2021 ANNUAL REPORT

SADS
FOUNDATION

The SADS Foundation has been our home, our anchor and our place of safety.

Dear Families, Friends, Colleagues, and Supporters,

This year, we're marking the 30th anniversary of the SADS Foundation becoming an official 501 (c) (3) organization. As the world-leading SADS organization, we've been working with and for families through our four pillars of Awareness & Prevention, Patient & Family Support, Medical Education, and Research & Advocacy for 30 years to empower families and educate health care professionals about SADS.

The SADS Foundation, founded by Dr. G. Michael Vincent, has been a critical member in the community of experts and organizations who have advanced the diagnoses, treatment, and management of SADS so that families with SADS conditions can live and thrive.

We've come a long way. During our early years as a nonprofit, mutations were unidentified, genetic testing was not possible, and ICDs hadn't been developed. Now, progress in genetics, technology, treatment, and management means that families with SADS conditions now live much richer lives, without the restrictions of the past placed on them.

The future brings even more promise. Through advancements in personalized care, and a rise in patient-powered research, researchers will identify critical trends in the treatment of SADS conditions. And gene therapy is on the edge of breakthroughs to eliminate arrhythmias completely. Here at SADS, we promise to remain the critical link between families, clinicians, and researchers until a cure is found.

We are a part of the yesterday, today, and tomorrow of your journey with SADS – thank you for making it all possible!!

Warmest regards,

Michael Ackerman, MD, PhD
President, Board of Trustees

Alice Lara, RN
President & CEO

SADS BY THE NUMBERS

1,697
New Families Joined SADS

And found support, education, and a community to help them on their journey.

37,284
People Tuned In to SADS Live

Dr. Michael Ackerman of the Mayo Clinic & international experts answered hundreds of your questions live.

61
Legacy Donors

Raised nearly $200,000 to support our mission here at SADS in 2021.

260,658
Website Visitors

Who accessed our extensive resources like physician referrals, info for schools, and updates on drugs to avoid.

Country	Users
United States	63,505
United Kingdom	20,074
Canada	6,229
Australia	5,088
Ireland	2,563

224%
Increase in International Conference Registrants

Since our annual conference went virtual in 2020, we've reached more families than ever across the globe.

756,965 People Reached on Social Media

With 48,842 engagements, our awareness & educational posts are reaching a huge audience - and making a huge impact.

$23,000
Raised by Sustainers

By donating each month, our 36 Sustainers support both immediate needs and the expansion of innovative and life-changing programs

1,763
Families Learned from the Experts

And got the latest info about their condition & topics like ICDs and pregnancy in our 19 new webinars from international experts.

968
SADS Families Served in 2021

Through programs like support groups, one-on-one support, and referrals to expert physicians.

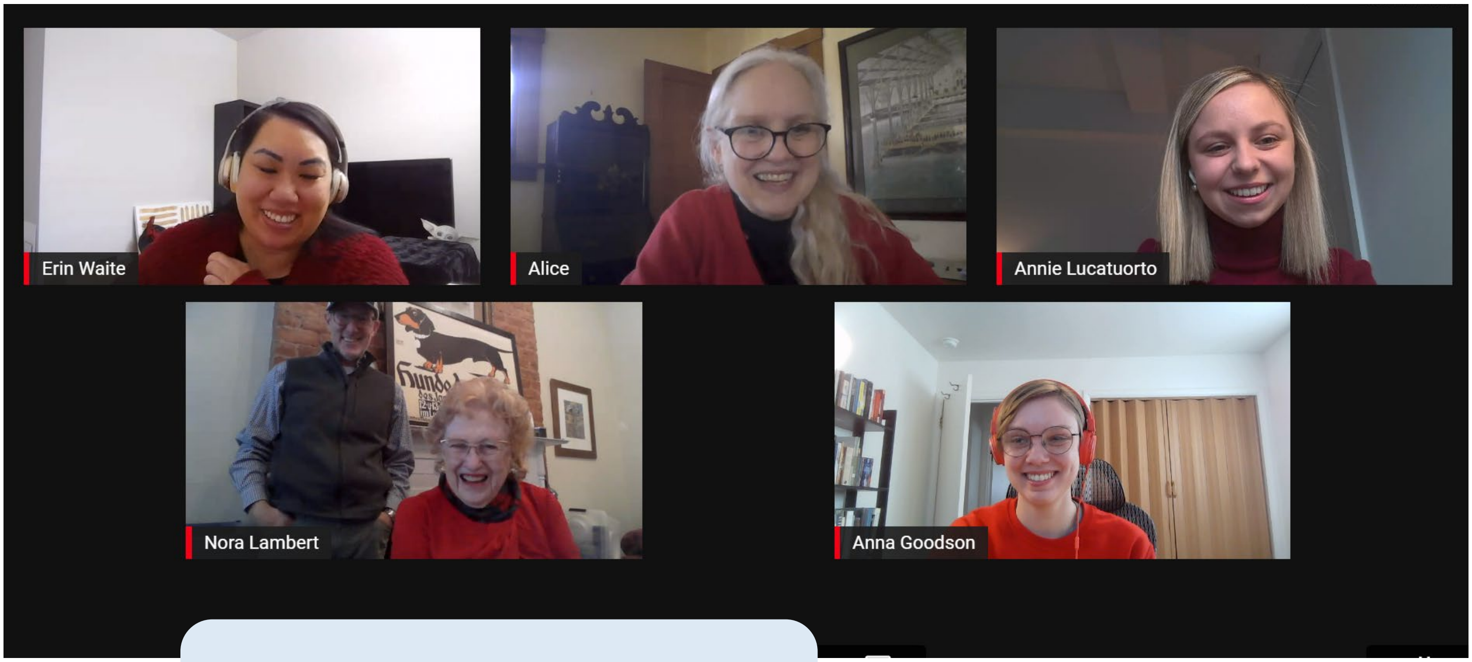
HIGHLIGHTS OF 2021

Family Support

Annie Lucatuorto, daughter of Cathleen and board member Anthony, had a cardiac arrest while swimming at a YMCA when she was ten years old. After genetic testing revealed LQTS, he got in touch with the SADS Foundation – and had other family members tested, resulting in several other diagnoses in the family. "The SADS Foundation is our rock," says Anthony. "They have been a source of information, comfort, support, and the gateway that has provided us the opportunity to meet other families who share our journey."

Anthony sits on the Board of Trustees and the Finance Committee for the SADS Foundation, where he helps us guide our Family Support services for other families – like yours. And Annie – who's now in law school – is a media volunteer for the SADS Foundation, and helps us spread awareness. "The SADS Foundation has been like a lighthouse for my family," says Annie. "We were in the dark, and they brought us into the light."

From helping find answers after a sudden death, to locating a physician with SADS expertise in your area, to helping you live & thrive despite your diagnosis through webinars and support groups, the SADS Foundation is here for you - no matter where you are on your journey.



Annie on SADS Live with volunteer Nora Lambert & Alice, Erin, and Anna from the SADS staff

> **SADS has been a great resource for me the past year and I look forward to our calls each month!**
>
> *- Jeff Bares, part of SADS ARVC ICD Support Group*

Awareness

One really impactful way to spread awareness is by sharing your heart story with your community. And Sandy Cowin, media volunteer and SADS advocate, has shared her story of Brugada Syndrome in several ways – including in her Employee Assistance Program (EAP) newsletter.

"I'm starting to get comfortable with sharing my story," she says. "I'm happy to finally start contributing to awareness in my community and now I don't want to stop!"

Her father passed away suddenly from cardiac arrest in 2009 as a result of Brugada Syndrome. Sandy and her siblings were then tested for Brugada Syndrome, but their initial test came back inconclusive. Seven years later, Sandy retested as part of a clinical trial at NYU Langone Health and tested positive.

Sandy's EAP newsletter article was distributed across the State University of New York System Offices to over 1,000 recipients, and included her story, the warning signs of SADS conditions, and info about the SADS Foundation.

Sandy was part of a group of 72 media volunteers in 2021 who shared their stories with their local media stations, radio stations, and newspapers to help spread awareness. We're thankful for media volunteers like Sandy for helping us get the word out about SADS conditions & help save lives – one story at a time.

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Volunteers Educating Our Community

Our amazing volunteer team of families, physicians and healthcare professionals help educate the SADS community, as well as their local communities, to spread awareness & improve the standard of care.

Sandy's father and her son, Jackson

Research

Kennedy Cooper's mother, Britni, died of a Sudden Cardiac Arrest in 2001 when Kennedy was six years old. "When you're six years old, and you lose a parent unexpectedly, there are so many unanswered questions," says Kennedy. "Why did she die? How did she die?"

Kennedy's grandmother, Pam, kept pushing for answers – and connected with the SADS Foundation. But for twelve years, there was still no answer for what had caused Britni's SCA. And then, in 2013, Kennedy also had a cardiac arrest. She survived, and genetic testing was now advanced enough to reveal the cause of the Cooper family's cardiac arrests: CPVT.

"It's because of the SADS Foundation that my family got answers," says Kennedy, who learned about her diagnosis from Dr. Michael Ackerman during a SADS Foundation conference in Ohio.

We're committed to advancing research on SADS conditions for families like Kennedy's – who need answers to get the treatment they need to stay safe. Research powered by the SADS Foundation helped the Coopers find answers, and we continue to work with researchers across the world to find answers for families just like yours.

Kennedy Cooper

Over 60 Challenging Clinical Cases

Over the past 4 years, our Challenging Cases program has brought together international experts to help provide guidance on difficult patient cases across the globe.

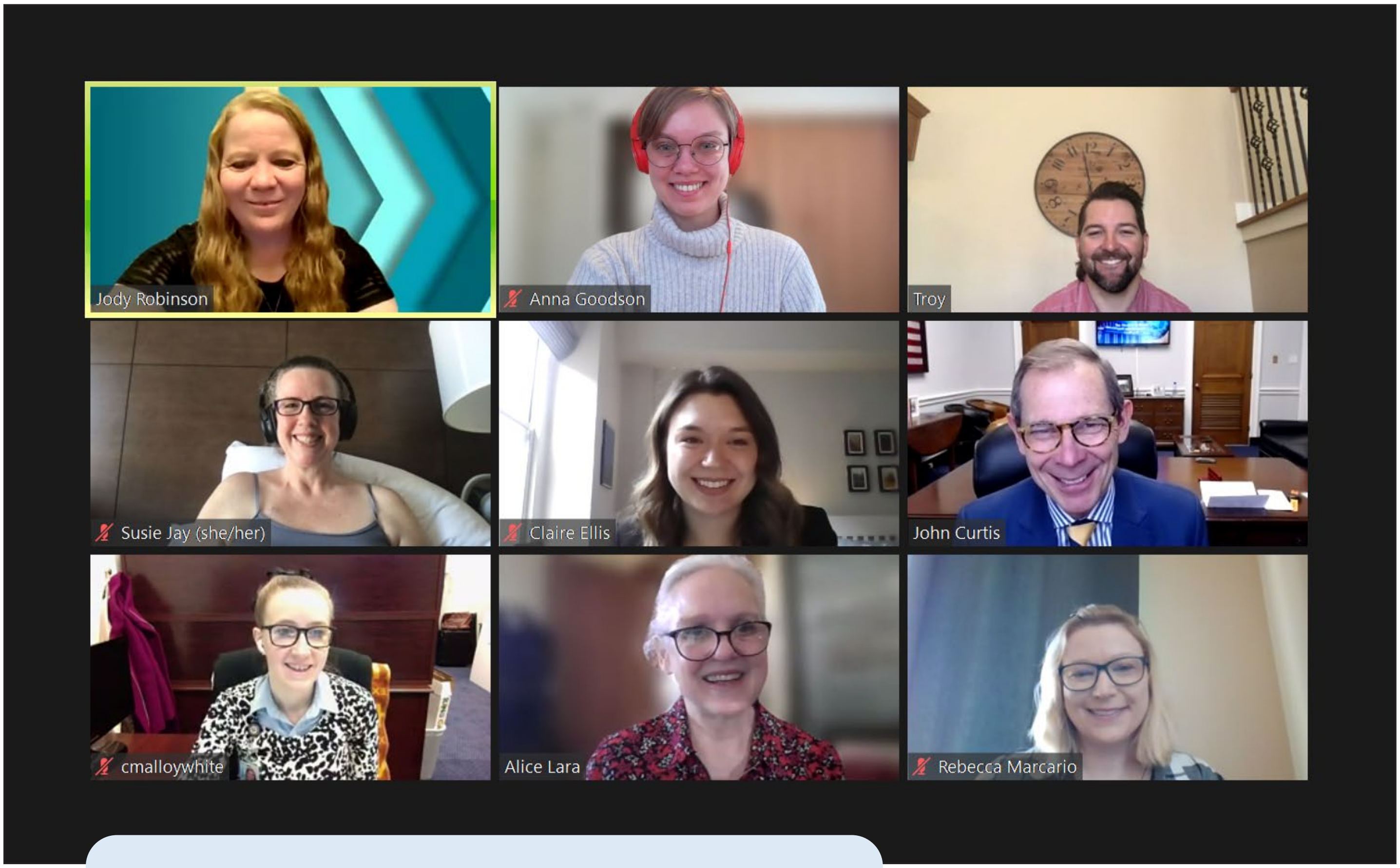
Advocacy

Access to new therapies, affordable treatment, and telehealth – these are just a few of the legislative issues that affect the SADS community. That's why the SADS staff participate in Rare Disease Week on Capitol Hill each year, and help explain to legislators why these issues impact families like yours – and which bills will help our community.

And we have an amazing team of volunteer advocates who are committed to helping us change legislation – and using their experiences, and their stories, to make a difference.

Volunteer advocate Carl Barnes has been involved with the SADS Foundation since he studied ARVC during his medical school residency. He attends Rare Disease Week to make sure that policies that affect our families – like telehealth and access to genetic counselors – are brought in front of legislators.

"We often think of rare diseases as very uncommon, but when you add all those rare conditions together, 1 out of 10 Americans have a rare condition," he says.



SADS CEO Alice and Communications Director Anna meet with Representative John Curtis during Rare Disease Week

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Hours Spent on Legislative Advocacy

Staff & volunteers learned more about the issues that impact families like yours – and the needs of the SADS community that could be addressed by federal legislation.

Medical Education

When Dr. Susan Etheridge came across a case of LQTS that seemed totally unresponsive to treatment, she submitted the case to our challenging cases program – and was able to hear from a panel of experts on possible next steps.

"This was a super complicated case of a young lady who clearly had Long QT Syndrome," says Dr. Etheridge, who's the Director of the Pediatric Cardiology Fellowship and Residency Program at the University of Utah School of Medicine and Primary Children's Medical Center, and Vice President of the SADS Board of Trustees. "She was unresponsive to everything – we had her on all sorts of medications, including mexiletine and two types of beta blockers. She had an ICD, and she got bilateral sympathetic denervation, and was still having multiple ICD shocks. Ultimately, she was uncontrollable with her heart."

Dr. Etheridge sent the case to SADS, and our scientific advisors across the globe reviewed the case. "It's always helpful to have a number of expert opinions, up to 10 or 12, concerning patient management," says Dr. Etheridge. "It was helpful on so many levels to hear from experts, and it's really helpful to share cases – both for the physician presenting them, and for the whole group, who get to experience what some of the experts think and say about different cases."

Dr. Susan Etheridge

Our Medical Education programs – like our challenging case program – are one of the core components of our work here at SADS. We're committed to supporting physicians who treat families with channelopathies through engaging expert voices and providing educational programs.

> **"We are so happy**
> *with our partnership with the SADS Foundation, and love seeing it grow. Thank you for your dedication to our patients!"*
>
> *- Crystal Tichnell, GC, Johns Hopkins University ARVC Program*

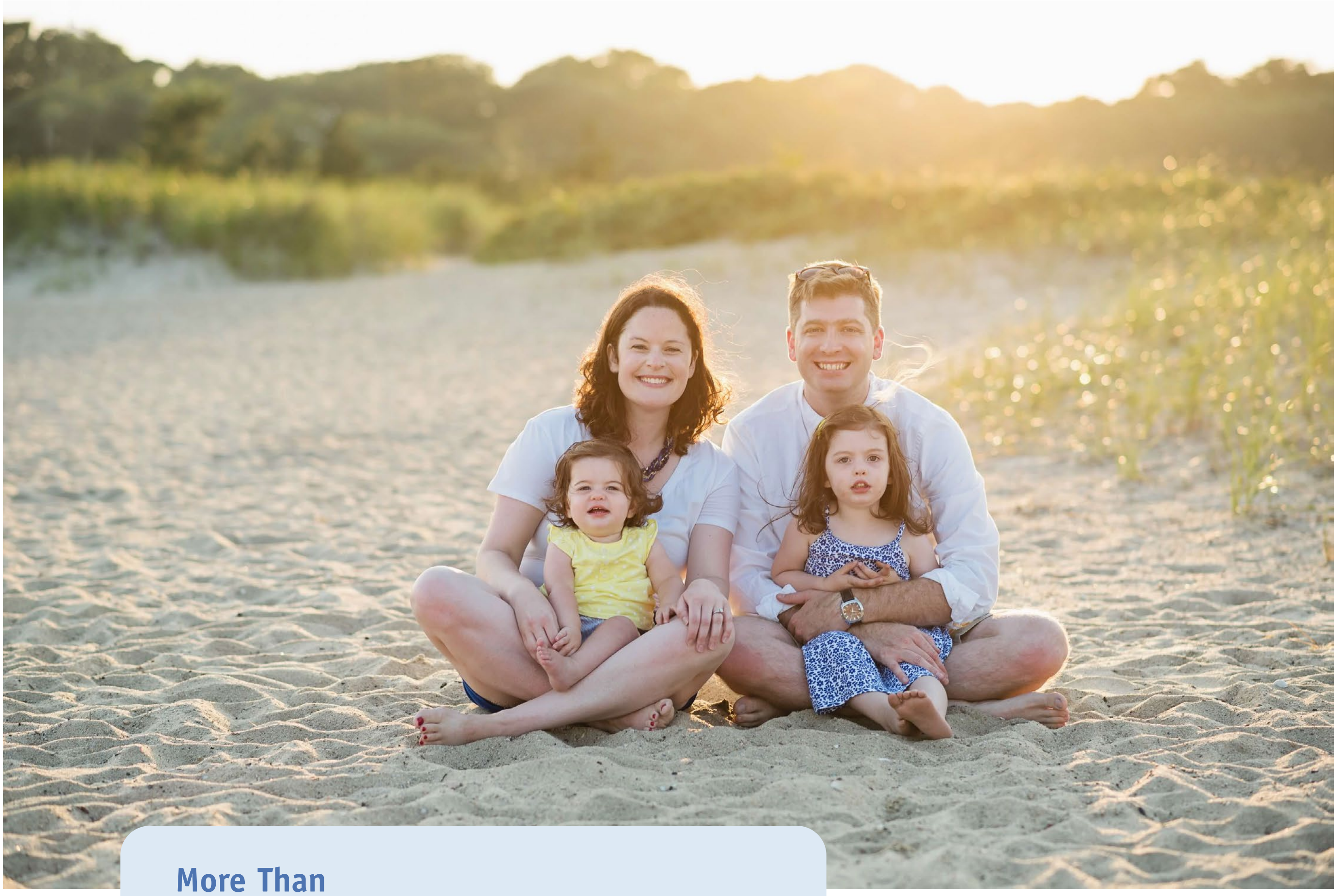
Fundraising Events

This year marks the 15th anniversary of Christie's Heartoberfest - an annual fundraiser for the SADS Foundation where friends and family gather to raise awareness and celebrate the life of Christie Tolosky, who passed away at just 24 years old from undiagnosed Long QT Syndrome.

"We loved seeing Heartoberfest grow each year, from a get together in our backyard to about 300 people joining us in memory of Christie," says Barbara Tolosky, Christie's mom. "Heartoberfest has become a gathering place for everyone who knew Christie and people getting to know her now, through the stories, photos and impact they can see and feel."

Over the past 15 years, Christie's Heartoberfest has raised approximately $150,000 for the SADS Foundation since 2006, and helped us raise awareness about SADS warning signs. "Each new person is another person aware of the warning signs, with the knowledge to make a difference," says Craig Tolosky, Christie's dad.

We are so grateful to the Tolosky family for their many years of support - and to the Toloskys (and our other volunteer fundraisers) for helping us raise funds and spread awareness. With your help, we're working towards preventing future tragedies - and helping families live & thrive despite their diagnosis.



Melissa Tolosky Russom (LQT 2 family)

More Than

$30,000

Raised by Facebook Fundraisers

101 fundraisers just like you raised more than $30,000 on Facebook alone in 2021.

SADS FOUNDATION AUDITED FINANCIALS 2021

Most of our donations come from families like yours. When you support the SADS Foundation, you help us educate physicians, support other families, and spread awareness – and we couldn't do it without you!

Why I Give

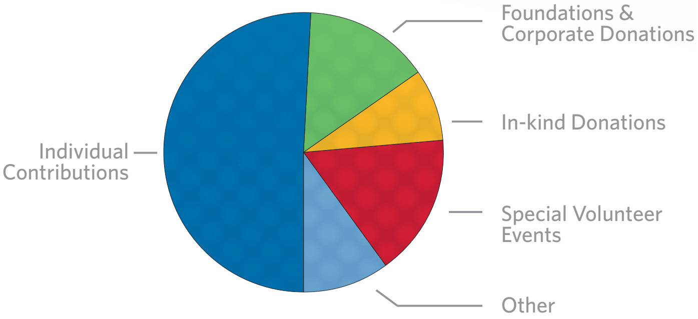
The SADS Foundation brings families together, conducts research, and has a network of doctors who can help you – and that means a lot to families like mine.

- Becky Knowles.

INCOME

Program Services

Individual Contributions	$352,478
Foundations & Corporate Donations	$101,500
In-kind Donations	$58,498
Special Volunteer Events	$111,698
Other	$69,344
Grand total	**$697,518**



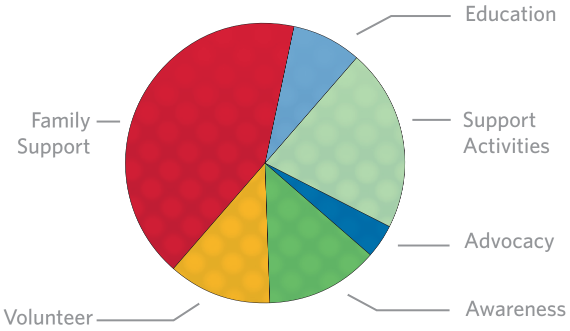
Supporting families is our mission here at the SADS Foundation – and the numbers show it! 73% of our funds are used on our programs (Programs Services) to support families like yours – through phone calls, video chats, support groups, and referrals to expert doctors. We also educate physicians so that they have the latest research and treatments available for you. And we let people know about the warning signs of SADS.

> **Having found SADS, Dr. Ackerman & SADS Live, and the Virtual Family Conference was like a gift from heaven for us. Being able to get good information, to ask questions and to see how positive we can still go on despite this condition is keeping us going.**
>
> **- Erica Heinrich, Germany**

EXPENSES

Program Services

Advocacy	$27,352
Awareness	$95,077
Volunteer	$86,567
Family Support	$307,130
Education	$54,881
Total Program Services	**$571,007**
Support Activities	
Management & General	$51,495
Fundraising	$101,062
Total Support Activities	**$152,557**
Total Expenses	**$723,564**



THANK YOU

Platinum Legacy Circle
$100,000

Courts K. Cleveland Foundation (endowment)

Gold Legacy Circle

Frederick and Diane Smith

Bronze Legacy Circle

Joanna Bewick
Alan and Pam London
Steele Family Foundation

Legacy Circle

Michael Ackerman, MD
Kelly Airey, MD
Donna Gaul and Russell Bobo
Priscilla and Anthony Beadell
Ellen Boles
Carlos and Lois Ann Bowman
Robert and Rita Campbell, MD
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Devon Rudloff
Maureen and William Schulman
Tommy Schuman Foundation
Linda and Bill Shockley
Lindsey and Steve Shockley
Glenda Stafford and LaDonna Watson
Linda B. and Howard S. Stern Family Foundation
Judy and Philip To
Nancy Walker
Eileen and James Wilkoff Philanthropic Fund
Cathy and Brian Zbanek

> **It constantly amazes me how much SADS has done over the years to educate our doctors and communities about heart arrhythmias and the benefits of having AEDs in public spaces, as well as the research that's happened in both genetics and in the underlying causes of so many different types of arrhythmias.**
>
> **- Judi**

$1,000-$500

Keona Allen
Gail Bartok
Pam Batten
Jodi and Richard Bewick
Kathi and Scott Blum
Camille and Stephen Coale
Jeff Coburn
Adrienne and Greg Coleman
Steve and Karen Compton
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John and Frances Parker
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Jordan Schraeder
Maureen and William Schulman
Sarah Shaw
Linda and Bill Shockley
Lindsey and Steve Shockley
Michelle and Peter Sollimo
Robert Stevens
George Welki
Lisa Yost
Jeralyn Zoch

Corporations
$25,000 or more

Medtronic

$24,999-$10,000

Boston Scientific Corporation
Invitae Corporation

$9,999-$5,000

Ambry Genetics
LifeSure Home AED Solutions

$4,999 or less

GeneDX
Philips

Foundations

$25,000 or more

Sorenson Legacy Foundation

$5,000 or less

Home for Orphans of Oddfellows of Pennsylvania

> **The SADS Foundation has been our home, our anchor and our place of safety – from providing information and getting us to the doctors that we needed, to helping us with resources like getting AEDS in our children's schools and in our home.**
>
> **- Julie Kotraba**

Matching Gifts

AARP
America's Charities
Boeing, Inc.
C N A Foundation
Google Employee Giving
Keybank
Liberty Mutual
Lockheed Martin
Medtronic
Microsoft Corporation
PepsiCo, Inc.
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Aiden Bewick
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Mandi and Madison Chesser
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Carson Patrick Coale
Josh Crutchley
Steve, Alora, and Alaraic Dennison
Melisa Doker
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Austin, Alexis, and Kaiden Ellis
Susan Etheridge, MD
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Sally Layton
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Noah Liasu
Annie Lucatuorto
Selena Lustig
Barbara Masters
Jorge McCormack, MD
Sharon and her son Billy McCrae
Matthew Osterhout and Britni Osterhout Cooper
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Timothy Syndrome Alliance
Tolosky Family
Brittany Valene
Kristyn Valene
Valerie Vivian
Emily Voigt
Abrielle Watschke
Samantha Wilder
Kristi and Sam Yeager

> **My son started his new job in Des Moines this week. Thanks to the SADS Foundation I'm okay with him moving 1,360 miles away.**
>
> **- Jill Collinson**

Memorial Funds

Elijah and Chloe Allen
John A. Antonell and Dorothea T. Antonell
Lois Barfield Robinson
Richard J. Barrett
Allison Bauer
Rosemary Bellavance
Inez Marie Bewick
Cynthia Boles Dailard
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Sarah Megan Callister
Lee Ciciarelli
Dwayne Archer Chow
Beau Cordova
Gregory Cove
Monte Davis
Brian Falzon
Mikhail Gertsberg
Emily Granath
Emma Greenspan

Lead Singer John Lambert III of Take 5 at our first Annual Jazz Night for SADS in Salt Lake City, UT

THANK YOU

Britnee Hatch
Jon and Kristen Hohulin
Ellen Wardlaw Hollums
Greg Holthaus
Jake Horton
Rob Kaas
Sandra Kneipp
Kelly Ann Kottmeier
Kerry Char Kottmeier
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James Renner
Thomas David Reubens
Evan Wayne Riepe
Rebecca Righeimer

2021 was the 17th year of Brittany's Trees, which raises funds for the SADS Foundation in memory of Brittany Valene

Kimberly Tanya Robinson
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Wayne Sawyer
Annie R. Schnitzler
Kerry Ann Schulman
Gregory Shea
Casey Lynn Shockley
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John and Will White
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Adam Walter Wilkens
Emma Jean Whorley Brown

For a complete listing
visit StopSADS.org

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Elijah Behr, MD
Scott R. Ceresnak, MD
Brynn Dechert Crooks, NP
Cynthia A. James, PhD
Prince Kannankeril, MD, MSCI, FHRS
Thomas Paul, MD, FHRS
Silvia G. Priori, MD, PhD
Shubhayan Sanatani MD, FHRS, CCDS
Jennifer Avari Silva, MD, FHRS, FACC, FAHA
Reina Tan, MD
Arthur Wilde, MD, PhD

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Yukiko Asaki, MD
Peter Aziz, MD
Elijah Behr, MD
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Ana Morales, MS, GC
Brittney Murray, MS, CGC
Kellie Moore
Melissa Russom

> **I've run 10Ks, played football and snowski, all because of the research done by your organization. Thank you.**
>
> **- Matt Lambert**

Shubhayan Sanatani, MD
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Danna Spears, MD
Katherine Standefer
Janette Strasburger, MD
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Arthur Wilde, MD, PhD
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Jennifer White, MD
Heather MacLeod, MS, CGC

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Brynn Dechert Crooks, NP
Deena Edwards, MS, CGC
Kathryn M. Edwards, MD
Susan Etheridge, MD
Rachel Flores, RN
Andy Golden, PhD
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Aimmy Tse
Tony Valene
Sami Viskin, MD
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Vicki Freedenburg, NP
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Sarah Lancour at Rachel's Race, which has raised funds for the SADS Foundation in memory of Rachel Lancour since 2016

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