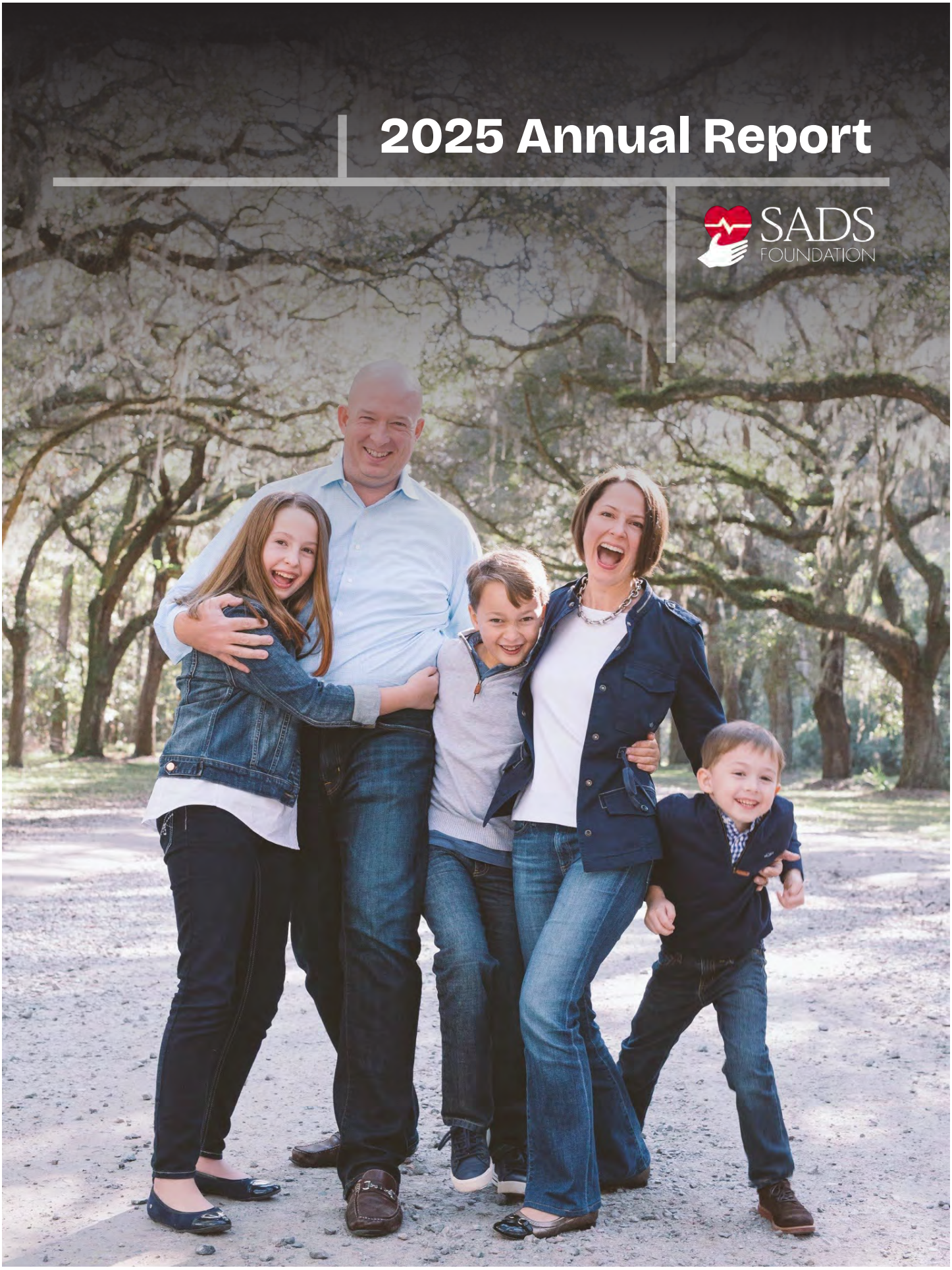
2025 Annual Report

SADS FOUNDATION



Julia, ACM. On the cover: Susan, ACM.

Dear friends, family, colleagues, and supporters,

Every year, someone finds us right after the most difficult moment of their life.

Maybe they just received a diagnosis that no one in their family had ever heard of. Maybe they lost a child suddenly – a child who seemed perfectly healthy – and they're searching for answers and for people who understand. Maybe they've carried an inherited arrhythmia condition for years, alone with the weight of it, until a stranger in an online community finally said: I have that too.

That moment of finding the SADS Foundation – that's the moment we work for.

In 2025, we worked harder than ever to shorten the distance between that moment and the help, hope, and connection people need. We reached more families, trained more healthcare professionals, and pushed further into the frontier of research than at any point in our history. The science is accelerating – gene therapy trials are no longer a distant aspiration but a present reality – and we are making sure the people who need that progress most can access, understand, and participate in it.

One particular moment captures this well. In September, the SADS Foundation met with the Centers for Disease Control and Prevention (CDC) to advocate for the creation of ICD-10 diagnostic codes for CPVT, ARVC (also known as ACM), and Brugada Syndrome.

Establishing these codes will mean better clinical recognition, more accurate data, stronger research, and lives saved through earlier diagnosis.

This type of advocacy is only possible because of what moves us every day: the families who turned grief into action, the patients who testified before the FDA so future generations might have better options, the researchers who were inspired by a family's story to think differently about a genetic variant, and the donors and volunteers who understood that this work is urgent.

This is a vital and exciting moment for our community. The research landscape is more promising than ever, and awareness of genetic heart conditions is growing. This report highlights the programs, partnerships, and people that defined 2025 for the SADS Foundation. **We hope you will see yourselves in these pages because this work belongs to you as much as it does to us.**

With gratitude,

Michael J. Ackerman, MD, PhD
President

Walker Frahm
Chief Executive Officer

Tia's children, LQTS.

2025 in Numbers

Patient Empowerment

509
Individuals supported through Family Support

19,749
Reached through webinars & SADS Lives

21,774
Members in online & peer support communities

Medical Education

2,490
Healthcare professionals reached

493
HCPs educated through accredited medical education programs

240
Providers in our Physician Referral Network

Community Reach

3,166,259
People reached through social media

56,157
People who engaged with our content

602
Donors supporting us from 47 U.S. states & 8 countries

You've seen what this community does. Now imagine what's possible with your support!
Every dollar helps us reach the next family who needs us. Visit **sads.org/2025** to make a gift.

Empowering the Whole Family

Matt, ACM.

A sudden collapse. An unexpected diagnosis. A test result that changes everything. In 2025, our **Patient Empowerment Program** showed up for 509 individuals and families like Matt's, making sure they had the knowledge, tools, and support they needed to move forward with confidence on their heart journey.

In October 2022, Matt collapsed during a dance rehearsal in New York City. He was shocked four times with an AED before waking from a coma with an ICD in his chest and no diagnosis.

The SADS Foundation was there from the beginning. "When Matt talked to Genevie, the Family Support & Research Director, he finally felt understood," says his mom, Christy.

Genetic testing confirmed that Matt had ARVC (also known as ACM). Our team connected his family with Johns Hopkins, the top program for ACM in the country, and kept supporting them as Matt's sister and father both tested positive for the same genetic variant (PKP2).

In 2025, our Patient Empowerment Program **supported 509 patients and families like Matt's** and **reached 19,749 individuals with webinars, conferences, and condition-specific resources** to give them the tools they needed to move forward with confidence.

Today, Matt is back on his feet. He performs, choreographs, and teaches at Zach Theatre in Austin. "You don't have to experience this journey alone," he says. And his family credits their "new normal" to the support they received from the SADS Foundation.

That's what our Patient Empowerment Program looks like: not just surviving a diagnosis, but living and thriving beyond it.

Building a World That's Ready

Behind every sudden cardiac arrest statistic is a family whose lives are changed forever. Nana's story is at the heart of our **Saving Lives Program** – because children like Nana deserve a world that's ready.

Delyth "Nana" Arthur dreamed of becoming a scientist or a doctor. But after a seemingly mild illness, she suffered sudden cardiac arrest and fought for five and a half months before passing away in November 2024 at just six years old.

Her mother Marie is now a certified CPR instructor. She's making sure that Nana's legacy prepares other families for a heart emergency.

We agree with Marie that knowledge saves lives. In 2025, **our digital outreach reached 3,166,259 people** across social media, generating 49,256 video views, 56,157 likes, shares, and comments; and growing our follower community to 21,378.

We distributed over 150 school nurse education packets to help school personnel recognize warning signs and connect families to care. We also signed onto federal legislative efforts – **including the HEARTS Act and Accelerating Kids' Access to Care Act** – to expand emergency preparedness and research funding for children with rare diseases nationwide.

In memory of all those we've lost, like Nana, we keep working toward a future with zero preventable deaths from inherited arrhythmia conditions.

Nana, who experienced SCA.

Getting to Answers, Faster

When a condition is rare enough that many clinicians will never see a single case, the stakes of not knowing are extraordinarily high. The SADS Foundation's **Provider Education Program** works to close that gap, reaching healthcare professionals who may be seeing the next Morgan right now.

Morgan, CPVT.

Morgan was nine years old when she passed out on the playground. Diagnosed with CPV, the active, soccer-playing girl pivoted to sewing, keyboard, singing, and Taco Tuesdays. In April 2017, she passed away after experiencing sudden cardiac arrest. She was fourteen years old.

CPVT – like other inherited arrhythmia conditions – is rare enough that many clinicians see only a handful of cases in their careers. Through our Medical Education Program, we're working to make sure that clinicians know how to diagnosis and respond to these conditions – even if they've never seen a prior case in their clinic.

In 2025, **we hosted 14 webinars, reaching 2,500 healthcare professionals**. This included an in-person presence at the Heart Rhythm Society's annual scientific sessions and collaborations with Heart University, which provides free education credits to physicians.

Kerwin, Morgan's dad, still wears the polka-dot tie Morgan sewed him for Father's Day. Their hope – and ours – is that the next child diagnosed with CPVT finds a provider who knows exactly what to do.

Far From Alone

Ruby, Brugada Syndrome.

In a rural corner of California, far from major medical centers, one family found exactly what our **Community Building Program** is built for – connection with others who truly understand.

At four months old, Daniel was diagnosed with Brugada Syndrome after a relative was hospitalized with the same condition. A few years later, his sister Ruby was diagnosed at two months old.

Their mother, Julie, who lives two hours from the nearest major city, had to navigate this rare diagnosis largely on her own – in a region where most providers still think of Brugada Syndrome as something that affects older adults, not children.

Nobody should have to navigate their heart journey alone. In 2025, we published **31 patient and family stories – reaching over 50,000 people** across our platforms – and **396 individuals participated in peer support groups**, finding solidarity that a doctor's appointment simply cannot provide.

Through the SADS Foundation, Ruby connected with Project Sunshine's Rare Disease TelePlay program and connected other kids living with rare conditions for the first time. "It was awesome for Ruby to be able to connect with other kids who understand," says Julie.

Today, Ruby is a lively, sports-loving kid who carries her own AED and has teachers trained to use it. Daniel is 12 and thriving. And with the SADS Foundation beside her, Julie is making sure her kids never have to feel alone.

We are grateful to our 2025 Corporate Roundtable for helping fund our work and move science forward for our community.

Landri, LQTS.

What the Research Is For

"You go through so much so you can live your life to the fullest. That's the reward." Through our **Accelerating Research Program**, we're working to make sure everyone like Landri has a future to fight for.

At age one, a nurse changed everything for Landri. Despite a doctor's dismissal, she pulled Landri's mother aside and told her to push for more testing – leading to a diagnosis of Jervell and Lange-Nielsen Syndrome, a rare form of Long QT Syndrome that also causes deafness.

Landri has had an ICD since age three, cochlear implants, and more procedures than most people face in a lifetime. She's also a teenager who plays sports, is learning Spanish, and is heading to Guatemala on a mission trip.

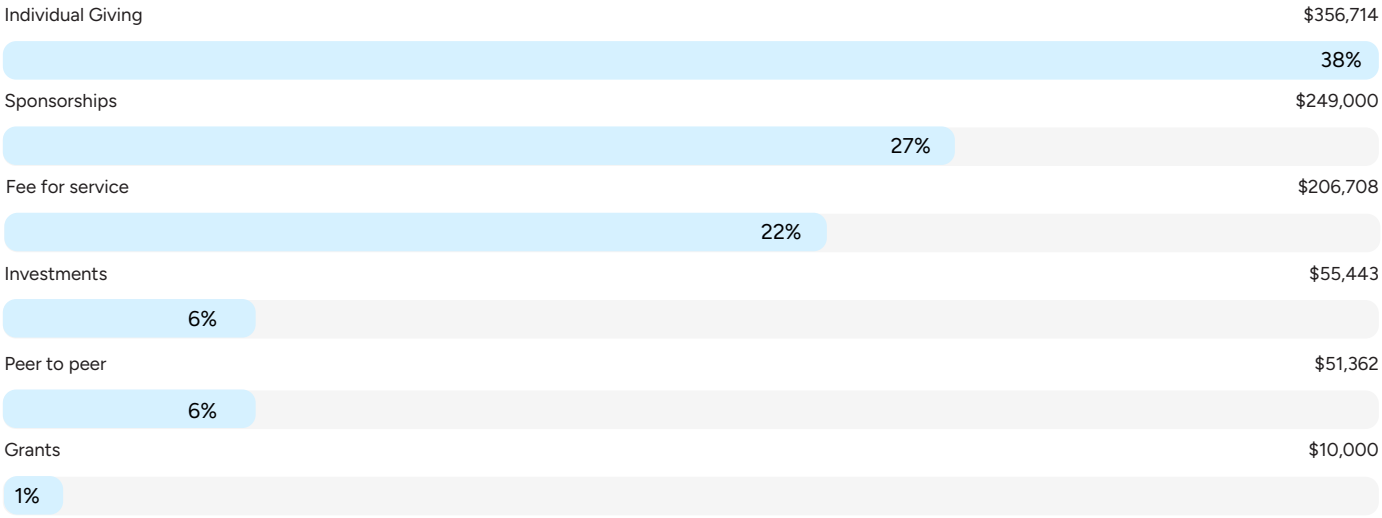
Now Landri wants to give back. She's considering a career as a device nurse – putting her insider knowledge to work for other kids on a rare heart journey. One day, Landri wants to be in that room. Our Accelerating Research program is making sure the tools are there when she arrives.

In 2025, we partnered with 12 companies across all stages of research and development, **referred 293 individuals to studies and clinical trials**, and presented to the CDC on new ICD-10 diagnostic codes for Brugada Syndrome, CPVT, and ACM – quiet, foundational work that clears the runway for the new and improved treatments our community is waiting for.

Every referral, every study, every diagnostic code points toward a full future for Landri. She hopes the research catches up. So do we.

Where Every Dollar Comes From

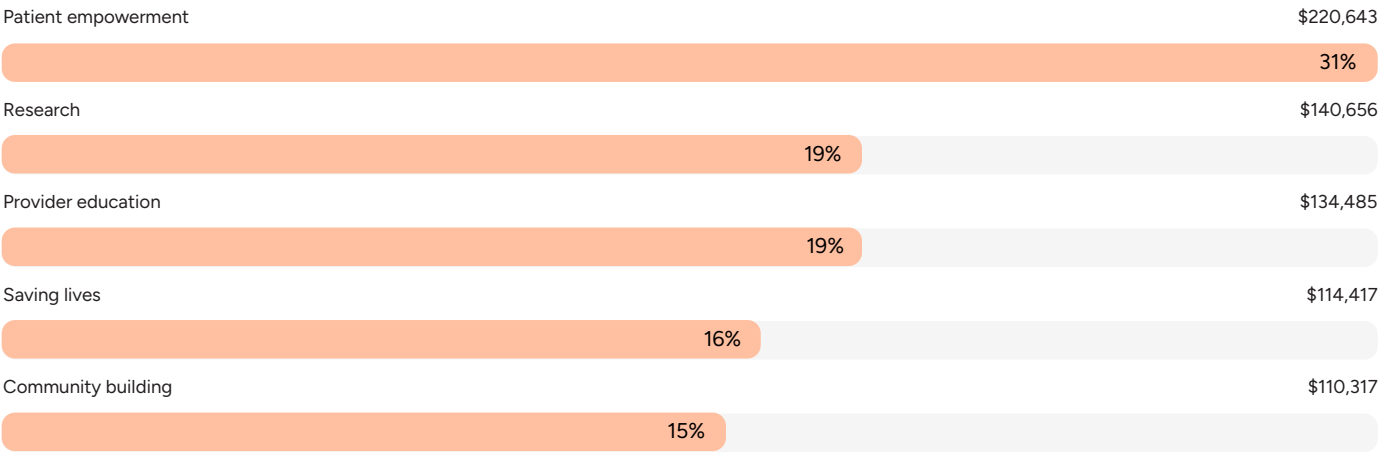
2025 Income: $929,228



Where Every Dollar Goes

2025 Total Expenses: $911,462

Programs: $720,509



Overhead: $190,952 | Management & general: $116,531 · Fundraising: $74,421