



2023

ALSAC / ST. JUDE  
ANNUAL REPORT



St. Jude Children's  
Research Hospital

Finding cures. Saving children.  
ALSAC • DANNY THOMAS, FOUNDER



This spread:  
St. Jude patient **Beckett**,  
brain cancer

Cover:  
St. Jude patient **Kaleb**,  
blood disorder  
pictured with his dad

## 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 to operate and maintain St. Jude, now and in the future.



After being diagnosed with an aggressive form of brain cancer called ATRT, St. Jude patient Beckett underwent surgery, proton therapy and chemotherapy. He is now out of treatment and back home.

Scan the QR code to see his story.



# Kenadie's Playful Spirit

Arearn laughs as her youngest child, 9-year-old Kenadie, resolutely proclaims that she is her mother's favorite. Arearn laughs a lot now, watching Kenadie dance and announce that she's an artist (with 100 canvases at home) or say that one of her favorite things to do is to bug her mother. To the staff at St. Jude Children's Research Hospital®, Kenadie was known as Miss Sassy.

Art and photo of St. Jude patient **Kenadie**, cancerous tumor pictured with her mom





Kenadie is full of spirit and likes things done in a certain way, her mom said. She will give you a “death stare” when something must happen that she doesn’t like but can’t avoid.

She doesn’t like needles or having to swallow pills. She wanted her own pillows and her own blankets until she decided she liked the warmed hospital blankets better. And sometimes she didn’t like the food, so they’d order out.

She’s still sassy. Fifteen months of cancer treatment couldn’t touch Kenadie at her core. For that, Arearn is grateful to God and to St. Jude.

Kenadie was diagnosed with high-risk neuroblastoma in April of 2022, less than a month after her eighth birthday. It wasn’t her first health complication.

When Kenadie was 2, doctors discovered her subclavian artery, a large artery that supplies oxygen-rich blood to the upper body, was going the wrong way around her heart. It was something she was born with. A vascular ring repair was done when she was 6 to correct it.

A few weeks before her cancer diagnosis, Kenadie woke her mother in the middle of the night. She felt sick and was vomiting.

“

For my family,  
for Kenadie to get  
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AREARN, KENADIE’S MOM

The next day it happened again. Because of Kenadie’s previous health challenges. Arearn was worried. She and her husband decided to take her to the emergency room.

At first they thought Kenadie likely had a stomach bug and a pulled muscle, but the hospital saw a mass in one of her scans. They reached out to St. Jude and the following day, Kenadie was admitted.

At St. Jude, doctors saw the tumor was about 18 inches long.

The tumor involved Kenadie’s adrenal gland and her kidney but had not spread to other organs.

Arearn said it was like “God had his hand around her.”

Early radiation therapy didn’t shrink the tumor. Kenadie underwent surgery and the tumor was completely resected. Surgery was followed by chemotherapy, a stem cell transplant and more radiation.

It took over a year, but Kenadie was cancer-free.

“The care they took with Kenadie, I don’t care if it was a time when we had to drive in the middle of the night when she was running a fever or if she was impatient with treatment, it was 110 percent that they gave every time,” Arearn said.

Families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.

Arearn knew about St. Jude and that assurance, but it resonates so much more when it’s your child receiving care. For that, she’s grateful to St. Jude and to the donors.

“Because for my family, for Kenadie to get treatment here without having to pay anything was a huge help,” she said. “That was stress we didn’t have to worry about.”

Arearn is a regular donor and since Kenadie’s diagnosis, other family members have become monthly donors, too.

Kenadie describes being in the hospital as both good and bad.

“The bad part about it is I want to go home. And the good part about it was I get to spend time with the nurses,” she said, happily recalling a long list of favorites.

“What got me through it was probably Kenadie’s strength. I was there every step of the way, every treatment, every appointment. And just seeing her go through it, that’s what got me through it,” Arearn said.

Kenadie is back home now with her sister and brother.

“I want to keep her in a bubble right now,” Arearn said. “As much as she wants to get out and do stuff and go here and there, she’s ready. But I’m not ready.”

But, because of St. Jude, Arearn thinks about what she wants for Kenadie in the future.

“To be a good person in society, to go for her dreams whatever that may be. She says she wants to be a doctor. I want her to go for it if that’s what she wants to do,” Arearn said.

Now that cancer treatments have ended, Kenadie will continue with follow-up visits and will eventually come back annually.

And for any other little girls who might also have cancer, Kenadie has words of encouragement.

“You can do it,” Kenadie said. “You’ve got this. You’re strong.”



# Research HIGHLIGHTS

July 1, 2022 – June 30, 2023

## Study reveals a new therapeutic target for aggressive type of rhabdomyosarcoma

Scientists at St. Jude Children's Research Hospital have identified an Achilles' heel in rhabdomyosarcoma driven by a gene fusion which revealed a promising treatment approach in the lab.

July 2022 | *Science Translational Medicine*

Investigator: Jun Yang, MD, PhD

## Hiding in plain sight: Improved CAR T-cell therapy for T-cell acute lymphoblastic leukemia

Scientists at St. Jude Children's Research Hospital developed a simple method to select for more effective cancer-destroying CAR T cells for patients with relapsed T-ALL.

August 2022 | *Blood*

Investigator: Paulina Velasquez, MD

## St. Jude finds a new way to identify 'safe harbor' for gene therapies

A tool created by scientists at St. Jude Children's Research Hospital may increase the safety of gene and cell therapy by finding safe places to add genes to human DNA.

September 2022 | *Genome Biology*

Investigator: Yong Cheng, PhD

## A link between hypoxia and fetal hemoglobin provides hope for sickle cell disease

St. Jude Children's Research Hospital scientists found the cellular response to low oxygen also increases fetal hemoglobin expression in adults, which could lead to novel treatments for some common genetic anemias.

October 2022 | *Nature*

Investigator: Mitchell J. Weiss, MD, PhD

## Pharmacotyping of childhood leukemia provides a blueprint for 'true precision medicine'

Researchers from St. Jude Children's Research Hospital performed the largest study yet examining drug sensitivity in childhood acute lymphoblastic leukemia across genomic subtypes and its association with treatment response.

January 2023 | *Nature Medicine*

Investigator: Jun J. Yang, PhD

## St. Jude scientists create more efficient CAR immunotherapies using a molecular anchor

St. Jude Children's Research Hospital scientists added a molecular anchor to chimeric antigen receptors (CARs), increasing the anti-cancer activity of cellular immunotherapies in cancer models.

February 2023 | *Genome Biology*

Investigator: Stephen Gottschalk, MD, PhD

## Integrated structural biology provides new clues for cystic fibrosis treatment

The cystic fibrosis transmembrane conductance regulator has been studied for years but the combined efforts of St. Jude Children's Research Hospital and Rockefeller University have yielded new insights.

March 2023 | *Nature*

Investigator: Scott Blanchard, PhD

## Prime editing shows proof of concept for treating sickle cell disease

Researchers at St. Jude Children's Research Hospital and the Broad Institute of MIT and Harvard showed how prime editing can correct the mutation that causes sickle cell disease in a potentially curative approach.

April 2023 | *Nature Biomedical Engineering*

Investigators:

Mitchell J. Weiss, MD, PhD | Jonathan Yen, PhD

## Genetic change increased bird flu severity during U.S. spread

Scientists at St. Jude Children's Research Hospital have discovered H5N1 avian influenza viruses gained the ability to cause severe disease and target the brain in mammals as they spread across North America.

May 2023 | *Nature Communications*

Investigator: Richard Webby, PhD

## SWI/SNF complexes "bookmark" cell identity during division

Scientists at St. Jude Children's Research Hospital found that subunits of the SWI/SNF chromatin remodeling complex, which is mutated in 20% of all cancers, help cells maintain a memory of differentiation during mitosis.

May 2023 | *Nature*

Investigator: Charles W.M. Roberts, MD, PhD

## St. Jude finds NLRP12 as a new drug target for infection, inflammation and hemolytic diseases

Scientists at St. Jude Children's Research Hospital found key 'on' switch, NLRP12, for innate immune cell death in diseases that cause red blood cells to rupture, which can lead to inflammation and multi-organ failure.

June 2023 | *Cell*

Investigator: Thirumala-Devi Kanneganti, PhD



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



# Life AFTER TREATMENT

Originally Published October 2023

*Pediatric cancer treatments save lives, but can increase health risks for survivors during adulthood. St. Jude LIFE is an unprecedented research study that brings childhood cancer survivors back to St. Jude for regular health screenings throughout their adult lives to help understand the long-term effects of cancer treatments.*

## **Q: What does your work here at St. Jude Children's Research Hospital® involve?**

A: The St. Jude Lifetime Cohort study hit the ground running in 2007 and is open to five-year survivors treated for cancer between 1962 and 2012 at St. Jude. Former patients visit every five years and undergo several days of comprehensive testing. It was initially for adults, but now the program has been enlarged. We have a human performance lab. We do strength and balance testing. We do exercise testing where they walk on a treadmill. If they aren't able to do that, we have a bike. We do neurocognitive testing. How are these adults doing with computation skills? Are they able to work? How are their social skills with friends, family? We see what their fitness levels are every five years. And there are interventional trials to decrease the risk of other cancers, heart disease, early diabetes, frailty. We measure over time and we measure for a lifetime. Long after I'm gone, this will continue.

## **Q: How is this information used?**

A: We are now able to help their local physicians learn more about their problems and to intervene for them. We have over 6,000 patients including Dwight Tosh, patient #17, who was treated here in April of 1962. He comes every five years along with all these others.

## **What happens to patients after the completion of their cancer treatment at St. Jude?**

A: The After Completion Therapy Clinic was established in the mid-1980s so the active treating doctors could transition their patients to a clinic where they could learn more about long-term problems. They knew that cancer was behind them, but the rest of life was ahead. They come to us when they're five years past diagnosis and at least two years past the end of their therapy, so the chance of relapse is pretty

low at that point. We see them annually or more often if needed until they're 18 or reach high school or 10 years after their diagnosis. So, if they come to us as a 17-year-old, we'll see them until they're 27.

## **Q: What happens at the ACT Clinic?**

A: We look at their treatment and find out what were the problems that were known to have occurred after that treatment over time. And (we) begin to educate them and their families. During these visits we do risk-based assessments. They see our social work team. We have neurocognitive testing. That's the most common problem after childhood cancer, neurocognitive issues – memory, processing speed. We begin to educate them and their families, so they are able to advocate for themselves. And we assist them with their local healthcare providers. I knew virtually nothing about this 16 years ago. We are now able to help their local physicians learn more about their problems and intervene for them. I've been blessed to be able to speak to large groups of physicians at statewide meetings and been well received because of the information I can share from St. Jude with them.

## **Q: Why is this so important?**

A: The majority of adults treated for cancer during childhood do not receive ongoing care that considers screening and prevention of health risks related to cancer treatment. And many oncologists and most primary care providers are not familiar with risk-based health screening recommendations for childhood cancer survivors. Each year in the U.S. around 15,000 are diagnosed with pediatric, childhood and adolescent cancer. It pales in comparison to adult cancers, but it's still huge. Because if you're 70 or 80 and have a cancer diagnosis, you may lose 5, 10, 15 years of life. If you're 2, you might lose 80 years of life.



**Dr. Tim Folsie**, Staff Physician,  
Department of Oncology  
and Director of the St. Jude  
Lifetime Cohort Study Team



# HOME Away From HOME

## For St. Jude Families

For Domino's and the supporters who helped make The Domino's Village a reality, it is deeply meaningful to see the extraordinary new patient housing facility that recently opened to St. Jude families. The 307,000-square-foot residential village features 140 furnished units, including one-bedroom suites and two- and three-bedroom apartments for short-term and long-term stays.

Warm hues interplay with bright bold colors in nearly every space. A nautical-themed toddler room featuring a walk-in lighthouse, toys and beach-inspired floor welcome young children. A recreation room showcases a pool table, foosball table and gaming stations for older kids. An outdoor playground includes accessible play equipment, patio tables and

a large LED movie screen. And spacious apartment suites offer all the comforts of home, from a slow cooker in every kitchen to a cozy family room.

The Domino's Village was made possible by Domino's as part of a 10-year, historic \$100 million commitment made to St. Jude in 2020. In May 2024, Domino's committed to raising a partnership total of \$300 million for St. Jude by 2034. Individual supporters and other partners also contributed to the facility.

The imaginative attention to every detail makes the new patient residence "just kind of everything," said supporter Christie Harmon.

Harmon knows firsthand the impact of having a "home away from home" for children and families staying at St. Jude during their difficult journeys.

Her family arrived at St. Jude two days before Christmas in 2015 because her young son, Sam, had a rare form of acute lymphoblastic leukemia (ALL). They stayed in patient housing while Sam was in treatment.

"Having a comfortable safe place, not only to sleep but to play, cook and have fun outdoors as well – it's just kind of everything," Harmon said. "It will mean everything for the kids and their families."

Sam loved superheroes and often wore a cape and mask on the St. Jude campus. His favorite thing to do was to pick up mail sent to him by friends and families from their Alabama hometown.

To honor Sam after his death in 2016, the Harmons established the Isaiah 41:10 Foundation to raise money for research and support of other patient families. After choosing to invest in The Domino's Village, the mail pickup room in The Domino's Village was named in honor of Sam. Harmon said seeing the mailroom now named for her youngest son was "very special."

"Families are going to be here for you don't really know how long," she said. "It is wonderful and very homey."

David and Larry Unger are long-time St. Jude supporters through The National Mah Jongg League. The brothers, from New York, provided support by naming a two-bedroom suite. A plaque outside the suite will remind families of supporters like them.



“  
Having a comfortable safe place, not only to sleep but to play, cook and have fun outdoors as well – it's just kind of everything.”

CHRISTIE HARMON, ST. JUDE  
BEREAVED MOM AND SUPPORTER

"The money that we give, you can see it goes to people that need the help. Supporting the families, the research, it just feels right to support St. Jude," David Unger said. "Seeing this facility reaffirms that St. Jude is indeed a truly special place."

St. Jude supporter Edith Kelly-Green, a cancer survivor, is comforted in the fact that donors ensure families never receive a bill from St. Jude for treatment, travel, housing or food – so they can focus on helping their child live.



St. Jude supporter Edith Kelly-Green visits The Domino's Village.

"This is just the ultimate step in taking one thing off the list of something they have to worry about and allowing them to keep their family together, a way to provide holistic family support to the child getting treatment," Kelly-Green said.

Supporters of a capital campaign like The Domino's Village help make a significant difference for patients and families while also helping drive research toward cures in facilities like the Inspiration4 Advanced Research Center,

which opened in 2021 and is named for the historic space mission led by supporter Jared Isaacman.

Substantial capital campaign investments are now helping with construction of a new 15-story Outpatient Clinic Building at St. Jude, planned for completion in 2026 among other projects. It will be accompanied by a second tower, the Clinical Office Building, that provides space for healthcare professionals and support personnel.

Jack Keffer named a one-bedroom suite in the patient housing facility and knows how much it would have meant to his late wife, Janet, to see the impact of their support.

"I just wish she was here to see St. Jude doing everything first class," Keffer said. "Seeing the rooms we sponsored, it made me feel bigger than life. Another thing that impressed me is that it is all about family. Everything is just first class."



## FY23 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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St. Jude patient **Aria**, blood cancer pictured with her mom





# Financial HIGHLIGHTS

Years ended June 30 (in thousands)

**2023**      **2022**

**REVENUES**

Total Support	2,457,562	2,415,238
Net Patient Service Revenue (Insurance Recoveries)	153,766	118,236
Research Grants	147,585	153,205
Net Investment (Loss) Income	479,296	(387,566)
Other	60,010	32,519
<b>TOTAL REVENUES</b>	<b>3,298,219</b>	<b>2,331,632</b>

**EXPENSES**

**Program Expenses**

Patient Care Services	662,358	551,616
Research	675,380	585,569
Education, Training and Community Support	311,651	256,278
<b>TOTAL PROGRAM EXPENSES</b>	<b>1,649,389</b>	<b>1,393,463</b>

Fundraising

Administrative and General	318,442	278,792
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<b>TOTAL EXPENSES</b>	<b>2,371,432</b>	<b>2,028,992</b>
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<b>LOSS ON DISPOSAL OF PROPERTY AND EQUIPMENT</b>	<b>(534)</b>	<b>(524)</b>
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Change in Net Assets	926,253	302,116
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Beginning Net Assets	9,275,669	8,973,553
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<b>ENDING NET ASSETS</b>	<b>10,201,922</b>	<b>9,275,669</b>
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St. Jude patient Micah,  
brain tumor





St. Jude patient **Mila**,  
blood cancer  
pictured with her mom

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