2022 ANNUAL REPORT

SADS
FOUNDATION

Genetic research and testing has given our family much-needed answers, and will save the lives of future generations.

Dear Families, Friends, Colleagues, and Supporters,

What a year 2022 has been as we celebrated our 30th anniversary. This special anniversary has seen many milestones. We've aired more than 100 episodes of SADS Live hosted by Dr. Michael Ackerman and over 500 Facebook Fundraisers have raised SADS awareness and more than $150,000 in funding!

And that's only the beginning of what we can report to you because of the support from our medical, non-profit, and corporate partners – but most of all, because of our SADS families! Together, we served 30% more SADS families, reached more than 1,000,000 people with SADS awareness messages, educated nearly 750 doctors and nurses, and held our International SADS Foundation Conference in person once more.

As we begin 2023, we will build upon the accomplishments of the past year as we do some of our most important work for SADS families to date. Beyond our established programs, services, and campaigns, we will give special attention to the following.

- Continue to promote SADS billboards and focus on a school nurse campaign to ensure schools are heart safe for our kids and the school community.
- Reach out to our families with regional seminars, specific disease communities, and a genetic testing campaign to make certain anyone who is interested may participate in research studies.
- Collaborate with other professional organizations to educate medical professionals about SADS conditions and the importance of genetic testing for SADS families.
- Work with sister organizations to advocate for public policy change to improve access to therapies, newborn screening, whole genome sequencing, and AED state legislation.
- Recruit patients for therapeutic research studies and the Patient Focused Drug Development presentation to the FDA so that the voices of SADS patients are recognized to shape the advancement of treatments.

Please enjoy reviewing all that has happened in the past year and continue to check in with us as 2023 unfolds. Your dedication to the SADS Foundation for the past 30 years was invaluable and your dedication for the upcoming 30 years will help to fulfill our future goals.

Thank you for being a part of the SADS family!

Michael Ackerman, MD, PhD
President, Board of Trustees

Alice Lara, RN
President & CEO

SADS BY THE NUMBERS

22,655
Families Learned from the Experts

Through programs like SADS Live with Dr. Michael Ackerman and our free Living with SADS webinars, we're here to provide the best education & support to your family.

Over 4,000,000
People Reached Through Awareness Billboards

With 19 placements, our billboards reached audiences in two states with an important message – that fainting might be more than a faint.

36
Sustainers Helped Keep Hearts Beating with Recurring Donations

SADS Sustainers raised nearly $26,000 from 36 donors.

1,145 New Families Joined the SADS Foundation

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

225,969
Accessed Resources on our New Website

With 93,790 first-time visitors, our brand-new SADS website, designed with your family in mind, is helping families access the best up-to-date info on their condition.

Over 500 Families Raised Funds on Facebook Through 2022

Facebook Fundraisers for the SADS Foundation hit 519 surpassing 500 fundraisers and more than $150,000 raised to help us support SADS families throughout the United States.

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.

490 Families Participated in Conference

This year we had our first in-person conference since COVID, with 136 participants. Make sure to join us at our four in-person Family Seminars in 2023!

Family Support

In 2022, we significantly expanded our Family Support program and hired our new Family Support Director, Genevie. As a result, we were able to serve 407% more families with resources like support groups, educational webinars – and personal guidance to help support families like Chaunté's on their journey.

During a routine visit to the pediatrician, Chaunté learned that her second daughter, Kadence, had Long QT Syndrome. Chaunté's family lives in the Bahamas, which means that they have limited access to expert care.

That's when Chaunté found the SADS Foundation online, and got in touch with Genevie, who helped connect Chaunté with expert telecare and start the process of genetic testing for Kadence.

"The SADS Foundation has provided me with so much information," says Chaunté. "Everyone there has reached out to me individually to try and help. They're setting me up with a doctor in Miami, and are constantly checking to make sure everything's okay. They're speaking to me individually, and in the Bahamas, where we have limited resources on certain medical conditions, including LQTS, that's so helpful."

We're so grateful to families like Chaunté's for sharing their journeys with us – and for the support of donors like you, which has allowed us to expand our Family Support program.

Chaunté and her daughter Kadence.

> *It was awesome to find support, advocacy and light at the end of the tunnel. Our conversation gave me clarity, insight, motivation that moving forward I don't have to feel defeated and overwhelmed. I look forward to being a lifelong friend, advocate, and supporter of SADS.* - *Kathryn S*

213 International families reached
And found support, education, and a community to help them on their journey.

Awareness

With the help of volunteers just like you, we reached millions of people in 2022 in brand-new ways. This year, we implemented a new billboard PSA about one of the most common warning signs of SADS conditions – fainting. And it all started with volunteers who've been working with the SADS Foundation for decades.

The Lamberts have supported SADS and helped spread awareness since 2005, when Dr. Michael Vincent, the founder of SADS, helped provide much-needed answers for their family. Their son, Matthew, started fainting at the age of four – and it took decades for their family to learn that he had Long QT Syndrome, with the help of Drs. Vincent and Ackerman.

In 2022, the Lamberts helped SADS connect with a billboard company in their hometown of New Orleans – and the company donated space for eleven billboards across the region that reached over three million people. Our billboard campaign has a simple goal: to make sure that as many people as possible know that fainting can be a potential warning sign of a cardiac condition, so they can ask their doctor about their heart and get a diagnosis.

Volunteers across the country have worked to place billboards in other cities – like Research Committee member Sandy Cowin, who placed eight billboards in Binghamton, NY, and our Communications Consultant Melissa Russom, who placed a PSA about fainting on a radio station in Spokane, Washington.

"So much has been achieved in the last 20-30 years," says Nora Lambert, Matthew's mother. "It's only going to get better, thanks to the SADS Foundation."

We are grateful to everyone who participated in our awareness program this year. From sharing social media posts to placing billboards, you're helping us make a difference – and reach more families before a tragedy happens.

Our awareness billboard in Binghamton NY – placed by awareness volunteer Sandy Cowin.

> *Thank you for all that you do. Increased awareness, education and action will lead to lives saved!* *- Becky S., school nurse*

22 new collaborators on social media

Our collaborators included Vanderbilt Children's Hospital, the National Society of Genetic Counselors, and influencer Dena DNA – and helped us reach new audiences so more people know the warning signs of SADS conditions.

Research

In the next few years, we'll see some of the biggest innovations so far in research for cardiac arrhythmias. Did you know that you can take the first step towards participating in new clinical trials right now – and help save lives too – through getting genetic testing?

Dick Stafford lost his son Andrew in 1991 after Andrew went into Sudden Cardiac Arrest while driving with his friends. Dick and his family learned in the months following Andrew's death that Andrew had Long QT Syndrome – along with Dick and two of Andrew's siblings.

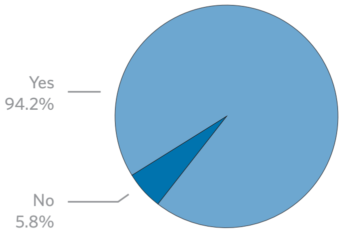
After connecting with the SADS Foundation's founder, Dr. Michael Vincent, Dick learned that all his first-degree relatives needed to get genetic testing. "There were a ton of people to contact, and this was in the early days of the internet," says Dick. "So the first thing I had to do was build a family tree of my cousins, track them all down, and mail them materials to give to their doctors. I became the custodian of my family history."

Despite Dick's family tree being "spread all over the country," the family went through full cascade screening – or screening of relatives who might be affected – and this process saved lives.

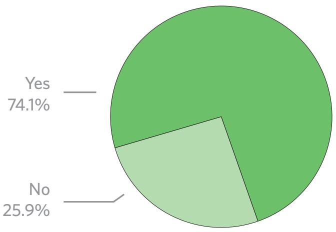
"Every person who walks a path that includes a sudden cardiac death of someone they love will have energy that comes from that," says Dick. "Sometimes you get angry, and sometimes you throw yourself into awareness. Telling your family about the condition and getting them tested is something you can throw yourself into and use some of that energy on."

In 2023, we're committed to helping more families access genetic testing and understand their results. We have resources available for every step of the process - so we can save lives and advance research, one family tree at a time.

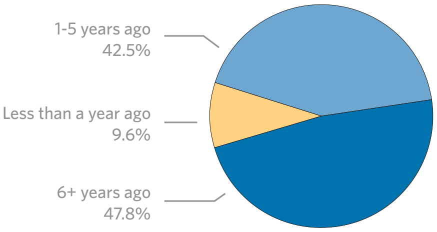
94% had received genetic testing



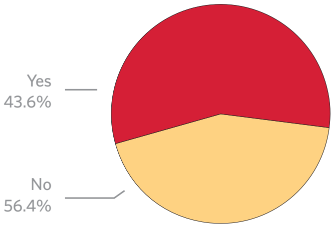
While most people had immediate family members tested.



Most people's genetic testing was done over 6 years ago.



Fewer extended family members were tested.



> *Thank you to everyone at the SADS Foundation for all you do! Genetic research and testing has given our family much-needed answers, and will save the lives of future generations.*
>
> *- Nancy A.*

396 families participated in our Genetic Testing Survey

This was the first part of our new Genetic Testing Initiative, starting in 2023 – which will help us connect families to genetic testing and support researchers.

Medical Education

We were so excited to host our outstanding CME course – LOOKING FORWARD: From Cutting Edge Therapies to Patient-Centered Care in Inherited Arrhythmias – for medical professionals in conjunction with Texas Children's Hospital in November of 2022.

We had 76 healthcare professionals - including doctors, fellows, and residents - register for our CME course. And our speakers came from across the world – including Dr. Koonlawee Nademanee, who flew in from Thailand – to present on the latest updates on treatment and research for arrhythmia conditions.

"I think this is the right time to have these conditions, because I think that the future is very, very bright," said Dr. Ron Kanter, one of our Scientific Advisors from Nicklaus Children's Hospital in Miami, Florida.

Our outstanding panel of speakers gave updates on the newest for all the SADS conditions and unusual cardiac arrhythmias (like Tango2 and neurocardiac arrhythmias). Highlights included Dr. Ackerman discussing cutting-edge treatment for LQTS, the newest updates on gene therapy research with Dr. Dominic Abrams, and new research on biomarkers for ARVC with Dr. Robert Hamilton.

Attendees also learned about upcoming treatments for SADS like gene therapies and precision medicine, and guidelines on devices, ablations, and returning to play. We ended the day with a really fantastic panel on advice some of the top experts in the field would have given their younger selves.

In 2023, we'll be sending experts to hospitals across to U.S. to educate YOUR local healthcare professionals on the latest in treatment for SADS conditions. With the help of supporters like you, we can help make sure that healthcare professionals across the globe know how to treat your family's condition - with guidance from the top experts in the world.

Panel on advice experts would give their younger selves at our 2022 Houston CME Conference.

Marcia Baker, Program Director, and Dr. Sam Sears.

Adrian Olmos from LifeSure AED, a conference sponsor, teaches kids and teens how to perform CPR.

> *Thank you to Dr. Ackerman and the entire SADS staff for these outstanding informative sessions bringing such valuable, data-driven education to patients and their loved ones.* - Andrew V.

Fundraising Events

Brittany's Trees – our biggest volunteer fundraiser for the SADS Foundation, which has raised over $431,000 for SADS since it started in 2005 – celebrated its 18th year in 2022.

"We sell Christmas trees – what we call Brittany's trees – to honor the memory of Brittany Valene," says Jim Guthrie, a neighbor of Brittany who helped found Brittany's Trees. "We decorate them with three sets of white lights, and all the profit goes to the SADS Foundation to help families who are going through this unique situation that affects children like Brittany."

Other families in the SADS community have helped start Brittany's Trees in their town – including the Lentino family and the Peck family, who joined this year.

"Brittany's Trees was so amazing," says Karen Peck, who started Brittany's Trees in her neighborhood in memory of her son, Brian, who passed away in 2019 and loved the Christmas season. "I lit a tree for Brittany – and a tree for Brian."

Jim says it's easy for new families to start Brittany's Trees in their town. "If you're looking to start this up in your neighborhood, we did just 22 trees our first year with three people," he says. "It's one of the more enjoyable events that I and the neighbors look forward to each year, and we're doing this for such a good cause."

We are so grateful to Brittany's Trees and all the families who are part of it for helping raise funds for SADS – and strengthen our outreach so more families find out about SADS before a devastating loss.

The Brittany's Trees team celebrating after their 18th year.

> *So proud to be part of the SADS Foundation. Congratulations to Dr. Michael Ackerman and the SADS team in Salt Lake City*
>
> *- Jim, Brittany's Trees*

13 families held fundraising events - and made a huge difference.

SADS Volunteer Fundraisers raised nearly $70,000 from 13 family events.

THANK YOU

Gold Legacy Circle
$50,000 or more

Fred Smith

Bronze Legacy Circle
$49, 999 - $10,000

Joanna Bewick
Shirley Chan
Dale Irvin – Cigar Peg, Inc.
Deby and Blair Jones
Alan London
Ronald W. Steele – Steele Family Foundation

Legacy Circle
$9,999 - $1,000

Michael Ackerman, MD
Kelly Airey, MD
Zoe Alikakos
Donna Gaul and Russell Bobo
Priscilla and Anthony Beadell
Ellen Boles
Carlos and Lois Ann Bowman
Robert and Rita Campbell, MD
Mary Carr
Darren and Mariesol Chamberlain
David Chiaruttini
John Contrata
Julia Dancy
Glennda Dawley
Chris DeFrancis
Mary and Jonathan Derry
Martin Elias
Susan Etheridge, MD
Kori and Tom Faulkner
Penni-Lynn Foley
Patrick and Anne Gallagher
Bill and Janet Grube
Ken Haller
Robert Hamilton, MD
Laurie and Steve Hooper
Shelley Horton
Phil Howard
Nathan Hurley
Dana Hyde
Traci and Derrick Jensen
Anthony Kales
Jeffrey Kim, MD
Sharon and Jim Lentino
Terry Little
Robert and Kristen Lopez
Meredith Loveless
Juliette and Jacob Magers
John Maguire
Susan Marker
William Mays
Peter McMillan
Conrad Mihalek
Mike O'Grady
John and Frances Parker
Steve and Karen Peck
Jim Peterka
Chris Petty
Rhonda Rand
Hal and Linda Reubens
Lene and Jim Righeimer
Ronda Robinson – Robinson Industries, Inc.
Dan Roden, MD
Devon Rudloff
Milford Scheer
Maureen and William Schulman
Dan Schuman – Tommy Schuman Foundation
Lindsey and Steve Shockley
Linda and Bill Shockley
Peter Sollimo and Michelle Moran-Sollimo
Glenda Stafford and LaDonna Watson
Kerry Stamper
Linda Stern – Linda B. and Howard S. Stern Family Foundation
Mary Stevens, APRN
Judy and Philip To
Eileen and James Wilkoff – Eileen and James Wilkoff Philanthropic Fund
Walter and Vivian Zagrobski
Cathy and Brian Zbanek

> *Thank you for all of your advocacy. I experienced SCA when I was 12 and was diagnosed with LQTS2. You guys are a passionate and trustworthy resource.*
>
> *- Morgan A. on our social media campaigns*

> *Thanks so much for an absolutely wonderful weekend. It was a family milestone.*
>
> *- Joanna D. on our 2022 SADS Family Conference in Houston TX*

$999 - $500

Keona Allen
Glenda Auerbach
Vanessa Baehr
Cyndie and Todd Baker
Anthony Barker
Gail Bartok
Pam Batten
Charles Berul, MD
Jodi and Richard Bewick
Kathi and Scott Blum
Rachel Brem, MD
Steve and Karen Compton
Lee and Caitlin Cooper
Jay and Harriet Cudrin
Jeff Crooks and Brynn Dechert-Crooks
Rocco DeFilippis
Genevie Echols
Denise and Chris Falzon
Jaye Ruth Friedman-Levy
Dana Hyde
Nicole Kalhorn
Ron Kanter, MD
Dennis and Adelyn Klarin
Nora Lambert
Rachel Lampert

Dr. Mary Niu was the winner of our AED raffle this Sudden Cardiac Arrest Awareness Month, donated by American AED.

Carrie McGovern
Tim Ozinga
Marilyn Parsons
Tia Pyle
Joseph Reubens
Michael Reubens
Sarah Shaw
Amanda and Lance Thibodeaux
Nancy Walker
Joe Wambach

SADS Sustainers not previously listed in other categories

Michele Alatorre
Harven DeShield
Tara Filiatreau
Katie Finley
Felicia Fischetti Panepinto
Jennifer Garrett
Sonja Graulds

The First Annual Sonny Jude Pancake breakfast, which raised funds for SADS in memory of Sonny Jude, who passed away from LQTS.

Mary Hardies
Michael Hedden
Sharad Jaiswal
Nicole Janes
Rachael and Nathaniel Krueger
Amy and Darryl Mansfield
Rhonda Moag
Dorothy Nacu
Victoria Pepper
Amy Reeves
Cornelio Reformina
Jordan Schraeder
Robert Stevens
Margaret Jo Swanson
Andrea Weiser
George Welki
Lisa Yost
Jeralyn Zoch

Foundations

$10,000 or more

Rona Jaffe Foundation
Sorenson Legacy Foundation
Timothy Syndrome Foundation

$5,000 or less

George S. and Delores Doré Eccles Foundation

Corporations

$25,000 or more

Boston Scientific
Illumina
Tenaya Therapeutics

$24,999-$10,000

Cardurion Pharmaceuticals
Medtronic
StrideBio

$9,999-$5,000

Ambry Genetics
Biosense Webster Inc.
Invitae Genetic Testing
LifeSure Home AED Solutions
Pfizer
Philips

Matching Gifts

AARP
American International Group
America's Charities
Boeing, Inc.
Google Employee Giving
PepsiCo, Inc.
Keybank
Liberty Mutual
Lockheed Martin
Medtronic
Microsoft Corporation
Red Hat
Salesforce
United Health Group

Living and Thriving Funds

Dr. Michael Ackerman
Kirsten Anderson
Nicholas Arruda
Sarah Atchison and Family
Brandt Baehr
Jack Baker
Aiden Bewick
Emily Boone
Phillip Breen

> *I wanted to give SADS a shoutout for all the education and support you have been providing over the years.*
>
> *- Mandi C. on our support groups*

McCovey and Dhana Browne
Sherry Cathcart
Sarah Clark
Cool Family
Sandy Cowin
Maureen Curran
Steven, Alora, Alaric Dennison
Adeline Dinin
Dr. Susan Etheridge
Isabella Flores
Anette Franek
Felix Garcia
Oscar Gray
Katie and Teagan Green and Jake Baker
Shea Gloria Greenfield
Joelle Hammann
Frances Hesford
Christy Johnson
Arabella Kasten
Janae King
Kristin Kraunelis
Bryar Lane
Rebecca Lauron-Flatters
Sally Layton
Lentino Gals
Stephanie Leyva
Eden Lily
Alexis Loveless
Annie Lucatuorto
Luca Masucci
Edwin Matos
Rosanna Metoyer
David Mills
Lindsay Mitacek

THANK YOU

Justin Paul
Brian Peck
Tom Pemberton
Marsha Peterson and Kristi and Sam Yeager
Paula Prucknicki
Nate Quinn
Nathan Ruud
Dara Sadinsky
Dr. Salem Sayar
Dr. Susan Schreiber
Maureen McArdle Schulman
Andrew Stafford
Dr. Hari Tandri
Greg Totero
Nick and Sarah Totero
Patti Klett Totero
Dee Vincent
Molly and Peter Westby
Kristi Yeager
Ron York
Brian Zbanek

> *Thank you for your unwavering advocacy.*
>
> *- Toby S. on our awareness resources*

Memorial Funds

Brianna Badger
David A. Barr
Allison Bauer
Rosemary Bellavance
Richard Bennett
Zachary Blair
Challis Blum
Mary K. Elizabeth Butt
Sarah Megan Callister
A. Charles Cappello
Ruth Fanette Chesser
Dwayne Cho
Lee Ciciarelli
Carson Patrick Coale
Gregory Cove
Kenneth Croll
Cynthia Boles Dailard
Savanna Leann Daniel
Elizabeth Anne Dempsey
Mark Driscoll
Dan Dwyer
Brian Falzon
Elisa Feldman
Barbara Ferretti
Chris Fischer
Anette Franek
Rachel Elizabeth Frederickson
Alan Greenberg
Emma Greenspan
Britnee and Ashley Hatch
James Holden Hendrix
Jon and Kristen Hohulin
Charlotte Holt
Jake Horton
Isla Hutton
Meg Ives
Graeme Jones
Robbie Kass
Sarah Nicole Katz
Darragh Kelly
Sandra Kneipp
Mary Ellen Knowles
Kelly Ann Kottmeier
Kerry Char Kottmeier
Don Kuasak
Wyatt Lee
Jenny Ann Lemay
Liza Repasky Lowe
Jacob Lulek
Selena R. Lustig

Family Support Director Genevie Echols and Lindsay Meyers, CGC in our collaborative story with the National Society of Genetic Counselors.

Jan Schiller, Development Director, and Marcia Baker, Program Director, at the 2022 Heart Rhythm Society conference.

> *I really appreciate you taking the time to talk with me - it is so rare to connect with another parent who understands.*
>
> *- Rachel B. on our Family Support program*

Johnny, Ginger, Kevin Mann
Anne Marie
Richard Martin
Danny Mauriello
Migliaci Family
Olivia Blue Miller
Jim Moody
Kate O'Hanlon
Elizabeth Moone O'Hara
David O'Hara Jr.
Matthew Osterhout and Britni Cooper Osterhout
Andrew Joseph Palmer
Brian Peck
Ismael Norbert Perez
Jeffrey Peter
Shane Thomas Pfister
Stewart Poulnot
Emilie Puricelli
James Renner
Thomas David Reubens
Windland Smith Rice
Rebecca Grace Righeimer
Ruben Rodriguez
Race Salazar
Joan Sansone
Wayne Sawyer
Kerry Ann Schulman
Casey Lynn Shockley
Rebecca Shulla
James M. Simpson
Jesse Aaron Smith
Stephen Smith
Gray Solana
Chad Stamper
Sarah Marie Stier
Carl Strand
Laura Tibbs
Christie Tolosky
Jeremy Twining
Dr. G. Michael Vincent
Emily Walls
Abigail Rae Wambach
Ryan Weidler
Brooke Whitworth
Adam Wilkens
Sarah Yesnowitz

Medical Education Webinar Speakers

Arthur Wilde, MD, PhD, Amsterdam UMC

Living with SADS Speakers

Aravind Asokan, PhD, Duke University
Aarti Dalal, DO, Vanderbilt Children's Hospital
Nisah Gilotra, MD, Johns Hopkins Medicine
Sharon Gohman, Boston Scientific
Will Heise, MD, Credible Meds
Andrew Landstrom, MD, PhD, Duke University
Adrian Olmos, LifeSure Home AED Solutions
Matthew Pollman, MD, Tenaya Therapeutics
John and Anne Jolley, SADS UK
Adrian Olmos, LifeSure Home AED Solutions
Shu Sanatani, BSc, MD, BC Children's Hospital
Harikrishna Tandri, MBBS, Johns Hopkins Medicine
Katie Wildhagen, SADS Family Member
Erin Clark, RN, SADS Family Member
Jocelyn Conroy, SADS Family Member
Nora Lambert and Lambert Family, SADS Family Members
Annie Lucatuorto, SADS Family Member
Renee Maler, SADS Family Member
Rebecca Sieg, SADS Family Member

The Tolosky and Russom families at the Saratoga racetrack, raising funds and awareness for SADS.

Paul Scheel III, MD, Johns Hopkins Medicine
Pirouz Shamszad, MD, Cardurion Pharmaceuticals
Heather Cartwright, SADS Family Member
Tracy Glumich, SADS Family Member
Darin Mattner, SADS Family Member
Nate Miller, SADS Family Member
Susan Ruhl, SADS Family Member
Becky Seig, SADS Family Member

SADS Live Guests

Danielle Belardo, MD, Preventive Cardiologist
Georgia Brugada, MD, PhD, Sant Joan Deu Barcelona Children's Hospital
Kristin Flanary (@LGlaucomflecken)
Pam Husband, SADS Canada

Virtual Conference Speakers

Michael J. Ackerman, MD, PhD, Mayo Clinic
Charles Berul, MD, Children's National Hospital
Brynn Dechert-Crooks, MSN, CPNP, University of Michigan Congenital Heart Center
Gretchen Eckstein, RN, Children's Hospital of Wisconsin
Susan Etheridge, MD, Primary Children's Medical Center
Andrew Landstrom, MD, PhD, Duke University
Katherine Spoonamore, MS, LCGC
Janette Strasburger, MD, Children's Hospital of Wisconsin
Harikrishna Tandri, MBBS, Johns Hopkins Medicine
Jennifer White, MD, Jefferson Health

THANK YOU

Suzanna Boyce Berndt, SADS Family Member
Joelle and Holly Jacobs, SADS Family Members
Deby Jones, SADS Family Member

SADS Foundation International HCP Conference Speakers

Dominic Abrams, MD, Boston Children's Hospital
Michael J. Ackerman, MD, PhD, Mayo Clinic
Charles Berul, MD, Children's National Hospital
Bryan Cannon, MD, Mayo Clinic
Stephanie Chandler, MD, Lurie Children's Hospital
Brynn Dechert-Crooks, MSN, CPNP, University of Michigan Congenital Heart Center
Mario Delmar, MD, PhD, NYU Langone Medical Center
Audrey Dionne, MD, Boston Children's Hospital
Susan Etheridge, MD, Primary Children's Medical Center
Robert Hamilton, MD, The Hospital for Sick Children
Prince Kannankeril, MD, Vanderbilt University
Ronald J. Kanter, MD, Nicklaus Children's Hospital
Jeffrey J. Kim, MD, Texas Children's Hospital
Andrew Landstrom, MD, PhD, Duke University
Christina Miyake, MD, MS, Texas Children's Hospital
Koonlawee Nademanee, MD, Heart institute at Bumrungrad Hospital
Tina Pham, MD, Texas Children's Hospital
Samuel F. Sears, PhD, Jr., East Carolina University
Janette Strasburger, MD, Children's Hospital of Wisconsin
Santiago Valdes, MD, Texas Children's Hospital
Gregory Webster, MD, MPH, Lurie Children's Hospital

Additional Program Committee Members

Michele Krenek, MSN, RN, FNP-C, Texas Children's Hospital
Alice Lara, RN, CEO and President, SADS Foundation
Marcia Baker, MS Ed, Program Director, SADS Foundation

SADS Foundation International Family Conference Speakers

- Family Agenda

Michael J. Ackerman, MD, PhD, Mayo Clinic
Charles Berul, MD, Children's National Hospital
Brynn Dechert-Crooks, MSN, CPNP, University of Michigan Congenital Heart Center
Jeffrey J. Kim, MD, Texas Children's Hospital
Andrew Landstrom, MD, PhD, Duke University
Lindsay Meyers, CGC, Genome Medical
Christina Miyake, MD, Texas Children's Hospital

- Kids and Teens Agenda

Michael J. Ackerman, MD, PhD, Mayo Clinic
Kate Cutitta, PhD, Psychologist, Texas Children's Hospital
Taylor Howard, MD, Texas Children's Hospital
Michele Krenek, CPNP, Texas Children's Hospital
Lisa Mills, RN, Primary Children's Hospital
Adrian Olmos, LifeSure Home AED Solutions
Abby Yesso, CGC, Texas Children's Hospital

Hailey, who has Wolff-Parkinson White, competes on aerial silks; we teamed up with Children's National Hospital to tell her story.

Scientific Advisors

Peter J. Schwartz, MD
Milan, Italy
Dominic J.R. Abrams, MD, MRPC
Boston, MA
Chris Anderson, MD
Spokane, WA
Charles Antzelevitch, PhD
Utica, NY
Pater Aziz, MD
Cleveland OH
Elijah Behr, MD
London, UK
Charles Berul, MD
Washington, DC
Marina Cerrone, MD
New York, NY
Mitchell Cohen, MD
Fairfax, VA
Isabelle Denjoy, MD
Paris, France
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
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
Georgia Sarquella-Brugada
Barcelona, Spain
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
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Amsterdam, Netherlands
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Genevie Echols
Family Support Director
Jan Schiller,
Development Director
Anna Goodson,
Communications Director
Erin Waite,
Technology & Operations Manager
Zach Hardy, Office
Administrator & Bookkeeper

Volunteer Fundraising Events

Brittany's Trees	Illinois	Tony Valene, Jim Guthrie and Team
Brittany's Trees	Illinois	Lentino Family and Team
Brittany's Trees	Illinois	Peck Family and Team
Amelia Runs for Arrhythmia Awareness	California	Amelia DeFrancis
Boot Camp	Maryland	Patrei Nengen
Saratoga Race Club House Box Raffle	New York	Tolosky Family
Jumpathon	Texas	Shelton School
Rachel's Race	Wisconsin	Lancour Family
Ruben Rodriguez	New Jersey	Grace Arroyo
Ryan Weidler Golf Tournament	Pennsylvania	O'Donnell, Weidler, Speece Families
Sonny Jude Pancake Breakfast	New York	Samantha Becotte
Adam Wilkens Golf Tournament	North Dakota	Amy Wilkens