The SADS Foundation is partnering with the University of Michigan and C. S. Mott Children’s Hospital to host the 11th Annual International SADS Foundation Conference on October 26-28, 2018, in Ann Arbor, Michigan.

The CME Sessions on Friday will feature Keynote Speaker Peter Swartz, MD, who is currently Professor and Chairman of Cardiology at the University of Pavia; Director of the School for the Board in Cardiology and Director of the Section of Cardiology—Department of Molecular Medicine at the same university; Chief of the Coronary Care Unit at Fondazione IRCCS Policlinico, San Matteo, Pavia (Italy); Extraordinary Professor in Internal Medicine at the University of Stellenbosch; and member of the Board—Hatter Institute for Cardiovascular Disease in Africa, University of Cape Town, South Africa.

Another feature at this year’s conference is the addition of the University of Michigan’s Young ICD Connection Conference. This program provides educational and support sessions as well as resources for patients and family members including the important benefit of realizing they are not alone.

As a follow up from last year’s event, we will present the 2nd Annual Scientific Posters Session with some of the latest information on SADS conditions. Additionally, we will once more offer disease-specific breakout groups including Long QT Syndrome, Timothy Syndrome, Brugada Syndrome CPVT, ARVC, HCM/DCM, and possibly others to better personalize sessions for SADS families.
Mission: To save the lives and support the families of children & young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

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Meet Our New Board Member

Phil Howard, Board Member

New Board Member Phil Howard is a partner in Ernst & Young’s Redwood Shores office (San Francisco Bay Area) and has over 14 years of experience serving life science clients of all sizes. He also has spent time auditing the financial statements of a number of not-for-profit entities.

Phil is an alumnus of Arizona State University where he played football and graduated summa cum laude with a bachelor’s degree in Finance and a master’s degree in Accountancy and Information Systems. He is a Certified Public Accountant licensed in the states of California and Arizona and is a member of the American Institute of Certified Public Accountants.

Phil enjoys spending his free time with his wife of 13 years, Stephanie, and their 5-year-old son, Philip “Cuarto,” and 2-year-old daughter, Pierce. When not working, Phil enjoys cooking with his wife, reading, watching his Arizona State Sun Devils, keeping up on his favorite TV shows and traveling to new places.

Phil’s daughter Pierce suffers from an undiagnosed SADS condition.

SADS Board Member and SADS Scientific Advisor Elected as Fellows of the American Heart Association (FAHA)

Congratulations to Susan P. Eberidge, MD, FAHA and Charles I. Berul, MD, FAHA for their election to the FAHA in the CVDY Council. This honor is reserved for physicians and medical scientists who are board certified in CV Disease, and who have demonstrated excellence, innovation and leadership in cardiovascular diseases in the young. They are recognized for their scientific and professional accomplishments and volunteer leadership and service.

The SADS Foundation is privileged to have their wise guidance and extraordinary expertise in diagnosing and treating people with SADS conditions.

Farewell Lynn

After working as Director of Family Support for the past 2 and half years, I will be leaving the SADS Foundation at the end of April. It was not an easy decision for me to make—my time at SADS has given me amazing opportunities to work with remarkable SADS families, volunteers, and health professionals. I have enjoyed meeting and learning from many of you at the conferences in San Diego and Toronto, as well as at family meetings in Chicago and New York. I will miss seeing you at the SADS Conference in Ann Arbor this fall, but I hope you will plan to attend—it will be fantastic! I look forward to continuing to watch as the SADS Foundation grows and supports each and every one of you.

William Departure

Changes come at funny times and some are hard to experience. Unfortunately, a recent change has been both. After serving as Director of Medical Education for the past 2 years I will leave the SADS Foundation on March 31st. It was not an easy choice to make as I have had many wonderful experiences at SADS and so enjoyed working with the many remarkable people at SADS. I have treasured getting to know so many of you better and the opportunities we’ve had to work together will always be a happy memory for me. I look forward to seeing the SADS Foundation continue to support health professionals and their patients. I wish all of you the very best and hope we will get to meet again soon!

Changes to LQT Drugs to Avoid List

These drugs have been added to the list since our last newsletter

- **Primaquine** (anti-malarial)
- **Lopinavir/Ritonavir** combination (anti-viral)

- **Fluorouracil** (anti-cancer)
Did you know?

SADS Hong Kong Foundation

Congratulations to SADS HK Foundation and Mrs. Shirley Chan Chow, Founder of SADS HK Foundation for initiating the first Sudden Cardiac Death study in Hong Kong with Princess Margaret Hospital and Forensic Pathology Services. The study unravels some of the causes of sudden death in youth and showed that one third of the victims were SADS related. Half of their first-degree relatives carry a SADS genetic variant. SADS HK Foundation is now launching a pilot scheme subsidizing relatives for clinical consultation. For more pictures and details of the projects, visit SADS.org.

Worldwide Candle Lighting

On December 10, 2017, The Compassionate Friends Worldwide Candle Lighting event united family and friends around the globe in lighting candles for one hour to honor the memories of the sons, daughters, brothers, sisters, and grandchildren we have lost. Over 100 people attended the virtual event through our Facebook event to share their experiences with loss and to support each other. Thank you to all who attended and be sure to be on the lookout for future events on our official SADS Foundation Facebook page.

Red Kits for Heart Month

The SADS Foundation enjoyed creating a Family Red Kit in celebration of Heart Month in February. Over 100 kits were received by our SADS community, and were delivered to places including churches, schools, and offices. The materials in these kits included informational flyers, wristbands, and posters. Thank you to all who ordered a Red Kit, and be on the lookout for future campaigns.

CPVT Community Group Meets in Chicago with the SADS Foundation

In November of 2017 CPVT family members met to establish a CPVT Community support group within the SADS Foundation.
We would like to welcome the Severt family to our SADS family! We learned about Mindy Severt’s story from an article in her local paper telling the dramatic story of her sudden cardiac arrest last July when she was 18 weeks pregnant. Thanks to the quick action of her husband Chris, who immediately began performing CPR, she recovered from her SCA, and in the hospital she was diagnosed with Long QT Syndrome. Mindy and her husband Chris welcomed their healthy baby boy last December 1st. The rest of Mindy’s family is in the process of getting screened for LQTS.

Now she has a Christmas miracle!

The SADS Foundation was contacted by 12-year old Claire Russell from Quakertown, Pennsylvania about materials for her Technology Student Association (TSA) project. Claire (on the right) and her friend Kelly chose the topic of Long QT for their medical project, because Claire’s mother is genetically positive for Type 2 Long QT. Because Claire and Kelly placed third in their regional competition, they have qualified for the state finals in April. Congratulations to Claire Russell on her winning project!

Congratulations to Claire Russell on Her Winning Long QT Project!

Alice and Lynn attended the recent American Heart Association Scientific Sessions and met with many of our Scientific Advisors and partner organizations. Listed below are just some of the sessions from which we learned the current status of research of SADS conditions. You’ll be seeing lots of this new science in the months ahead as the research is published.

- Lessons From 25 Years of Identifying and Treating Brugada Syndrome
- Advances in Genetic Testing, Diagnosis and Treatment of Long QT Syndrome
- Exercise Recommendations in Patients with Inherited Arrhythmias, From Long QT Syndrome to ARVC
- Hydroquinidine Abolishes Life-threatening Arrhythmic Events in Patients with Short QT Syndrome
- The Fetal Cardiac Patient: Treatments to Improve Outcome
- Genetic Engineering to Mend the Heart
During 2017, more than $100,000 was raised by 20 SADS families who held fundraising events to benefit the SADS Foundation. There are as many ideas as there are families, but take a look at the following ideas for inspiration.

**Take Steps to Stop SADS**

Many families host different types of fun runs or join established runs. Check out sads.org/Get-Involved/Take-Steps-to-Stop-SADS to learn about our signature event or join together with family and friends to create a run with your own special theme.

**Brittany’s Trees**

In Illinois, one special neighborhood started selling small Christmas Trees—complete with three strings of white lights and a base. It started small, but now they sell more than 2,000 trees every year. Call the SADS Foundation to receive a how-to manual put together by the Brittany’s Trees team.

**Or consider one of the following ideas:**

- Sell SADS wristbands
- Create a personal fundraising webpage on CrowdRise
- Gather unique items for silent or live auctions at an event or online
- Coordinate Tournaments: Golf, Tennis, Bowling
- Host Theme Parties: Spaghetti Dinners, Progressive Dinners, Wine and Cheese Parties, or Oktoberfests
- Organize Yard Sales, Car Washes, Lemonade Stands, or Bake Sales
- Use your imagination to turn one of your interests into a way to raise funds!

Visit sads.org/get-involved/fundraising-event-ideas for further details or contact Jan at 801-272-3023 or jan@sads.org. Let’s raise awareness about SADS conditions and raise funds for the SADS Foundation.

**It’s Easy to do an Event!**

**No Ball at All 2018**

The SADS Foundation is celebrating the 24th Anniversary of No Ball at All! This year, we are grateful to Laurie Sayre for allowing us to remember her daughter Samie who passed away from a sudden cardiac arrest two years ago. Samie was a vivacious young woman who had won the Miss North Dakota crown and dedicated her life to family, friends, and individuals in need.

Samie’s family found the SADS Foundation who helped with diagnoses and making certain family members received appropriate care. And more importantly, the SADS Foundation provided critical information and understanding through this tragedy. Now, Laurie wants to be Samie’s biggest supporter as she raises awareness of SADS and funds for the SADS Foundation. Please visit sads.org/Donate-No-Ball-At-All to read Samie’s full story and to help to save young lives of individuals with SADS conditions.

**Become a SADS Sustainer of Hearts, Receive a 25% Conference Discount**

Join us and save lives in the easiest and most effective way possible by making a monthly pledge as a SADS Sustainer of Hearts! Through donating each month, SADS Sustainers of Hearts support both current needs and the advancement of ground-breaking programs.

As a special thank you gift, if you make a monthly donation of $15 or more, you will receive a code to receive a 25% Special SADS Sustainer Discount. Visit sads.org/2018-Conference-Sustainer.

Please contact Jan at 801-272-3023 or jan@sads.org, should you have any questions or need further details.
Final Push for LIVE-LQTS Enrollment!

The true risks and benefits of exercise in LQT syndrome remains unknown. You can help us figure out the answer to this question by signing up for the LIVE-LQTS Study. The SADS Foundation is a big contributor to the LIVE-LQTS study—thank you to everyone who has signed up! We still need 500 more participants and you can help! Have the whole family sign up! livelqts.org

We are seeking individuals age 8 to 60 years old with a confirmed diagnosis of LQTS. Whether you like to run, walk, play baseball, or sit and read a book, you can participate in this study and help us learn more about lifestyle choices and LQTS. For more information or to sign up visit the LIVE-LQTS website, or contact the study coordinators at 866-207-9813 or live.lqts@yale.edu

Comments from participants: “I’m so excited to start the study!” “This study captures the biggest question in my life right now...” Many families are participating together, parents and children—And all the kids (and adults too) are excited to get and wear the Fitbit.

2018 Budget Agreement Increases Funding for NIH Heart Research!

Thank you to everyone who took action to support an increase in funding for heart research. The Bipartisan Budget Agreement of 2018 that Congress just passed includes a commitment to increase NIH funding by $1 billion in each of the next two years.

Mutations in several genes—including the CASQ2 gene—are known to cause CPVT. If you or someone you know has CPVT, a genetic test can confirm the diagnosis and help identify the cause. People who meet the eligibility requirements can receive genetic testing at no cost through the Uncovering CASQ2-CPVT program, sponsored by Audentes Therapeutics. Visit casq2.com to get started.

We’re advancing the understanding of CPVT. You can help.

Courts K. Cleveland, Jr. Young Investigator Awards

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Jaeger Ackerman  
Sponsor: Dr. Michael Ackerman

Conor Lane  
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Sponsor: Dr. M. Roselle Abraham

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Christiaan Veerman  
Sponsor: Dr. Connie R. Bezzina

Not pictured:

Not pictured:
Shared Decision-Making Critical for Athletic Participation by Patients with Heart Disease

Dr. Rachel Lampert, who is conducting the LIVE-LQTS Study believes that shared decision making is critical for athletic participation by patients with heart disease. This concept is a major focus in an October paper in Circulation by Rachel J. Lampert, MD, Michael J. Ackerman, MD, PhD, and Aaron L. Baggish, MD. Research studies such as the LIVE LQTS Study are essential in order to find out more about how to exercise safely with inherited heart conditions. If you have LQTS and have not yet signed up for this important study, now is the time! Our goal is to have 2,000 LQTS patients enrolled—we are over halfway there, and only need 600 more participants. Sign up today!

The comments and feedback on these cases are highly valued by both the referral physicians and the Scientific Advisors, as well as by the families: “Thank you to the SADS Advisors for their immediate and informative responses to my recent patient with Torsades... The patient went home today. The family gives 1000 thank yous and more. They are grateful for the expert opinions around the globe.”

And from our experts: “Although we often reach a general consensus, it has been a real comfort to several of my own patients to recognize that a global forum has been consulted for their own, specific issue. And - it is also a comfort to me to know that I have in fact covered all the bases and made appropriate allowances for the uncertainties that exist in this case. “SADS plays a pivotal role in bringing us together and motivating a friendly and constructive exchange.”

The SADS Foundation Brings Worldwide Expertise to YOUR Care!

The SADS Foundation has a panel of expert electrophysiologists from around the world who are available to consult on difficult cases submitted by our referral physicians. In late October, a case from one of our U.S. referral physicians was circulated by Alice Lara, our CEO, to our Scientific Advisors. Within a matter of days, 13 experts from all over the US, Canada, the UK, the Netherlands, Israel, and Italy weighed in with their opinion on the diagnosis and suggestions for the best management of the case.

SADS and Research

As the only advocacy organization devoted to channelopathies, the SADS Foundation supports research by serving as the critical link between patients, healthcare providers, and researchers:

The SADS Foundation supports research in the following ways:

- Our database of more than 10,000 individuals allows us to connect our families with research. Academic researchers and companies in biotech, drug development, and genetics count on us to find patients to participate in their studies to find new genetic mutations, determine who most is at risk for a sudden cardiac arrest, and to develop new treatments. The SADS Foundation always “vets” these research studies before promoting them, in order to protect the interests of our families.

- Our disease-specific communities can identify previously unrecognized questions for researchers. Most physicians have only a few SADS patients, which makes it difficult for them to identify those questions for research that may lead to diagnostic, management or treatment breakthroughs. Our families provide us with information, insights, and questions that can lead to new research questions, which benefit the researchers, our families, and the healthcare providers who care for them.

- Our Research Committee composed of SADS family members, medical professionals, and staff evaluates the research projects and companies that approach SADS. The goal of the Research Committee is to identify worthwhile projects, and protect our family members without being a roadblock to research.

In 2017 the SADS Foundation contributed to several important research and research-related projects:

- The LIVE-LQTS study – a 3-year NIH-funded study for people from ages 8-60 with a diagnosis of LQTS, designed to study the effects of lifestyle and exercise on LQTS (liveqts.org)

- Two Pregnancy studies – The first study focuses on fetal heart rates and can be done from anywhere; the second is an NIH-funded study at the University of Wisconsin on the role of fetal magnetocardiography (fMCG) in diagnosing LQTS during pregnancy (sads.org/Living-with-SADS/Pregnancy)

- Four studies conducted by Genetic Counseling students on genetic testing, the influence of SADS conditions on competitive athletes, and how well people with SADS conditions receive exercise recommendations.

- Started the SADS Channel Blog which provides information on a variety of topics of interest to our families, including Crispr research (sads.org/blog)

- Successful first Scientific Poster Session at our annual conference in Toronto last fall, with approximately 15 posters. Our second Scientific Poster Session will take place at our conference this fall in Ann Arbor (sads.org/SADS-International-Conferences/2017-Family-Conference). Instant results are not guaranteed by donating a large amount of money or by any one particular study or researcher. But beneficial steps towards living longer, living better, and finding a cure will continue to emerge with the joint collaboration of the SADS Foundation, SADS families, their healthcare providers, and researchers.

Rare Disease Day 2018

We encouraged our SADS community to take part in Rare Disease Day 2018 through in-person attendance, as well as participating in the online conference streams and events. A big thank you to everybody who joined. Under the theme of “Research” this year’s events included a Legislative Conference, a Congressional Caucus Briefing, and other various events focused on raising awareness among policymakers and the public about rare diseases and their impact on patients’ lives. Thank you to all who participated!
Visit StopSADS.org for links to the full articles and other information from this newsletter.

Remember to Sign-Up for our eNews!

If you enjoy receiving our newsletter in your mailbox, you’ll love to receive our monthly eNews through email! The eNews gives you easier access to our articles, with options to read more in depth about our articles. Sign-up by emailing Chelsey@sads.org. See you next month!

The Take Steps to Stop SADS Event will be extra special this year as it will be a tour at the University of Michigan Football Stadium (the largest stadium in the U.S.). Everyone will have time to play on the field and attend an After-Tour Reception at one of the VIP reception rooms at the stadium. You won’t want to miss this amazing evening with family, friends, staff, and docs!

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<tr>
<th>Date</th>
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<td>Jonathan R. Cowley Golf Tournament</td>
<td>Glen Allen, VA</td>
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<tr>
<td>TBD, 2018</td>
<td>Lemonade Stand for SADS Foundation</td>
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<tr>
<td>July TBD, 2018</td>
<td>Ryan Weidler Memorial Golf Tournament</td>
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