



SADS Safe Schools Month in September *Prior Planning Can Save a Life*

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

Parents, now that your kids are back in school you need to ensure they are safe for the 2015-2016 school year! Make sure your child has an updated care plan in place with a current list of medicines and emergency information, and know who is responsible for it. Talk to all teachers and staff who will have any interaction with your child to verify they know your child's condition and how to monitor it. This includes their homeroom teacher, P.E. teachers, recess

monitors, lunch room monitors, bus drivers, school secretaries, principals, coaches, etc. If your school has a Heart Safe School accreditation, you're done. If not, you'll need to make sure there are AEDs at school and a medical emergency plan. Download the Back to School Checklist at www.StopSADS.org/SADS-Safe-Schools and order your packet online or email SSchools@sads.org for more information.



Lifestyle and Exercise in Long QT Syndrome

"LIVE-LQTS" is an exciting new study whose goal is to determine how lifestyle and exercise impact the well-being of individuals with 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, please visit www.StopSADS.org or email Matt@sads.org.

CPR Graduation Requirements Legislated

The good news? CPR is required of all high school graduates in almost half of the United States.

The bad news? CPR is not yet currently required in the other half of the U.S.

With a wide variety of training options to choose from (e.g., web-based versus in the classroom, certification versus hands-only training, etc.) your home state might be a whole lot closer to requiring CPR training in order to graduate from high school. If you're curious as to whether your home state is one of those that requires CPR training (and how to get involved in those who do not yet require it), please visit www.StopSADS.org/Awareness/CPR.



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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Welcome Our New Director of Family Support

The SADS Foundation is pleased to announce that Lynn Johnson, MD has joined our team as our Director of Family Support! Below is a quick note of introduction from her:

"I am very excited to join SADS as the Director of Family Support. A genetic cardiac condition runs in my family, and I have been a strong advocate for greater awareness of sudden cardiac arrest, especially after my brother unexpectedly collapsed while working out at the gym. Thanks to expert CPR provided by his wife and a fellow gym member, he survived.

I received my undergraduate degree in history from Dartmouth, my MD from the University of Virginia, and I did my postgraduate training in radiology at UCSD and Stanford. My husband and I live in Northern California and have three children attending college on the east coast. I enjoy distance running, triathlons, walking our dogs, book clubs, and traveling (especially if historical sites are involved).

I am looking forward to using my medical background and experience as a patient advocate and researcher to help families live and thrive with SADS conditions."



Dr. Chris Anderson Leaves the SADS Board and Joins the SADS Scientific Advisors

It has been an honor and pleasure to work with all of you. I hope that in the 7 or so years of my involvement with SADS that I have helped at least in some small way to fulfill the mission of SADS Foundation. In the 13 years of my EP practice I have already seen huge and inspiring advancements. I am sure that as the organization continues to grow and evolve that you all will continue to have a major positive impact on those patients, families and providers affected by, and caring for, these often devastating conditions.

-Dr. Chris Anderson



"On behalf of your fellow board members, THANK YOU for giving SADS 7+ great years!"

-Dr. Michael Ackerman

"He truly exemplifies a dedicated board member and an outstanding SADS physician."

-Alice Lara



Grace's Goodbye

Thank you to all of the SADS Families and Staff Members that have made my two years here so memorable and worthwhile. I am so grateful to have been a part of the SADS Staff and Family. During my time here at the SADS Foundation I met and worked with amazing people and feel that together we have genuinely made a difference. It has genuinely been a pleasure and I will miss all the wonderful friends I have made during my time here.

SADS International Conference 2015

The 8th Annual International SADS Foundation held on May 29-31 in New York is now behind us and was our best conference to date! All of us at the SADS Foundation and NYU Langone Medical Center would like to express our gratitude to each person who helped to make the conference successful and to everyone who came to share the weekend with us as we learned about the latest research and treatment of SADS conditions and supported one another.

Thanks to our Sponsors and Exhibitors as well as a very special individual donor listed below. Without their financial support this conference would not have been possible.

- Ambry Genetics
- Biosense Webster
- Boston Scientific
- Gene DX
- Gilead
- Invitae
- Medtronic
- One Beat CPR
- St. Jude
- Familion a subsidiary of Transgenomic
- Ricki Kane Larimer in memory of her loving husband, Robert Walker Larimer.



MEDICAL SESSIONS

Congratulations to Program Directors Glenn I. Fishman, MD, and Silvia G. Priori, MD, PhD, for jointly planning, organizing, and providing the scientific symposium *Sudden Arrhythmic Death Syndromes: Recent Advances and their Role in Improving Outcomes* with the SADS Foundation at NYU Langone Medical Center. More than 125 attendees were highly engaged and stayed to the very end to discuss the 16 separate presentations.

FAMILY SESSIONS

Bravo to the committee members for planning and hosting the Family Sessions with education about the newest research and treatment of SADS conditions, an exchange of ideas between experts and families, and entertainment by Cherub Improv Group to jumpstart the Networking Night Out. The conference boasted an attendance of families from 19 states and from four countries: Chile, Germany, Ireland, and Spain.

KIDS SESSIONS

A special track for kids and teens included creating their own Healing Wall submission, question and answer sessions with health care professionals featuring Board President Dr. Michael J. Ackerman and AED/CPR training. Both parents and kids agreed it was a terrific opportunity for kids to meet other kids who are impacted with SADS conditions.

All of us at the SADS Foundation are honored to have spent time with our families during our 8th Annual International SADS Foundation Conference. Check out the pictures on www.StopSADS.org/Conference2015. We are anxious to see you again at our next conference!

2015 Volunteer Awardees

The Knowles Family

Great friends and supporters of the SADS Foundation, the Knowles Family (Mark, Rebecca, Cameron, and Zach) have been extremely busy volunteers preparing both kids and adults at school to respond to someone in sudden cardiac arrest through the Heart Safe School Accreditation program!



Nancy Walker

Nancy Walker, Director of StorSimple, Central, at Microsoft nominated the SADS Foundation to be the recipient charity at the yearly kick-off event of the Microsoft Incubation Team in honor of her daughter Cecilia who is living and thriving with a SADS condition. The total of pledges from employees and the company matches from Microsoft raised more than \$22,000 for the SADS Foundation!

SADS Foundation Board Finance Committee Members

Anthony Lucatuorto who joined the SADS Foundation Board in 2010 and Joanna Bewick who joined the SADS Foundation board in 2013 have been dedicated to performing their board duties as well as raising awareness and funds for our programs and services for our organization. The hours they give working with board and staff members is truly valuable to the success of the SADS Foundation.



Heart Hero Ellie Wilhelm

Ellie Wilhelm from St. Louis, Missouri, is a heart hero in every sense, rising above her own physical challenges to inspire and support others. After receiving a pacemaker at age 16, Ellie began running as a way to test her limits and improve her cardiovascular health. She eventually completed her first marathon and was selected as a 2012 Medtronic Global Hero. Ellie is also a "SoleMate" for Girls on the Run in St. Louis, an organization that provides self-esteem, healthy living and team building programs for girls. She is involved in support and fundraising events for The Children's Heart Foundation, St. Jude's Hospital and a captain for the Ironheart Racing Team. Ellie's motto is, "Never give up. Aim high. Stay positive. Surround yourself with supportive people. Finish strong!"



Heart Hero Genevie Echols

Genevie Echols from Rochester, Minnesota, joined the SADS family in 2008 as one of our active Utah supporters. Genevie then became an official SADS Ambassador in 2012 and this year is a No Ball at All Committee Member. The SADS Foundation has been truly fortunate

to have the support of Genevie and her family right here in Salt Lake City. After moving to Wisconsin in 2014, the family then relocated to Minnesota. With the move to Minnesota, Genevie has been accepted to the Cardiovascular Invasive Specialist Program at Mayo Clinic College of Medicine. Genevie looks forward to using the knowledge she gains through the program to be an even better volunteer and ambassador. All of us send her our congratulations and best wishes for her success!



Remembering Gray Solana

Mark and Graham Solana were blessed with four children, two of whom (Joe and Gray) were diagnosed early in life with LQTS 3. They were fortunate to have a local doctor who knows about LQTS and they received Beta Blocker treatments from the beginning. Joe and Gray never had a fainting spell and lived fairly normal lives for boys with LQTS. Joe never participated with any competitive team sports, but was a pretty prolific golfer. Gray, on the other hand, loved basketball. He was cleared by his doctor to play on teams under close supervision, but was never allowed to do wind sprints or be in a game more than a few minutes.

On February 8, 2015, the two older boys came home from college to have an early birthday celebration for Gray. On Saturday, the family had lunch with their maternal grandmother and then went out with Dad for a round of skeet shooting. That night, Graham was preparing a birthday meal for the family and when it was ready, they called Gray to the table. No answer. The family went

looking for Gray discovered Gray passed out on the floor in the hall bathroom. They rushed in to find that he had no pulse – CPR was started immediately and 911 was called. Eight minutes later Gray was in the back of the ambulance and with the help of a neighbor who is a cardiologist, his heart was started again as he was taken to the hospital.

Unfortunately, he had been passed out so long, it was feared that he had brain damage due to lack of oxygen. Gray fought bravely for his life for 36 hours, but it was determined that he did indeed have brain damage so severe his vital organs would soon shut down. He was declared officially brain dead and several hours later was taken off of life support. Even with foreknowledge of the deadly risks associated with LQTS, the worst case scenario sometimes can't be avoided. The family designated the SADS Foundation as a core beneficiary of donations made in Grays' memory so that they may continue to support families and save young lives through awareness and education.



Lighting Your Neighborhood for SADS

Two of our SADS families have started traditions in their neighborhoods of two different ways to light up their streets for SADS. Proceeds from both events benefit the SADS Foundation.

The first is Brittany's Trees established in 2005 by Tony Valene and Jim Guthrie to celebrate the holidays and memory of eight-

year-old Brittany Valene who died of Long QT Syndrome. Brittany's vibrant spirit inspired her family, friends and neighbors in Carol Stream, Illinois to place a glowing Christmas tree in each neighbor's yard representing Brittany's heart. Brittany's Trees began with 22 trees and has continued to grow over the past ten years as more and more people catch the spirit.

The second is the Annual Coconut Creek Luminary Night started by the Halle Family three years ago in Ft. Myers, Florida. Neighbors gather for an evening of holiday food, fun, and cheer as well as spreading awareness and raising funds for SADS. Each family displays



luminary bags that light their pathways for the holiday season.

Both events not only benefit SADS, but have become a part of a meaningful holiday tradition in the middle of the rush of the season. Please contact Jan at jan@sads.org or 801-531-0937 for more information about either of these neighborhood celebrations.



Style with Heart

SADS Foundation volunteer Mary Ann Ciciarelli hosted the first Style with Heart on June 20 in Charlotte, North Carolina. A variety of local artists and businesses brought items to sell with 10% of the profits benefitting the SADS Foundation. The afternoon was full

of sipping, shopping, and several sensational raffle items. And, to make the event even more successful, Mary Ann and her husband Christian requested matching funds from their respective companies. What a great way to have fun and benefits SADS all at the same time!



Easy Ways to Give

Vehicle Donation Program

Donate your car, boat, truck, RV, Jet Ski or snowmobile to The SADS Foundation and receive a tax deduction.

This no-cost, no-hassle process begins when you contact our fundraising partner, Donation Line LLC at 877-227-7487. Make sure to ask for our extension: 2828. Or visit www.sads.org/Get-Involved/Vehicle-Donation-Program to donate online. Be sure to have your title in hand.



Give While You Shop

iGive.com



Join for free and help the SADS Foundation! Be a part of the largest online network of shoppers, online stores, and worthy causes dedicated to turning everyday online shopping and searching into much-needed donations. Plus, you get access to free shipping deals and exclusive coupons, on top of the great deals you'll find every day through iGive.com's network of 1,000+ stores.

Raise a Penny Per Search at www.iGive.com every time you search the web? Try iGive's search engine and enjoy free, easy fundraising for the SADS Foundation. Please visit www.iGive.com/SADSFoundation.

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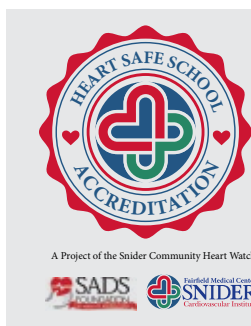
Start each shopping session at smile.amazon.com, and choose the SADS Foundation as your charity of choice. Please contact Jan at jan@sads.org or 801-531-0937 if you have any questions.

First Two HSSA Schools in Utah

Congratulations to the first two schools in Utah to earn Heart Safe School Accreditation (HSSA) awards. Led by Salt Lake City School District nurses Judi Yaworsky and Wade Capps, both Nibley Park K-8 School and Emerson Elementary School were presented with HSSA plaques and banners at an Awards Ceremony in May of 2015.

Ms. Frances Battle, principal of Nibley Park K-8 School said, "That we are one of the first schools to be a Heart Safe School in Utah speaks to how important we think it is to teach our students to be lifetime citizen first responders."

"Earning the Heart Safe School Accreditation has taken months of hard work," says Ms. April Reynolds of Emerson Elementary School. "Being certified is important to continuing to provide a safe and healthy environment our kids, staff, and entire community."



The SADS Foundation looks forward to many more schools becoming Heart Safe School Accredited. If you want to find out how schools in your state can earn this crucial accreditation, please visit www.StopSADS.org/HSSA or call 801-531-0937 for more information.

Thanksgiving is National Family History Day

Thanksgiving is National Family History Day, a day designated by the US Surgeon General that encourages Americans to share a meal and their family health history.

The SADS Foundation hopes you'll take a few minutes to talk with your relatives this holiday season, obtain health histories with our Pedigree Kit, and help them through the steps of screening for SADS conditions. The Pedigree Kit contains information on family history, risks, and testing, as well as easy to fill out forms for creating a family's complete health history. SADS-related sudden death is preventable, but only when every family is informed. The Pedigree Kit can be found on our website: www.StopSADS.org/Pedigree-Kit. Have a safe and happy holiday!

Make Your School a Heart Safe School Starting Now!

Heart Safe School Accreditation Elements:

1. Risk assessment completed to determine students' risk of sudden cardiac arrest.
2. Well-organized care plans prepared and on file for all students with a known cardiac diagnosis.
3. Medical emergency drills conducted by school personnel several times per school year.
4. AEDs available and located in appropriate areas.
5. At least one member of the school staff trained in CPR for every fifty students enrolled (1:50).
6. CPR training for all students as part of the curriculum.
7. Ongoing education on sudden cardiac arrest in youth for continued preparedness.

To find out how your school can earn this crucial accreditation, please visit www.StopSADS.org/HSSA or call 801-531-0937 for more information.



Sports Participation in Genotype Positive Children with Long QT Syndrome

SADS Medical Education Committee Member Peter Aziz, MD of the Cleveland Clinic recently published research on LQTS and sports. Participation in both competitive and recreational sports may be safer than previously thought for pediatric patients with congenital long QT syndrome.

In an accompanying editorial, Michael J. Ackerman, MD, PhD, FACC, director of the Long QT Syndrome Clinic at Mayo Clinic in Rochester, MN, said decisions to play sports should be determined by a long QT syndrome expert in conjunction with the athlete and his or her family so that they can make a well-informed decision knowing all the risks. Find links to the articles at www.StopSADS.org.

Changes to LQT Drugs to Avoid List

Just a reminder to make sure you check the LQTS Drugs to Avoid list often and especially before you take any new medication. There have been more than 20 changes to these lists so far this year. Either contact us with a question or register on the CredibleMeds page to look up your medication and to receive an email whenever any changes are made. You can find the site here: www.StopSADS.org or www.QTDrugs.org.



Heart Rhythm Society Scientific Sessions 2015

This past May the entire staff traveled to Boston, Massachusetts for the Heart Rhythm Society's Scientific Sessions with a significant presence! Staff members attended the Pediatric and Congenital Electrophysiology Society's pre-conference and hosted lunches with both Allied Health Professionals and Genetic Counselors with record attendance.

For the 2nd year in a row, we organized a scientific session on SADS conditions with more than 110 people in attendance learning about the complexities of treating SADS families.

The New SADS Speakers Bureau

Dr. Ackerman formally launched our Speakers Bureau program for health professionals with a well-attended training session of potential participants. These participants have committed to speaking in their local region to target groups including Emergency Physicians, Pediatricians, Family Physicians (and their professional staff members), and School Nurses.

With support from the SADS Foundation and our volunteers, these newly trained SADS experts aggressively seek opportunities to present this life-saving information across the United States so that we may increase the number of young lives saved from a preventable death. For more information, contact Matt at 801-531-0937 or matt@sads.org or visit www.StopSADS.org/Speakers-Bureau.



8th Annual Courts k. Cleveland SADS Foundation Young Investigator Awards In Cardiac Channelopathies

The Young Investigator Awards in Cardiac Channelopathies administered by the Pediatric and Congenital Electrophysiology Society (PACES) were presented at the annual PACES evening meeting on May 13, 2015, by Dr. Shubhayan Sanatani, Chair of the Committee and PACES President for Research. This year's winners are:

Basic Science Winner

Author/Investigator: **Helene Altmann**

Mentors: **Michael Ackerman, MD, PhD – Mayo Clinic**

Institution: **University of Wisconsin - Madison**

Homozygous/Compound Heterozygous Triadin Mutations Associated with Autosomal Recessive Long QT Syndrome and Pediatric Sudden Cardiac Arrest - Elucidation of Triadin Knockout Syndrome



Translational/Clinical Winner

Author/Investigator: **Thomas Roston, MD**

Mentor: **Shubhayan Sanatani, MD/FRCP**

Institution: **University of British Columbia**

Catecholaminergic Polymorphic Ventricular Tachycardia in Children: An Analysis of Therapeutic Strategies and Outcomes from an International Multicenter Registry



We have been honored to present 14 Young Investigator Awards since 2008 and are committed to supporting the investigators of the future.

Did Your Insurance Cover Your AED?

The SADS Foundation has been contacted many times in the past by families who have had trouble obtaining insurance coverage for an automatic external defibrillator (or AED) for a family member or child with Long QT Syndrome and/or other SADS condition. If you or a member of your family has been prescribed an AED please take this short online survey to help us design a campaign to advocate for support with the insurance companies. Go to www.StopSADS.org and click on AED and Insurance in the middle of the page. The SADS Foundation thanks you for your help!

Advocacy in Action: Your Voice Matters!

In the past few months, we've asked you to take a number of actions in support of important legislation. The response has been overwhelming! Most recently we sent out an advocacy alert about the 21st Century Cures Act, asking you to support the Act but not the Brat amendment, which would have put NIH funding in serious jeopardy. In less than 24 hours, 245 organizations (SADS Foundation included) rallied to defeat the amendment—which would have cut funding for NIH research. The Cures Act now moves to the Senate, and when we know it's up for debate, we'll be sure to tell you. Sign up for the E-Newsletter and advocacy alerts at www.StopSADS.org or contact matt@sads.org. Thank you again for being some of the many "voices" of the SADS Foundation!



Check www.StopSADS.org for the newsletter
to find links to the full articles and other
information from this newsletter.

Do you take care of patients diagnosed with Type 3 Long QT syndrome?

If so, they may be interested in this study. Patients who have been diagnosed with LQT3, and are between the ages of 18-65, may be eligible to participate in a clinical trial whose purpose is to evaluate an investigational drug for use in patients with LQT3.

The study will consist of approximately 6 months of treatment, and will include multiple clinic visits during the course of the study. If eligible, participants may receive compensation for time and effort. Travel reimbursement will be provided to participants and an optional accompanying companion.

For more information, please visit clinicaltrials.gov and search for this study: NCT02300558 or email LQT3@gilead.com.

SCA Survivors, family, and friends are invited to:



INTERNATIONAL EDUCATIONAL CONFERENCE & EXPOSITION
DECEMBER 8-11, 2015 • MANCHESTER GRAND HYATT SAN DIEGO

JOIN A MARCH TO SAVE LIVES ON THURS., DEC. 10TH

For more info, visit www.StopSADS.org/ECCU2015

Upcoming Events

Volunteer Fundraising Events

Sept. 11	Race to Keep Hearts Beating Benefit Dinner & Texas Hold 'em Tournament	Folsom, CA
Sept. 12	Christie's Heartoberfest	Saratoga Springs, NY
Sept. 19	Hanss Oktoberfest	Colorado Springs, CO
Oct. 05	Jonathan R. Cowley Golf Tournament	Glen Allen, VA
Oct. 23	Wine and Cheese Evening	San Diego, CA
Nov. 28	Brittany's Trees	Carol Stream, IL
Dec. 12	3rd Annual Coconut Creek Luminary Night	Ft. Myers, FL

Conferences

Oct. 2-6	National Association of Medical Examiners' Conference	Charlotte, NC
Nov. 7-11	American Heart Association's Scientific Sessions	Orlando, FL
Dec. 7-11	Emergency Cardiovascular Care Update	San Diego, CA
Jan. 7, 2016	National Heart and Stroke Coalition at the NIH	Washington, DC



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