SADS NEWS
FOUNDATION
Supporting families. Saving lives.
Spring 2019

12th International SADS Foundation Conference

"We are thrilled to announce our partnerships with Children's Healthcare of Atlanta to host the 12th International SADS Foundation Conference.

This year's conference highlights will include a Friday afternoon session with adult conference attendees, including healthcare professionals, entitled "Communicating about SADS Conditions", which will be the inaugural Dr. G. Michael Vincent Tribute Lecture. On Friday evening there will be a "get to know you" reception. We will be featuring a special Casino night on Saturday night showcasing fun family games. There also will be an After Hours Family Room where you can meet and network with other families attending the conference.

Kids and teens will again have their own programs, with special sessions to include: STEM activities presented by Georgia Tech, new guest speakers and the "No Parents Allowed" session with Dr. Ackerman.

We are bringing back favorites from past years such as: "Ask Questions from the Experts: Dr. Ackerman, Dr. Abrams, Dr. Etheridge, Dr. Campbell", "Cutting Edge Research", "Sports and Exercise Participation", and "Disease-Specific Breakout Sessions"

Don't miss out on this year's conference. Visit SADS.org/Conference2019 for Early Bird registration (ends before July 4th)."

Don't miss the 12th International SADS Foundation October 4-6 in Atlanta.

SADS Safe Schools: Early Planning For a Safe Year

All students with a SADS Condition need a Care Plan at their school.

Attention parents! It's never too early to plan for the upcoming school year. SADS Safe Schools month is coming in September and we have materials and forms for you to use with teachers, school nurses, etc. Download the Back to School Checklist at SADS.org/Awareness and order your school materials online or email sads@sads.org for more information.

Once again, the SADS Foundation is leading a nationwide effort to ask that states, counties or cities proclaim September as SADS Safe Schools Month. If you'd like to participate, please let us know at sads@sads.org. And watch for more information on the process in our upcoming enewsletters and at SADS.org/Awareness.

Together we can make our schools SADS Safe Schools!

In This Edition

June 1-7 is National CPR/AED Awareness Week

By now you've heard the news about hands-only CPR, but have you told anyone else? Did you know that CPR is rarely used by the average person during the event of an emergency? Studies have shown that even watching a simple YouTube video can give someone the skills to actually perform hands-only CPR and yes—save lives! You have an important opportunity to inform your friends and family of one of the most simple and effective ways to keep your community safe: CPR!

Visit SADS.org/Advocacy/CPR for a variety of videos demonstrating hands-only CPR and the use of Automated External Defibrillators (AEDs) as well as materials and other helpful tools. Even furry friends need a safe environment, so while you're there brush up on CPR for cats and dogs too!

Remember:

1. Immediately upon a person collapsing (going into cardiac arrest), **CALL 911.**
2. **Push hard and fast** in the center of the person's chest. (Until emergency services arrive or an AED can be used.)

Improving SCA Survival Rates with CPR Over the Phone

We know that SCA survival rate depends on where you live. Training emergency dispatchers to coach CPR over the phone can improve survival rate up to 50%—an easy answer to saving lives!

We urge every city and county to voluntarily have its 911 dispatchers coach CPR over the phone.

CPR Mandate for High School Graduation

38 states and Washington, DC have passed laws or adopted curriculum changes to require hands-on CPR training to graduate from high school. Thus, nearly 2.3 million public school students will be trained in CPR each year.

How the SADS Conference Changed My Life (& My Treatment Plan)

by Alexis Holmgren

When we heard the 2017 SADS Conference was going to be held in Canada, it seemed like a sign for my mom and me as Canadians. In the past, we had not been able to get insurance to travel outside of the country after her sudden cardiac arrest 5 years prior. Since it was in Canada, we no longer had to worry about getting out of country travel insurance to go. Even so, it seemed like a totally crazy idea at the time, but my mom told me she had a feeling we needed to be there. So, my mom and I flew approximately 3,000 km from the western province of Alberta to the other side of the country to Toronto, Ontario to attend the conference. Since I was diagnosed with Long QT Syndrome when I was 12, I had always wanted to attend the SADS conference. I wanted to meet other teens and people my age living with Long QT. It was a maybe, someday, sort of dream for me. In the years prior, I had diligently followed the conference posts on Facebook support groups and on Twitter. Even so, seeing posts in my news feed is completely different from actually being in the room with the experts.

Read more about Alexis' experience at the SADS Foundation International Conference and how it affected her life at SADS.org/blog.

Hear from attendees from past SADS conferences

"Dr. Perry & Dr. Ackerman being here. So personable. No white coat. Easy to talk to; AWESOME!!!" (San Diego, 2016)

"As a family member of a LQTS, I am happy to report that my knowledge of this subject has increased 10-fold. Much of my fear has been ameliorated. I do wish that the slide presentations were copied and handed out for all to take notes and write questions. Overall—Incredible Experience!" (Ann Arbor, 2018)

"It was fantastic. This was our first year attending a conference and not even an hour in, I was so glad we finally came to one." (Ann Arbor, 2018)

"Loved the presentation by Dr. Campbell and the chance to speak with him. Great info from him during our talking regarding pacemaker, stamina, loop recorder and competitive sports with some contact. My children and I are still involved in competitive sports, so appreciated this opportunity." (Ann Arbor, 2018)

Selfies with AEDs

by Melissa Russom, SADS Blog, March 1, 2019

If you're at work, out shopping, working out or participating in your everyday activities – could you find the AED immediately if someone were to need it? I'm the mom of two girls with Long QT and I wasn't in the habit of noticing AEDs when we were out of the house. It sounds kind of crazy, right? If one of my little girls were to experience cardiac arrest, the fast use of an AED is their best chance of survival – and I didn't know where they were! If we needed one, my first step wouldn't be to get it, my first step would be to find it.

Becoming more aware to keep my kids safe

A light bulb went off one morning when I was with my family eating breakfast at our favorite country store. I saw an AED on the wall right over my daughter's head and realized I felt good knowing it was there. It addressed an unknown I hadn't realized was lurking in my subconscious.

Since then we committed to looking for them at our other regular spots: the grocery store, pharmacy, play places, libraries…

As SADS families, you understand how important this is, too.

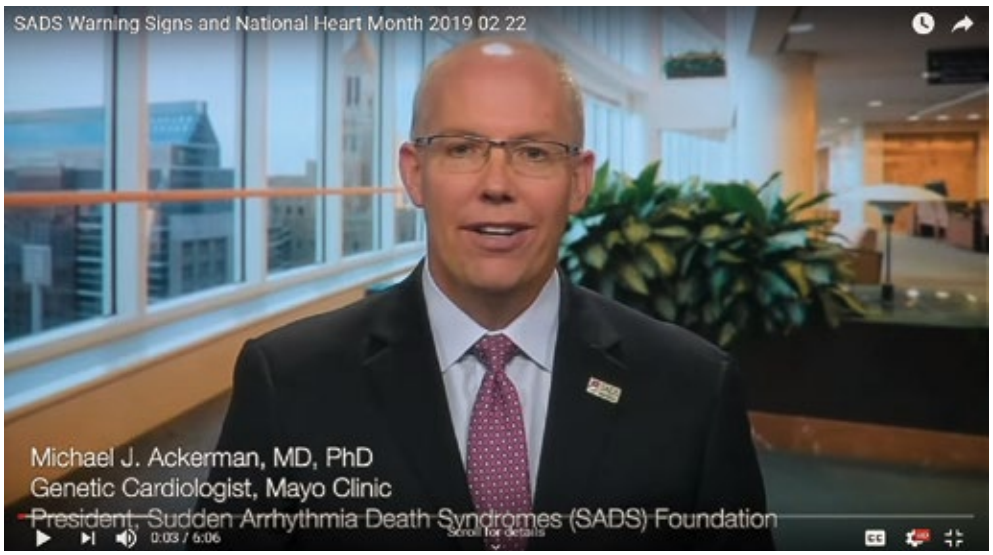
Selfies With AEDs is a social media campaign designed to get people into the habit of noticing where the AEDs are in the places they visit most frequently.

It's super simple:

1. Look for an AED wherever you are
2. Take a selfie (pets, kids, groups included!)
3. Post it on social media and tag @SelfiesWithAEDs

SADS Celebrates Heart Month!

SADS Foundation celebrated February National Heart Month. The first American Heart Month took place in February 1964, proclaimed by President Lyndon B. Johnson.



A few of the SADS Foundation activities during Heart month include:

Dr. Michael J. Ackerman, genetic cardiologist at Mayo Clinic and president of the SADS Board, producing a YouTube video explaining the SADS warning signs. It was posted on both the SADS Foundation and Mayo Clinic accounts and had more than 1,100 views in February. It can be views on the SADS YouTube channel.

SADS staff mailing over 150 Red Kits to families. Each kit included awareness posters, bracelets, etc. to pass out to their communities.

The biggest success for February was our increased social media presence (#SADSHeartMonth). We reached over 60,000 Facebook users and many more on Twitter and Instagram. We want to thank everyone that participated by sharing our infographics, putting up posters, passing out bracelets, and talking to your communities.

This post reached over 23,000 people on Facebook.

These gorgeous cookies were made by Amber, owner of Flour & Frosting in Spokane, Washington to raise awareness of SADS for National Heart Month!

Enjoying a Heart Friendly Summer

Summer safety is something that every parent is concerned with—especially SADS families. With a few easy precautions, everyone can plan a fun summer full of swimming, summer camps, and other activities for their kids to enjoy.

Swimming Facts and Tips:

- Always swim with a buddy who knows CPR.
- Bring an AED with you to the pool or make sure the pool has an AED on site.
- Make sure someone with you has a cell phone with service at all times.
- Consult with your doctor. about your specific disease with water. Some diseases (i.e. LQTS type 1) might have more issues than others.

Summer Camps:

While kids do not need to attend camps that cater to SADS-specific conditions, many families have told us that specialty camps create a unique experience and can help to address support issues that regular camps are not as well-equipped to address. There are camps in many areas—check here to see our list: StopSADS.org and search for camps. If you know of any other specialty camps, please e-mail us at sads@sads.org.

Regardless of whether or not your child attends a SADS-specific camp or a generic summer camp, following a few safety precautions will help alleviate your stress during the summer.

- Educate the staff about your child's SADS condition, medications and schedule.
- Make sure the staff is CPR trained and properly prepared to respond in the event of an emergency.
- Make sure the camp has an AED or send one with your child.

SADS 2019 Heart Hero: Terry Bishop

The SADS Foundation would like to congratulate Terry Bishop for being selected as a SADS Heart Hero. Terry Bishop was nominated by his wife, Whitney. He lives with Brugada Syndrome and has been a great role model for his family. Read the winning submission below.

Terry has been so strong through this learning experience we have gone through. He is the carrier and 2 of our 5 children, both girls, have Brugada Syndrome. He has shown our girls that fear is okay but God and knowledge are so powerful! He is there every step of the way for our family. He continues to work his bottom off and strives to be an amazing husband and father all while dealing with a life-changing heart condition. He continues to show love and support for our girls. He is definitely a hero to them. They know that they are NOT alone on this journey because together they share a bond that not one of us can compare to. He builds them up when they are scared and assured me daily he's not going anywhere when I am scared! He is so stressed all the time and he never lets it show. He is my Heart Hero because he is the rock of this family!

Thanks to everyone who submitted a Heart Hero nomination! All the nominations were inspiring and we enjoyed each one. Visit SADS.org/blog to read more inspirational stories submitted by the SADS community.

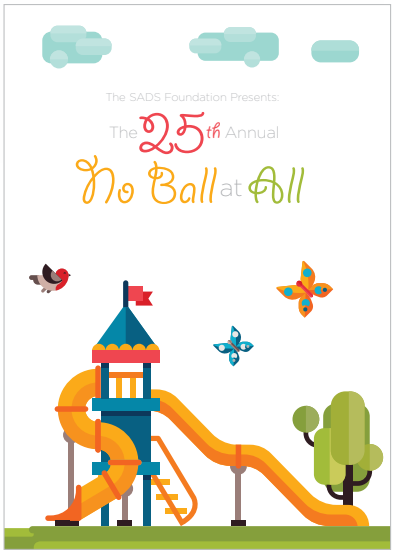
Heart of the Matter—Question of the Month Video Series

Dr. Michael Ackerman (Mayo Clinic) and The SADS Foundation are partnering to provide brief answers (3-5 min) to questions from SADS patients and families. The first video posted in March is responding to the question, "Can I take vaccinations if I have a SADS condition?"

The video may be viewed on SADS Foundation YouTube channel, Mayo Clinic YouTube channel, SADS social media and on StopSADS.org (Living With SADS)—along with our past Heart of the Matter videos.

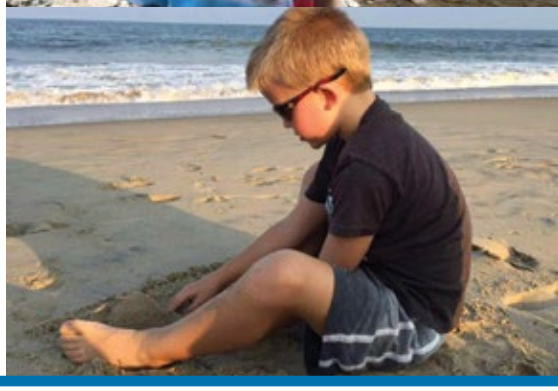
25th No Ball at All Campaign

The Hyzy Family's Story: Our beautiful son Ian was 7 years old when he passed away from Long QT Syndrome. We were unaware that he had this condition, as he had never exhibited any symptoms. Ian went into sudden cardiac arrest at home. At the hospital, an EKG was done that showed he had Long QT. Over the course of his hospital stay, Ian went into cardiac arrest four more times. Through genetic testing, it was confirmed that Ian had Long QT Syndrome, Type 3.



Ian was always happy and so full of life. He was loving, caring, sweet, and empathetic. Ian's hugs were the best medicine and held all the love he had inside of him. He loved playing Minecraft, Terraria, and Super Mario Bros. Ian also loved Legos, baseball, swimming, being at the beach, playing at his school playground, Angry Birds, writing little stories, playing with friends, and reading books while cuddling with his mom.

We miss Ian more than words can ever say. It is important to us to support the SADS Foundation to raise awareness about Long QT through the wonderful work they do in providing resources to patients and families. To give a gift and read our full story, visit SADS.org/NoBall#.



Extra Ways to Give

Giving to the SADS Foundation is easy and every little bit helps us support SADS families!

Combined Federal Campaign (CFC)

CFC is the world's largest workplace campaign. Pledges may be made by Federal civilian, postal and military employees. Visit opm.gov/combined-federal-campaign for more information.

United Way

If your company has a United Way campaign, choose the SADS Foundation for your payroll deduction to be a part of the campaign and support us at the same time.

Workplace Giving and Matching Campaigns

Ask your company if they have a Workplace Giving Program and/or a Matching Fund Campaign. You can easily give through a payroll deduction and make your donation go even further through a company match.

Vehicle Donation Program

Donate a vehicle and receive a tax deduction. Just contact our office for the required information to process your vehicle donation for the SADS Foundation.

AmazonSmile

Choose the SADS Foundation on AmazonSmile.com every time you shop and donate 0.5% for the services we provide.

iGive.com

Join for free at iGive.com/SADSFoundation to turn online shopping into much-needed donations.

Contact Jan at 801-272-3023 or jan@sads.org for assistance.

Fabulous Facebook Fundraisers!

Wow! Last May, when the SADS Foundation signed up to be able to do Facebook Fundraisers we had no idea how many families would respond! It's only been a year, but nearly 150 fundraisers have been held raising more than $50,000! THANK YOU!

If you would like to do a fundraiser on Facebook, visit facebook.com, search SADS Foundation and look for the fundraising page. If you have any questions, contact Jan at 801-272-3023 or jan@sads.org.

SADS Sustainers of Hearts Doubled

During 2018, so many families signed up to be a SADS Sustainer of Hearts we doubled the number of sustainers! We ask you to help us to double the number again in 2019. With just $5 a month or more if you'd like, you will support the many services that we provide for SADS families.

SADS FOUNDATION Sustainer of Hearts www.StopSADS.org

The easiest way to become a SADS Sustainer of Hearts is to visit SADS.org/ Donate-Sustainer# to make a monthly contribution from your checking account – this will ensure revenue stability for the SADS Foundation as we will not lose critical funding when credit cards expire.

Please contact Jan at 801-272-3023 or jan@sads.org, should you have any questions.

Medical Mystery: After He Fainted, Man's Diagnosis Unraveled a Frightening Family History

Volunteer Jennifer L. White, MD and Melanie Root

A 60-year-old man came to the emergency department after he passed out in public. According to bystanders, the fall happened so quickly that no one was able to catch him before he hit the ground and sustained a facial injury.

He reported having a fever for several days before his fainting. Blood work and a CT scan were ordered, along with a standard electrocardiogram. Results of the testing indicated the man had an infection, which was in line with his symptoms.

When we returned to his ED room after the testing, the man experienced a life-threatening heart rhythm called torsades de pointes, or "twisting of the points." He went into cardiac arrest because of the erratic rhythm in his heart.

His care team quickly administered one electrical shock to his heart and began CPR until his heart returned to its normal rhythm. This serious development in symptoms signaled to the doctors that something more than an infection was going on. So what could it be?

As SADS families, you know that this older gentleman has Long QT Syndrome. Visit StopSADS.org and click News to read how the medical team did further investigation and discovered his family history.

SADS Will Now Have a Monthly Podcast

The SADS Foundation will now be featured monthly in the weekly podcast **Pediheart: Pediatric Cardiology Today with Robert Pass.** Check out the past year's topics and add the podcast to your program list on iTunes and other podcast apps or at SADS.org/Medical-Professional-Education.

Monthly Featured Interview on Pediheart: Pediatric Cardiology Today—Podcast by Robert Pass, MD

This podcast is a review of the latest literature and thought leaders in pediatric cardiovascular care in which Dr. Pass provides balanced appraisals of cardiovascular research in an easy to understand manner. His editorials are useful and the interviews are valuable. Dr. Pass and the SADS Foundation will be featuring a SADS-related expert once a month on his weekly podcast to advance the education of medical professionals about SADS.

Changes to LQT Drugs to Avoid List

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

Glasdegib (Daurismo)—anti cancer drug

Lofexidine (Lucemyra)—used for opiate withdrawal

Lofexidine (Lucemyra)

Hydroquinidine—antiarrhythmic drug

Xylometazoline—decongestant nasal spray

SADS Difficult Cases

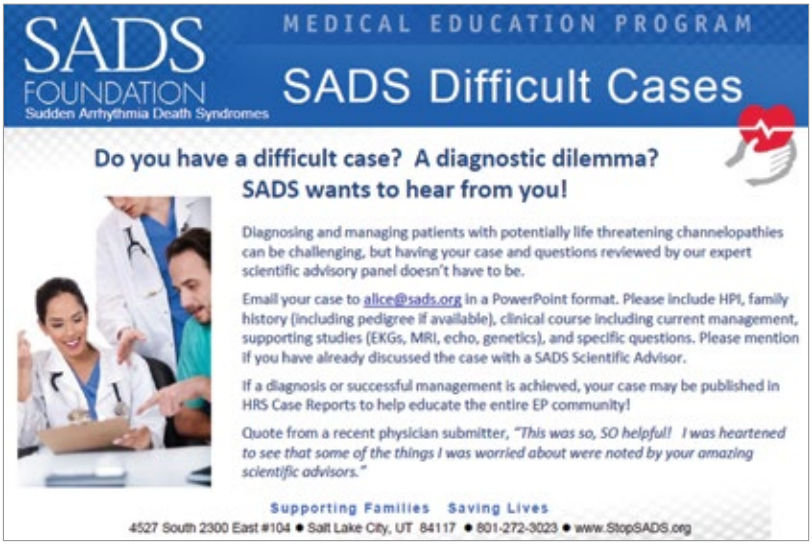
Do you have a difficult case? A diagnostic dilemma? The SADS Foundation wants to hear from you!

Diagnosing and managing patients with potentially life threatening channelopathies can be challenging, but having your case and questions reviewed by our expert scientific advisory panel doesn't have to be.

Email your case to alice@sads.org in a PowerPoint format. Please include HPI, family history (including pedigree if available), clinical course including current management, supporting studies (EKGs, MRI, echo, genetics), and specific questions. Please include if you have already discussed the case with a SADS Foundation Scientific Advisor.

If a diagnosis or successful management is achieved, your case may be submitted to HRS Case Reports to help provide education to the entire EP community!

Quote from a recent physician submitter: "This was so, SO helpful! I was heartened to see that some of the things I was worried about were noted by your amazing scientific advisors."



Christine Johnson Inspires Girl Scout Troop

Muirlands Middle School has the admirable distinction of being the first public school in California to receive the Heart Safe School Accreditation.

Christine Johnson encouraged and led Girl Scout Troop 3803 in San Diego to make the schools they attend Heart Safe Schools because, as one girl related, "About 5 years ago, my dad suffered a cardiac arrest at the height of an intense workout at a Bird Rock gym. He was healthy and fit, but one day he collapsed. He received 12 minutes of CPR before paramedics arrived. There was no AED at the gym, so my father's chance of survival was very slim. Once the paramedics arrived, they were able to shock his heart back into rhythm. He was in coma for four days, but survived."

From that point on, the troop's mission was clear. The girls themselves learned CPR training in fourth grade, and then they trained other Bird Rock Elementary School students and the entire fifth-grade class. Once they moved to Muirlands Middle School, they organized CPR and AED training for staff and teachers there, as well as 600 students in the past two years through PE classes.

Thanks to all organizations involved in the effort, including Girl Scouts San Diego, San Diego Project Heartbeat, Sudden Arrhythmia Death Syndrome Foundation or SADS (which offered the accreditation), American Heart Association, and the office of County Supervisor Ron Roberts.

Rare Disease Advocate, Courtney Waller

As part of Rare Disease Day 2019, the SADS Foundation had the opportunity to interview Courtney Waller, whose daughter Theodora lives with Timothy Syndrome, about her experience with rare disease advocacy. Below is part of her interview.

"You started as an advocate for your daughter then became an advocate for Timothy Syndrome and rare diseases. Can you tell us how that happened?"

"I have always been an activist, since I was a young kid. As I got older and started a family it sort of fell by the wayside. When Theodora was born, there was not a lot of information on Timothy Syndrome, no cure and no real ongoing research. I guess, I felt I had to do something to help her… so I returned to my roots. I remember doing a simple Google search for rare disease support groups and found RDLA, an organization that works on legislation specific to the rare disease community. It just happened they were having a conference in DC the following month. I bought a plane ticket and began my journey as a rare disease advocate."

To read more about Courtney's advocacy experience and her advice for those who are interested in getting more involved with rare disease advocacy, check out the full interview at SADS.org/blog

Courtney Waller and 3 of her children with Theodora's portrait painted by artist Jennifer Cahoon as part of the Beyond The Diagnosis exhibit.

CPR & AEDs in College Dorms

The SADS Foundation—along with Project A.D.A.M., Project S.A.V.E. and Parent Heart Watch—are just starting a project aimed to make sure every RA (Resident Assistant of a dorm) be CPR trained as part of the job requirement. In a quick search of several colleges/universities and their RA responsibilities, of 13 only 2 require CPR/AED/First Aid certification. And some are not allowed to start CPR or use an AED! We think this is crazy and needs to be addressed.

And if you're interested in helping with a college campaign, just let rachel@sads.org know.

SADS FOUNDATION
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If you enjoy reading our newsletters remember to sign up for our eNews! Stay up to date with monthly articles and programs. Visit stopSADS.org to sign up.

Upcoming Summer/Fall Events

May 8-11	Heart Rhythm Society Scientific Sessions	San Francisco, CA
May 11	1st Annual Hops for Hearts	Oaks, PA
May 19	3rd Annual Gertsberg Memorial 5K	Farmington, CT
June TBD	Rob Kaas Memorial Golf Tournament	Costa Mesa, CA
July TBD	3rd Annual Beat the Heat with Maddy's Lemonade Stand	Carol Stream, IL
July TBD	13th Annual Ryan Weidler Memorial Golf Tournament	Norristown, PA
October TBD	2nd Annual USA Swim Club Meet	Cleveland, OH
October 4-6	12th International SADS Foundation Conference	Atlanta, GA
October 5	4th Annual Rachel's Race	Janesville, WI
November 16-18	AHA Scientific Sessions	Philadelphia, PA

Don't miss out on this year's conference.

Visit SADS.org/conference2019 for Early Bird registration (ends before July 4th).

If you already are or if you become a SADS Sustainer, you will receive $20 off individual registration fees