Thank you and the organization for helping my son and our family. I will always be indebted to all of you.

I'M SO THANKFUL I FOUND THE SADS FOUNDATION.

2019 ANNUAL REPORT

SADS
FOUNDATION

2019 SADS FOUNDATION ANNUAL REPORT

Dear Families, Friends, and Colleagues,

On behalf of the SADS Foundation Board of Trustees and staff members, we would like to express our heartfelt gratitude for the many members of our SADS community who generously gave of their time, talent, and treasure. Through this selfless support, the SADS Foundation continues to achieve far beyond the size and scope of our organization.

Our SADS families provide us with inspiration each and every day as they triumph in their lives as well as give of themselves to the Foundation and to other families. The SADS Foundation continues to expand and enhance our services so that people with SADS conditions may live and thrive. During this past year, we increased our efforts to prevent young avoidable deaths, to educate and support SADS members, to ensure medical professionals have the most current knowledge to diagnose and treat SADS conditions, and to encourage research to improve treatments and find a "cure".

The SADS Foundation is proud to carry on the mission of our founder Dr. G. Michael Vincent and the original founders. Now, as before, we believe in working as a team comprised of everyone who has a vested interest to improve the lives of individuals at risk of sudden cardiac death. We have made much progress since we began in 1991, but still we know that there is more progress to come--the future will bring breakthroughs that already are in development and ones that are still to be discovered. The SADS Foundation will continue to play a valuable role in the days to come.

As you review this Annual Report, we hope you take a moment to appreciate the many individuals and organizations that come together each year in their own way and are a vital part of our success. We thank all the families who spread awareness, raise funds, and strengthen the SADS community. We thank all the medical professionals who care for SADS families, educate other health care professionals, and lead the way in treatment and research. We thank all the allied friends and organizations who partner with us to provide programs and services. Without each of you, the SADS Foundation could not support families and save lives.

With genuine gratitude,

Michael Ackerman, MD, PhD
President, Board of Trustees

Alice Lara, RN
President & CEO

> **As a support person to someone with SADS, this organization has helped me to better understand their condition.**
>
> **I am so grateful to the SADS Foundation for the news on disease and stories and connections with other families made at the conference.**

WHO WE ARE

MISSION

The Sudden Arrhythmia Death Syndromes (SADS) Foundation exists to save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

VALUES

It is important that values and beliefs be shared between SADS families, medical professionals, researchers, educators, board members, and staff members. The values of passion and compassion are the underlying forces that carry us to fulfill the purpose and mission of The SADS Foundation.

GOALS

1. Increase Awareness of SADS Foundation and SADS Warning Signs: Increase the general public's knowledge of the warning signs that may identify the child or adult at risk for sudden cardiac death.

2. Enhance Patient and Family Support: Provide information, resources, and support to assist children and their families to make informed medical decisions and to live and thrive despite the challenges of these conditions.

3. Expand Education to Health Care Professionals: Facilitate early recognition and accurate diagnosis and treatment of heart rhythm abnormalities by ensuring that healthcare providers have all available current and relevant information.

4. Increase Advocacy for Research, Screening (Diagnosis) and Medical Treatment: Encourage increased arrhythmia research, nondiscriminatory treatment and efforts that will improve the quality of life for patients with heart rhythm abnormalities.

Brittany's Trees Gang

The SADS Foundation creates a sense of community with others who share the same illness that I and my family have.

The SADS Foundation helped me discover how SADS families are supposed to be supported. I have been accepting sub-par care and now am excited about the care and support that I will be receiving from now on.

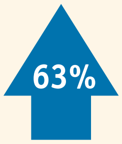
Celebrating Samantha's 40th Birthday

SOCIAL MEDIA

Each month, 8,185 households received the SADS Foundation E-Newsletter full of the most recent SADS information, family stories, and activities.

Social Media became an increasingly important venue to connect with our families that featured the following:

- More than 33,000s of SADS Blog stories and posts from our SADS families
- More than 5,000 followers on Facebook (a 16% increase over prior year)
- More than 300 followers on Instagram (a 63% increase over prior year)
- Approximately 1,800 followers on Twitter (11% increase over prior year)

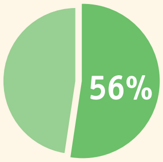


Additionally, we are a critical resource for the latest SADS information for nearly 14,000 participants who are part of several volunteer-directed Facebook support groups by condition.

DEVELOPMENT

SADS families held 16 volunteer fundraising events raising nearly $90,000 for the SADS Foundation's mission.

Individual contributions, including the volunteer fundraising events, were 56% of the SADS Foundation's total revenue.



Because of amazing SADS families and their supportive friends we continue to save young lives!

Dr. Mike Ackerman, Courtney Waller with her child's portrait, Dr. Janette Strasburger and Katherine Timothy at the Beyond the Diagnosis art unveiling, SADS Conference, Atlanta.

Courts K Cleveland Young Investigator Clinical Award L-R: Michael Ackerman, Sponsor Arthur Wilde, Alice Lara, YIA Krystien Lieve of Amsterdam AMC and Maully Shah, PACES President.

THANK YOU

Platinum Legacy Circle $100,000 Endowment

Sally Cleveland - Courts K. Cleveland Foundation

Gold Legacy Circle $99,999-$50,000

Frederick and Diane Smith

Bronze Legacy Circle $24,999-$10,000

Joanna Bewick
Alan and Pam London
Brooke Morrow
Linda B. and Howard S. Stern Family Foundation

Legacy Circle $9,999-$1,000

Michael Ackerman, MD, PhD
Kelly Airey, MD
Priscilla and Anthony Beadell
Donna Bobo
Ellen Boles
Carlos and Lois Ann Bowman
Penelope Boyden, PhD
Robert Campbell, MD
Mary Carr
Steve and Karen Compton
Linda Cowley
Scott Dailard
Martin Elias
Julia Eslinger
Susan Etheridge, MD and Michael Pond
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Mary Ellen Rowan
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Maureen and William Schulman
Dan Schuman-Tommy Schuman Foundation
Sarah Shaw
Linda and Bill Shockley
Lindsey Shockley and Steven Edel

Jim Guthrie, Tony Valene, and the Bagpipe Player who kicks off Brittany's Trees

CONTINUED THANK YOU

Glenda Stafford and La Donna Watson
Ronald W. Steele-Steele Family Foundation
Judy and Philip To
Nancy Walker
Samantha Rae Wilder
Eileen and James Wilkoff-Eileen Philanthropic Fund
Cathy and Brian Zbanek

$999-$500

Omar Alibrahim
Melinda Asp
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Mary and Bruce Beauchamp
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Jodi and Richard Bewick
Kathi and Scott Blum
Darren and Mariesol Chamberlain
Mary Ann Ciciarelli
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Glendda Dawley
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David and Kathy Salisbury
Sarah Shaw
Anne Soto
Katherine and Michael Timothy
Svjetlana Tisma-Dupanovic, MD
Harry Ungeheuer
Lamar and Wanda White

SADS Sustainers of Hearts

Michele Alatorre
Keona Allen
Paul Allonby
Norene and Kent Berry
Joanna Bewick
Jodi and Richard Bewick
Darren and Mariesol Chamberlain
John Contrata
Lee and Caitlin Cooper
Genevie Echols
Julia Eslinger
Tara Filiatreau
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Barbara Mattison
Victoria Pepper
Jim Peterka
Cornelio Reformina
Maureen Schulman
Sarah Shaw
Jennifer Shea
Linda and Bill Shockley
Lindsey and Steve Shockley

Attending a SADS Conference was AMAZING! I would highly recommend going to anyone diagnosed with a SADS condition. Having that personal connection with other families, meeting the team at the SADS Foundation, the hearing from doctors brought in to present is so extremely helpful.

I just received a letter from my insurance company that they will cover my genetic test after they had previously denied it. I sent information from the SADS support group and I really believe it helped to support that genetic testing is the standard of care.

Isabella and Rachel Flores with Dr. Chad Mao at the SADS Conference in Atlanta

Scientific Advisors

Peter J. Schwartz, MD (Chair)
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Dominic Abrams, MD
Boston, MA
Michael J Ackerman, MD, PhD
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Utica, NY
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Cleveland, OH
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Wynnewood, PA
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Fairfax, VA
Marina Cerrone, MD
New York, NY
Isabelle Denjoy, MD
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Prince Kannankeril, MD/MSCI
Nashville, TN
Ron Kanter, MD
Miami, FL
Ian Law, MD
Iowa City, IA
Heather MacLeod, MS, CGC
Elmhurst, IL
Jorge McCormack, MD/MBA
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James C. Perry, MD
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Sylvia Priori, MD
Pavia, Italy
Dan M. Roden, MD
Nashville, TN
Shubhayan Sanatani, MD
Vancouver, BC
Phil Saul, MD
Morgantown, WV
Georgia Sarquella-Brugada, MD
Barcelona, Spain
Katherine Timothy
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Jeffrey A. Towbin, MD
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John Triedman, MD
Boston, MA
Martin Tristani-Firouzi, MD
Salt Lake City, UT
Victoria L. Vetter, MD
Philadelphia, PA
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Tel Aviv, Israel
Arthur Wilde, MD
Amsterdam, Netherlands
Raymond L. Woosley, MD, PhD
Phoenix, AZ

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Marcia Baker, *Director of Programs*
Jan Schiller, *Director of Development*
Rachel Goss, *Program Coordinator*
Mikayla Viny, *Awareness & Outreach Coordinator*
Erin Waite, *Administrative Coordinator*

CONTINUED THANK YOU

Peter and Michele Sollimo
Robert Stevens
Jennifer Walker
George and Jodi Welki
Samantha Rae Wilder
Kristi and Brent Yeager
Jeralyn Zoch
Anonymous from United Health Care

Corporations

$49,999-$25,000

Boston Scientific Corporation

$24,999-$10,000

Invitae Corporation
Medtronic, Inc.

Atlanta was our first conference and we realized how great it was for us to attend.

$9,999-$5,000

Sibley Heart Center

$4,999 or less

Ambry Genetics
Blueprint Genetics Ltd.

Foundations

$10,000

Sorenson Legacy Foundation

$5,000 or less

George S. and Dolores Doré Eccles Foundation
Home for Orphans of Oddfellows of PA

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America's Charities
Boeing, Inc.
C N A Foundation
Google Employee Giving
PepsiCo, Inc.
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Landon Thagard
Sarah & Harper Thomas
Gregory Totero
Stephanie Tubergen
Madeline Valdivia
Victoria Vetter, MD
Ryan Weidler
Dale Yoo, MD

Kaleb Echol's Eagle Scout 5k

Casino Night

Zoe and Melissa Price with Betty Glasheen during Shelton School's annual jump-a-thon in memory of Bryan Price.

Memorial Funds

Brett Anderson
Brian Anderson
Brianna Badger
David Barr
Richard J. Barrett
Elizabeth Barry
Allison Bauer
Rosemary Beilavance
Samuel E. Berry
Challis Blum
Cynthia Boles Dailard
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Mathew Chiapetta
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Britni Cooper and Matt Osterhout
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Elisa Feldman
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Nicholas Alexander Funk
Timothy Greene
Stevie Grieshammer
Frederic Hatet
Justin Garrett Hendrix
Sandra Henery
Jon & Kristen Hohulin
Ryan Horton
Jake Horton
Ian Hyzy

AWARENESS CAMPAIGNS

Raised awareness of SADS warning signs to identify kids with SADS conditions and what to do if an SCA happens with 95,000 reaches were made on Facebook and 126 Red Kits were mailed during February National Heart Month.

Celebrated CPR & Awareness Week during June with more than 10,000 reaches and impressions on social media.

10K

Ensured your kids and everyone else are heart safe at school with 14,000 reaches on social media and over 100 SADS Safe Schools Kits were mailed during SADS Safe School Month.

Broadened awareness about CPR and AED Training with 60,000 reaches on social media during October SCA Awareness Month through the Call-Push-Shock campaign.

Increased family awareness of SADS conditions to make certain everyone who has a SADS condition is appropriately treated with 22,000 reaches on Facebook, Twitter and Instagram during November Family Health History Month.

Volunteer Award Drs. Robert Campbell and Mike Ackerman

MEDICAL EDUCATION

Nearly 5,000 health care professionals strengthened their knowledge of SADS conditions through live webinars and podcasts sponsored by the SADS Foundation. These remain available as downloads.

Co-sponsored with Children's Healthcare of Atlanta, the SADS Foundation hosted an accredited healthcare provider conference, led by Dr. Robert M. Campbell and attended by approximately 100 physicians, nurses and genetic counselors.

The SADS Foundation International Scientific Advisory Council of world-leading experts was presented with 16 Difficult Cases and 5 Family Cases to review and then to give their suggestions for best possible care and treatments.

The SADS Foundation also connected 200 family members through Physician Referrals to pediatric and adult EPs to make certain they received the best care from the needed specialists.

Through SADS Foundation presentations at medical conferences, at least 1,700 healthcare professionals (emergency medicine physicians, nurses, residents, and medical students learned about diagnosing SADS conditions and the latest in research and treatments.

Once more, the SADS Foundation Courts K. Cleveland, Jr. Young Investigator Awards in Cardiac Channelopathy Research were presented to students and mentors in coordination with PACES to encourage the next generation of researchers in SADS conditions.

CONTINUED

THANK YOU

Robert Oliver Jacobs
Cody Jordan
Rob Kass
Bob Kelley, MD
Donna Marie Kelly
Jake Kiester
Sandy Kneipp
Kelly Ann Kottmeier
Jenny Lemay
Ryan Lewis
Liza Lowe
Johnny, Ginger, Kevin Mann
Barbara Palaska Masters
Danny Mauriello
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Mary Elizabeth Poutt
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Nora Shuman
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Stephen Smith
Windland Smith Rice
Gray Solana
Jeffrey Peter Stiefield
Sarah Stier
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Francis Carleton Strand
Joe and Daniel Talomie
John Thalhimer
Michael W. Todd
Christie Tolosky
Mark Van Dyke
Matt Vandercook
G. Michael Vincent, MD
Abbey Wambach
Jonathan Welki

For a complete listing visit StopSADS.org

RESEARCH AND ADVOCACY

The SADS Foundation promoted 14 different research studies to encourage enrollment of SADS patients and families to advance science directed towards improved treatment and discovering a cure.

Thousands of families were kept up to date through SADS Actions Alerts on NIH research funding and implantable cardiac device updates.

The first ever Research BY the Patients...FOR the Patients Session was held at our Atlanta Family Conference where families gathered to generate ideas to build online patient communities and advance patient-centered research.

PATIENT AND FAMILY SUPPORT

SADS Foundation team members helped guide more than 1,000 patients and families (29% increase) on a successful journey with a SADS condition so that they may live and thrive in their daily lives through phone calls, e-mail messages, and physician referral services.

Families from 24 separate states and 4 international countries came to learn, connect, and build together at the 12th International SADS Foundation Conference in Atlanta, Georgia.

Kaleb Echol's Eagle Scout 5k

Christie's Heartoberfest

CONTINUED
THANK YOU

Thanks to our 2019 Conference CME Program Committee and Speakers

Robert Campbell, MD-Children's Healthcare of Atlanta, GA
Brynn Dechert-Crooks, RN, MSN, CPNP, CCDS-C. S. Mott Children's Hospital, Ann Arbor, MI
Erin Demo, CGC-Children's Healthcare of Atlanta, GA
Susan Etheridge, MD-University of Utah School of Medicine, Salt Lake City, UT
Linda Knight, MS, CGC-Children's Healthcare of Atlanta, GA
Richard Lamphier, RN-Children's Healthcare of Atlanta, GA
Alice Lara, RN, BSN-SADS Foundation, Salt Lake City, UT
Patricia Simpson, FNP-BC, RN, MSN-Children's Healthcare of Atlanta, GA
Robert Whitehill, MD-Children's Healthcare of Atlanta, GA

Speakers
Dominic Abrams, MD
Michael J. Ackerman, MD, PhD
Peter Aziz, MD
Charles Berul, MD
Robert Campbell, MD
Aarti Dalal, DO
Soham Dasgupta, MD
Erin Demo, MS, CGC
Susan Etheridge, MD
Peter Fischbach, MD
Ronald Kanter, MD
Prince Kannankeril, MD
Trudy Kremer
Heather MacLeod, MS, CGC
Patricia Simpson, FNP-BC, RN MSN
Bruce Stambler, MD
Jennifer White, MD
Robert Whitehill, MD

Thanks to our 2019 Family Conference Committee and Speakers

Committee Members
Genevie Echols
Andy Golden, PhD
Amanda Koch
Sharon Lentino
Alan London, MD
Aimmy Tse

Speakers
Dominic Abrams, MD, MRCP, MBA
Michael Ackerman, MD, PhD
Peter Aziz, MD, FHRS
Charles Berul, MD
Robert Campbell, MD
Jennifer Cory, MS, MAPP, LCSW
Aarti Dalal, DO
Brynn Dechert-Crooks, MSN, CPNP
Thomas Deering, MD
Erin Demo, MS, CGC
Susan Etheridge, MD
Peter Fischbach, MD
Rachel Flores, RN
Sally Goza, MD

The Mundondo Family at Hops for Hearts

Learning CPR and AED Use at Christie's Heartoberfest

Prince Kannankeril, MD
Ronald Kanter, MD
Linda Knight, CGC
Richard Lamphier, RN
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Lisa Mills RN
Brittney Murray, GC
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Matthew Sorensen, MD
Bruce Stambler, MD
Janette Strasburger, MD
Crystal Tichnell, MGC, RN
Jennifer White, MD
Robert Whitehill, MD

Timothy Syndrome Alliance Speakers

MaryAnn Ciciarelli–TSA Parent
Andy Golden, PhD
Heather MacLeod, MS, CGC
Maureen McComas-TSA Parent
Geoffrey Pitt, MD
Paul Thornton, MD
Katherine Timothy
Les Vines–TSA Grandparent
Courtney Waller–TSA Parent

TSA group at Atlanta Conference

I love the webinars, have enjoyed in-person seminars, and look forward to newsletters from the SADS Foundation.

The SADS Foundation has been a great support system for myself and my family from the moment my son received his diagnosis.

Volunteer Fundraising Events

Brittany's Trees	Illinois	Tony Valene, Jim Guthrie, and Team
Brittany's Trees	Illinois	Lentino Family
Heartoberfest	New York	Tolosky Family
All for Al	Illinois	Bauer Family
Celebrating Samantha's 40th Birthday	North Dakota	Laurie Sayre
Gertsberg Memorial 5k	Connecticut	Gertsberg Family & Friends
Holiday Hoop Fest	Georgia	Solana Family
Hops for Hearts	Pennsylvania	Mundondo Family
Jumpathon	Texas	Shelton School
Kaleb's Eagle Scout 5K	Minnesota	Kaleb Echols
Rachel's Race	Wisconsin	Lancour Family
Rob Kaas Memorial Golf Tournament	California	Rob's Family and Friends
Rocks for Ryan	California	Mari Lewis
Ryan Weidler Golf Tournament	Pennsylvania	O'Donnell, Weidler, Speece Families
Super Lee Charity Golf Tournament	California	Michael Harrington and Friends
Stevie Grieshammer High School Preview Meet	Ohio	Great Lakes Sailfish Swimming, Inc.

Brittany's Trees Gang

I find value in seeing things written by other people with SADS regarding treatments and therapies that are being used now.