

2020 ANNUAL REPORT

SADS FOUNDATION

SADS Foundation made me feel better about being different and reminds me I am not alone—there are others just like me!

- Bella Alvarez, Age 11



Dear Families, Friends, and Colleagues,

It's been quite a year, but together we have turned challenges into opportunities to connect with you and even more SADS families in new, exciting ways. On behalf of the SADS Foundation Board of Trustees and staff members, we would like to thank the many members of our SADS community who helped us during this difficult year. You keep us moving forward, no matter what, and we're deeply grateful for your support.

We are forever grateful to the many specialists and experts who have donated their time and allowed us to bring our SADS families the best and brightest in the field. And as we look into the future towards new advancements in treating SADS conditions, we also took time this year to recognize pioneers in the field, whose combined efforts built the foundation for today's research and advocacy. Their work led to the discovery of genes for Long QT Syndrome types 1, 2, and 3, and Timothy Syndrome, and we would like to express our thanks to Mark Keating, MD; Michael Sanguinetti, PhD; Igor Splawski, PhD; and Katherine Timothy for their groundbreaking research.

This has been a year of exciting growth for us – but it has been a year of loss as well. This year we lost our founder, Dr. G. Michael Vincent, whose visionary work changed the lives of thousands of patients and paved the way for what the SADS Foundation has accomplished. We continue to miss Dr. Vincent's guidance and friendship as we work to bring his vision to life.

We hope you'll join us as we reflect on this year's accomplishments and celebrate the many community members who make our work at the SADS Foundation possible. Thank you to our volunteers and families who find ways to fundraise and support each other virtually, to our amazing medical professionals who help us bring answers to the SADS community, and to our partner organizations who help us provide programming – we are grateful for all of you who continue to help the SADS Foundation save the lives of those with inherited arrhythmia conditions.

Warmly,

Michael Ackerman, MD, PhD
President, Board of Trustees

Alice Lara, RN
President & CEO

THANK YOU

Platinum Legacy Circle \$100,000 Endowment

Brooke Morrow
Courts K. Cleveland
Foundation (endowment)

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

John Carlson
Frederick and Diane Smith

The team has brought together true thinkers and clinicians in the field and made them part of the foundation, the international conferences, and the scientific board. I'm more impressed every year by how much visibility this organization has among patients and the medical community.

- Susan Etheridge, MD, Primary Children's Medical Center, Board Vice-President

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

Joanna Bewick
M. A. Dyster-Camann
Penni-Lynn Foley
Alan London
Harold Reubens
Ashok Singh, MD
Linda B. and Howard S. Stern
Family Foundation

Legacy Circle \$9,999-\$1,000

Michael Ackerman, MD
Kelly Airey, MD
Carl Barnes, MD
Priscilla and Anthony
Beadell
Ellen Boles
Carlos and Lois Ann Bowman

358 Red Kits shared for Heart Month—the most ever in SADS history!



Penny Boyden
Robert Campbell, MD
Mary Carr
Darren and Mariesol Chamberlain
David Chiaruttini
Camille and Stephen Coale
Scott Dailard
DePorre Family Foundation
Martin Elias
Susan Etheridge, MD
Kori and Chuck Faulkner
Chris Flatters
Patrick and Anne Gallagher
Todd and Sandra Gorder
Bill and Janet Grube
Phil Howard
Nathan Hurley
Kevin and Anne Lemoyne
Sharon and Jim Lentino
Anthony and Cathleen
Lucatuorto
Juliette and Jacob Magers
William Mays
Peter McMillan
Stephanie Miller

Jim Peterka
Rhonda Rand
Lene and Jim Righeimer
Robinson Industries, Inc.
Dan Roden, MD
Devon Rudloff
Maureen and William Schulman
Tommy Schuman Foundation
Linda and Bill Shockley
Lindsey and Steve Shockley
Glenda Stafford and
LaDonna Watson
Steele Family Foundation
Judy and Philip To
Nancy Walker
Eileen and James Wilkoff
Philanthropic Fund
Cathy and Brian Zbanek

\$999-\$500

Nancy Adams
Keona Allen
Donna Gaul and Russell Bobo
Gail Bartok
Pam Batten
Jodi and Richard Bewick
Kathi and Scott Blum
John Contrata
Lee and Caitlin Cooper
Jay and Harriet Cudrin
Brynn Dechert Crooks
Barbara Egan

Julia Eslinger
Denise and Chris Falzon
Beatrice & Leon Friedman
Charitable Foundation
Grey Mountain Partners
Laura Gruber
Carole Hashimoto
Franceska Hinkamp
Traci and Derrick Jensen
Michael Jenson
Cathy and Chuck Knutson
John and Dawn Lambert
Nora Lambert
Filippo Maria Moscati
Edward and Susan O'Connell
John and Frances Parker
Marilyn Parsons
Sarah Shaw
Joe Wambach
Jeremy and Stacy Whiddon
Lamar and Wanda White

I am thankful to have found the SADS Foundation because it has given me the tools to be sure I am making heart-conscious choices and even to make sure my son's school is prepared to handle his condition.

- Heather Darling

SADS Sustainers of Hearts

Michele Alatorre
Keona Allen
Joanna Bewick
Darren and Mariesol Chamberlain
David Chiaruttini
Genevie Echols
Tara Filiatreau
Katie Finley
Mary Hardies
Michael Hedden
Sharad Jaiswal
Nicole Janes
Rachael and Nathaniel Krueger
Nora Lambert
Juliette and Jacob Magers
Michele Moran and Peter Sollimo
Victoria Pepper
Jim Peterka
Cornelio Reformina
Maureen and William Schulman
Sarah Shaw

Bella Flores received SADS Volunteer Award for her outstanding efforts during Walk for the BEAT online fundraiser



Linda and Bill Shockley
Lindsey and Steve Shockley
Robert Stevens
George Welki
Jeralyn Zoch

\$24,999-\$10,000

Boston Scientific Corporation
ICON plc
Invitae Corporation
Medtronic, Inc.
Sanguine BioSciences, Inc.

\$4,999 or less

Ambry Genetics
Lifesure, LLC

Foundations

\$25,000 or more

Sorenson Legacy Foundation

\$5,000 or less

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

Matching Gifts

AARP
America's Charities
Boeing, Inc.
C N A Foundation
Google Employee Giving
PepsiCo, Inc.
Keybank FLiberty Mutual
Lockheed Martin
Microsoft Corporation
Salesforce
United Health Group

SADS LIVE program on COVID-19: Drs. Mike Ackerman & Stacey Rizza video received the highest views!

Living and Thriving Funds

Michael
Ackerman, MD
Nicholas Arruda
Connor Badame
Carl Barnes, MD
Michael Edward Barry
Jack Bevington
and Family
Aiden Bewick
Emily Boone
Phillip Breen

Kloosterman
Audrey Koch
Sally Layton
Sharon Lentino
and Family
Carole Lindner
Annie Lucatuorto
Selena and
Daniel Lustig
Anne Marie
Deena McAndrew
Lindsay Mitacek
Danielle and Alanna
Mundondo

Last Fall was my first conference, and I wish I'd gone sooner! I can't begin to explain how good for your soul it is to meet other people that just get it.

- Samantha Wilder

Mandi and Madison
Chesser
Jacob Collinson
Caitlin Cooper
Jeffrey and Julie
Cooper
Owen Day
Kevin Echols
and Family
Susan Etheridge, MD
Lizzy Felgoise
Amelia Gentile
Betty Glasheen
Alyssa Hatch
Aurora Hill
Jake Horton
Nathan Hurley
Blake, Grady, Megan

Sophie Muir
Justin Paul
Edie Platkowski
Renenger Family
Liza Repasky Lowe
Penny Rush
Dara Sadinsky
Susan Schreiber, MD
Kaitlin Delaney Shaver
Sutch Family
Timothy Syndrome
Alliance
Gregory Totero
Victoria Vetter, MD
Katie Wildhagen
Kristen Yeager &
Sam Yeager

Catch the spirit and light up the night with Brittany's Trees!



Memorial Funds

Brian Anderson
Dorothea T.
Antonell
John and Dorothea
Antonell
David Barr
Michael Barry
Allison Bauer
Rosemary Beilavance
Challis Blum
Caleb Bohman
Cynthia Boles Dailard
Phillip Breen
Lorraine Brosius
James Stanley Byard
Caldwell Boys
Sarah Megan Callister
Dwayne Arthur Chow
Lee Ciciarelli
Carson Patrick Coale
Lauren Melissa Courtney
Annette Cross
Scott Elton Daniels
Colton Darr
Mariah Michelle Davis
Dora Dillon
Jack Donatelli
Pat Egan
Brian Falzon
Elisa Feldman
Albert Eugene Fiorina
Gene Fiorini
Ashley Fouts
Nicholas Alexander Funk
Mike Gertsberg
Emily Granath
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Meg Ives
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Graeme Jones
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Donna and Laura
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Kipp Kinsley
Kelly Ann Kottmeier
Jorale Lambert
Matthew LeMoyne
Jordan Maler
Johnny, Ginger, and
Kevin Mann
Danny Mauriello
Mark Mayfield
Colton McCarthy
Mary Elizabeth
"Libby" Murphy
Ben Murray
Neal Nelson
Elizabeth Noone O'Hara
Kate O'Hanlon
David O'Hara Jr.



Conor O'Mahony
Richard Ohmes
Matthew Osterhout
Britni Starr Osterhout
Jared Paepke
Andrew Palmer
Stewart Poulnot
Mary K. Elizabeth Poutt
Brian Price
Emilie Puricelli
Christopher Rengel
Thomas David Reubens
Evan Wayne Riepe
Rebecca Righeimer
Cally Rogers-Witte
Julia Romanowski
Race Salazar
Wayne Sawyer
Kerry Schulman
Tommy Schuman
Gregory Shea

Medical Webinar Speakers

Michael Ackerman, MD, PhD
Robert Campbell, MD
Stephanie
Chandler, MD
Mary Hardies, RN
Prince Kannankeril, MD
Richard Lamphier, RN
Dianalee
McKnight, PhD
Robert Pass, MD
Dan Roden, MD



Casey Lynn Shockley
Jesse Aaron Smith
Windland Smith Rice
Gray Solana
Andrew Stafford
Tiehrra Marie Stewart
Jeffrey Peter Stiefeld
Sarah Marie Stier
Carl Strand
Joe and Daniel Talomie
Jack Thalhimier
Patricia Tice
Christie Tolosky
F. Lillian Turner
Mark Van Dyke
G. Michael Vincent, MD
Gillett Vincent
Emily Walls
Abigail Rae Wambach
Ryan Weidler
Amy Yeast

For a complete listing visit StopSADS.org

Ryan Schaefer
Mary Sheppard, MD, FRC
Elizabeth
Sherwin, MD
Jonathan Skinner, MD
Richard Lamphier, RN
Allison Thompson,
Project Adam

SADS Live Guests

Katie Agre, GC
Peter Aziz, MD
Elijah Behr, MD
Charles Berul, MD
Georgia Brugada, MD
Hugh Calkins, MD
Robert Campbell, MD
Allison Cirino, GC
Lee Cooper

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Jolly (Founders
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& CEO of SADS
Foundation
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of Lovin' Every
Day Foundation
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Robert Nussbaum,
Chief Medical
Officer, Invitae
Silvia Priori, MD
Stacey Rizza, MD
Peter Schwartz,
MDChris
Semsarian, MD
Maully Shah, MD
Paul Thornton, MD
Katherine Timothy,
Timothy Syndromes
Alliance
Tolosky Family
Sami Viskin, MD
Arthur Wilde, MD
Ray Woosley,
MD, PhD

2020 Virtual Conference Speakers

Michael Ackerman, MD, PhD
Yukiko Asaki, MD
Peter Aziz, MD
Hugh Calkins, MD
Stephen Chelko, PhD
Mary Ann Ciciarelli
Aarti Dalal, DO, CEPS-P
Brynn Dechert-Crooks, RN, MSN, CPNP
Susan Etheridge, MD
Andy Golden, PhD
Jennifer Hair, MS, CGC
Robert Hamilton, MD
Jeffrey Kim, MD
Prince Kannankeril, MD
Andrew Landstrom, MD, PhD

Heather MacLeod, MS, CGC
Deena McAndrew, RN, CPN
Lisa Mills, RN
Sophie Muir
Brittney Murray, MS, CGC
Mary Niu, MD
Melissa Olen, ARNP
Sergio Pasca, MD
Geoffrey Pitt, MD
Karen Smoots, MSN, RN, CCDS
Paul Thorton, MD
Crystal Tichnell, MGC, RN
Harikrishna Tandri, MD
Jennifer Ty, MD
Robert Whitehill, MD
Julianne Wojak, MS, LGC
Ray Woosley, MD, PhD

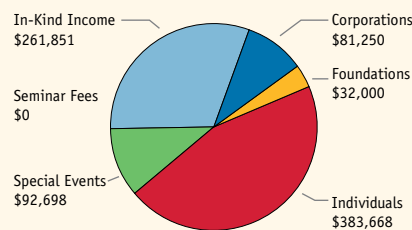
Timothy Syndrome Alliance Speakers

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

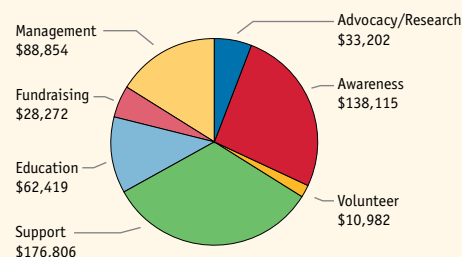
Shelton School, Dallas jumpers during February 2020 Bryan Price Memorial Jump-a-thon



Income



Expenses



Volunteer Fundraising Events

Brittany's Trees	Illinois	Tony Valene, Jim Guthrie, and Team
Heartoberfest	New York	Tolosky Family
All for AI	Illinois	Bauer Family
Holiday Hoop Fest	Georgia	Solana Family
Jumpathon	Texas	Shelton School
Rachel's Race	Wisconsin	Lancour Family
Ryan Weidler Golf Tournament	Pennsylvania	O'Donnell, Weidler, Speece Families
Super Lee Charity Golf Tournament	California	Michael Harrington and Friends

Virtual Events

Super Heart Bowl

Virtual Comedy Improv Night

Walk for the Beat

Scientific Advisors

Peter J. Schwartz, MD (Chair)
Milan, Italy
Charles Antzelevitch, PhD
Wynnewood, PA
Charles Berul, MD
Washington, DC
Mitchell Cohen, MD
Phoenix, AZ
Isabelle Denjoy, MD
Paris, France
Prince Kannankeril, MD/MSCI
Nashville, TN
Ron Kanter, MD
Miami, FL
Jorge McCormack, MD/MBA
Tampa, FL

James C. Perry, MD
San Diego, CA
Sylvia Priori, MD
Pavia, Italy
Dan M. Roden, MD
Nashville, TN
Shubhayan Sanatani, MD
Vancouver, BC
Phil Saul, MD
Morgantown, WV
Katherine Timothy
Brigham City, UT
Jeffrey A. Towbin, MD
Memphis, TN
John Triedman, MD
Boston, MA
Martin Tristani-Firouzi, MD
Salt Lake City, UT

Victoria L. Vetter, MD
Philadelphia, PA
Samuel Viskin, MD
Tel Aviv, Israel
Arthur Wilde, MD
Amsterdam, Netherlands
Raymond L. Woosley, MD/PhD
Phoenix, AZ

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