matter their race, religion or where they came from. They were treated just the same. But he couldn't do it alone, he said. He needed help.

"You have this man – that is famous – that is doing something for people regardless of what their status is in life," Krcmar said. "He represented the giving and the caring that we all would like to have, I think. You just don't hear of this now. He sold that to our organization.

"When he told us all the story, I don't know how you could not be moved."

The message so touched Krcmar that it directed the course of her life for the next 50 years.

"Once you hear about St. Jude and learn what it does for cancer patients and other catastrophic diseases, of course you can't not do it," the octogenarian said.

Check Point	Distance	Stamps
1	9 1/2	"SMILE"
2	10.2	"KEEP SMILING"
3	15.8	"KEEP PEDALING"
4	20.9	"DID I VOLUNTEER?"
5	25.2	"I THINK I CAN, I THINK I CAN!"
6	30.1	"I CAN'T BELIEVE I RODE THE WHOLE THING!"

In 1972, Judy Krcmar participated in her first fundraising event for St. Jude Children's Research Hospital, the Million Dollar Bike Ride.

Her support for the St. Jude mission hasn't wavered through more than five decades as she hosted fundraising fashion show luncheons and baby beauty contests, made 500 pounds of chocolate candy to sell at Christmas and volunteered at charity golf tournaments. Even a pandemic couldn't stop Krcmar from supporting Danny's dream.

She couldn't gather with her usual group to plan events. So, she decided to put a contest in her neighborhood newsletter: For the highest bidder, she'd bake a pie a month for a whole year. She'd done it once for church and raised a couple hundred bucks. But this time the bids rolled in, and she raised \$2,100 for St. Jude.

"And all I had to do was make a pie a month," she said.

After 50 years, little acts of kindness can lead to a whole lot.

The speech Krcmar heard Danny give so many years ago still resonates. She has no plans to stop carrying on his dream.

"I think I'm gonna live to be 100 so I can't imagine I wouldn't keep doing it."

FY20 ALSAC/St. Jude Boards of Directors and Governors

The members of the ALSAC/St. Jude Boards of Directors and Governors are volunteers who serve without compensation. They come from across the country to support the lifesaving work of St. Jude, and many represent the second and third generations of their families to serve on the Boards. An honorary body of emeritus members recognizes the distinguished service on the Boards by those unable to continue to actively participate.

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Melanie, pictured with her mom, has brought her innate positivity to bear against the challenges of treatment for brain cancer. View more of Melanie's story at stjude.org/inspire/melanie



fiscal year
2020 combined

financial highlights

Years ended June 30 (in thousands)

2020 **2019**

Revenues

Total Support	\$1,786,051	\$1,716,247
Net Patient Service Revenue (Insurance Recoveries)	125,905	109,173
Research Grants	119,389	109,636
Net Investment Income	158,855	363,174
Other	20,306	26,490
Total Revenues	\$2,210,506	\$2,324,720

Expenses

Program Expenses		
Patient Care Services	517,969	490,685
Research	477,972	436,939
Education, Training and Community Support	194,237	171,734
Total Program Expenses	1,190,178	1,099,358
Fundraising	288,060	262,087
Administrative and General	227,734	205,787
Total Expenses	\$1,705,972	1,567,232

Loss on Disposal of Property and Equipment (671)

Change in Net Assets	504,534	756,817
Beginning Net Assets	6,059,690	5,302,873
Ending Net Assets	\$6,564,224	\$6,059,690



St. Jude patient Fletcher, brain cancer



To view the 2020 St. Jude Annual Report online, visit stjude.org/financials
To read more inspiring St. Jude stories, visit stjude.org/inspire

Cover: St. Jude patient Lucas, brain tumor, pictured with his mom
This page: St. Jude patient Pops, brain cancer, celebrating his “No More Chemo” party, pictured with his mom