



New Friday Events at the Conference This Year!

SADS Ambassador Training—Friday afternoon

Ambassadors help promote the mission of the Foundation by educating your community about SADS, spreading awareness about programs and services, and reaching out to community agencies in your area. This training will give you all the skills and resources necessary. To sign up for this training, e-mail anne@sads.org.

Three different support groups will be offered Friday: ICDs, Grief and Loss issues, and Parenting. These groups will be moderated by experts, but most of the wisdom will come from the participants.

Friday evening we will have a dinner with the experts and a tour of Primary Children's Medical Center. This casual time will prepare you for the wealth of information starting Saturday morning.

We hope you will be able to join us for this very special Friday program, it has something for everyone!

2012 SADS Conference Deadline Approaching



The 6th Annual International SADS Foundation Conference in Salt Lake City, UT on Oct. 12-14, 2012 features programs for children, teens and adults living with SADS conditions and their family members.

Come enjoy great Utah hospitality while sharing in a unique educational and fun-filled weekend with your family and others with SADS conditions. Hear about the latest research, learn from expert doctors, and make life long friendships.

Registration is 50% off before September 1st!

SADS Safe Schools Month in September

The annual SADS Safe Schools campaign has begun! Children with SADS conditions should have SADS Care Plans and their school should have Medical Emergency Plans (including AEDs). This year, the cam-

paign will also focus on the importance of CPR Education as a requirement for high school graduation. Studies have shown that kids are just as good—or better than—adults at CPR and the use of an AED.



Volunteers (including School Nurse Ambassadors) will be delivering materials, hanging posters and advocating for student health forms to include risk assessment questions. They will also be speaking with PTA/teachers/coaches about the warning signs of SADS.

The ever popular Flat Bob is a new addition to the campaign. Flat Bob will be featured on our awareness posters for schools, encouraging CPR education. Stay tuned for upcoming videos from volunteers via YouTube and the SADS website. Contact Adrienne Butterwick, Program Manager, at Adrienne@sads.org or call 800-STOP-SAD to get involved today!

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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Flat Bob - Raising Awareness Around the Globe!

What is this Flat Bob phenomenon all about? It's the SADS Foundation's 2012 campaign to raise awareness of SADS all around the world. We've received pictures from China, Japan, London, Costa Rica, Italy, France, and Australia—even the Isle of Man! Flat Bob has been spotted in many of our 50 states in the USA, but there is more to be done. Have you submitted your photo with Flat Bob yet? It's easy. Just visit www.StopSADS.org/FlatBob, download, print, and take him with you. As Sara Lopez-Rivera said, "He got passed around and the girls got quizzed about him. He's an awesome conversation starter!"



SADS International Partners

Did you know the SADS Foundation works with physicians and patients around the world? Below is a list of countries with active SADS partners. We also have many individuals from various countries who participate in our FaceBook groups, etc. We're always seeking new partnerships and connections and welcome your suggestions. Please contact Anne Maurer, Director of Family Support, if you have questions or information to add to our network.

Visit www.StopSADS.org for more information about physicians and research happening in each country below



New SADS staff: Monica Hasebi and Carol Lai



Argentina

Australia

Canada

Chile

China

Israel

Italy

The Netherlands

The United Kingdom

Heart Beater

Dear SADS Foundation:

Over the past two years I have spoken to many individuals involved in this organization. My mom was introduced to the SADS Foundation when I was diagnosed with Long QT Syndrome November of 2010. I was a sophomore in High School and we had no idea what Long QT Syndrome was. Through this amazing organization my mom and I have met many people who have the same syndrome I have been diagnosed with, or were in a pretty similar situation.

I started speaking to many people through e-mail around the end of my junior year. I was making my schedule for my senior year and in my school there's a program called Senior Project. Senior Project is a program where high school seniors learn or work on something that they are deeply passionate about. Along with doing an actual project, we had to write a college level paper, do a presentation in front of a board of judges, and make a portfolio of the last year's work on this project. I had always



Alyssa Balsamello

wanted to be a part of this program, but I had no idea what my project would be. Through talking to many people I came to the decision of raising money for this foundation. I also came to the decision I would write my paper on the severity and awareness we need to bring to Long QT Syndrome.

I am now finishing my senior year of High School. I went forward with this idea and hosted a fundraiser for the Foundation. I hosted a tricky tray on March 24th at my school. The fundraiser was more successful than I could have ever imagined. I raised \$1,330 for this Foundation. Not only did I raise an incredible amount of money, I brought awareness to this condition to my friends, family members and other members of my community. That was my main goal and it was fulfilled. I could have not been more excited for the success of my project, but I'm even more proud that the money I raised is going to this organization. I hope this money helps educate and support people affected by heart arrhythmias.

SADS Foundation Welcomes New Youth Advisor

We are pleased to welcome Brittan Suttphin to our group of Youth Advisors. Brittan was diagnosed with CPVT at age 16 after surviving a cardiac arrest at her high school swim practice. Today she is a student at Claremont McKenna College studying Spanish and Biochemistry and plans to become a physician scientist in the future.



Do You Have Concerns About Insurance?

SADS families often report concerns like "how can my son get health insurance when he goes away to college?" or "what about life insurance?" This is your chance to help us understand the issues for individuals with SADS in obtaining health, travel, disability and life insurance.

We need your help! Visit: www.StopSADS.org or call 1-800-STOP-SAD to participate.

Health Care Reform: How Does it Affect SADS Patients?

By now you've heard that the Supreme Court voted to uphold the Affordable Care Act (ACA), but what does that mean for SADS patients? As each and every individual needs health care, this will ensure that access including the 122 million Americans with pre-existing conditions will no longer be denied coverage or forced to pay higher premiums based on their condition. Also essential is the elimination of annual and lifetime insurance caps and the fact that insurance companies will no longer be allowed to discontinue coverage for individuals who receive dire diagnoses after coverage begins. We at the SADS Foundation are very optimistic about the affects of the ACA as we face the future.

New Materials!

We're excited to announce a new section of our website for all our Spanish language materials including a poster and risk assessment form. Special thanks to Veronica Jaime and Dr. Alejandra Guerchicoff for their translation assistance.

Also, check out the latest addition to our new medical awareness cards: Timothy Syndrome. The Timothy Syndrome cards will be instrumental in helping educate anesthesiologists and orthopedic surgeons on the warning signs and treatment for Timothy Syndrome.

All of the SADS Foundation materials are available to download directly from the SADS website (www.StopSADS.org/Library) or you may submit a materials request for hard copies mailed to you free of cost.

SADS 20th Anniversary Dinner

The Gala Dinner at the SADS Foundation 6th International Conference on October 13, 2012 and will be held in honor of David Salisbury. David was one of the founders of the SADS Foundation and served as a key SADS Trustee for 15 years. This dinner celebrates 20 years of saving lives and honors individuals who have helped the Foundation achieve success.

Be sure to celebrate with us each month by participating in the month's activities. Visit www.StopSADS.org to see the plans.

Make a Pledge – Save a Life!

What better way to celebrate 20 years of the life-saving work of the SADS Foundation than by pledging \$20 a month to help us reach our year-end goal of \$750,000?

You will feel great doing it, and knowing that the dollars are being used to support families and save young lives.



Maureen Schulman and the Northern Star Quilter's Guild donate \$5,380 from Quilt Raffle!

SCA Awareness Month 2012 - What You Can Do!

October is national Sudden Cardiac Arrest Awareness Month. This election year is a great time to get to know your federal representatives by visiting their office in your state or inviting them to a SADS event you're hosting. We want everyone to know that SCA is a national problem that can be solved and that they can be a hero and save a life!

Please get involved and:

- Urge your Congress people to advocate for CPR training for all high school students.
- Ask your city/county to have local emergency dispatchers (911) coach CPR over the phone.
- Take Flat Bob with you to promote awareness and submit your photos!
- Learn CPR and share this live-saving knowledge with your community, family and friends!

To learn more about ways to get involved visit www.StopSADS.org/CPR.

New! "The Heart of the Matter: Ask the Experts"

We hear from patients with unique questions on a daily basis, many times our team is able to answer these questions however sometimes we refer to our medical advisory board for answers. We've decided to create a special space for these questions and answers on our website in order to facilitate thorough resources for our patients and families.

Questions can be submitted at www.StopSADS.org and will be collected once a month, reviewed and presented to our medical advisory board. We will keep an updated stream of questions and expert answers on our website for reference and invite you all to submit your questions! A special thanks to the SADS Facebook group, "LQTS Kids & Families," for their help in spearheading this initiative.

SADS School Nurse Champions

The June launch of the SADS School Nurse Champions Program at the National Association of School Nurses (NASN) Annual conference was a huge hit!

Over 200 school nurses took the SADS School Nurse Champions Pledge—empowering them to become advocates in their schools for creating the next generation of life-savers and ensuring greater awareness in their community. School nurses will also be asked to advocate for the inclusion of risk assessment questions on their health forms and for the adoption of Medical Emergency Plans, including AEDs, at all schools

Our goal is to have SADS School Nurse Champions in every state—with a total of 300 nurses participating this year. To make your pledge, visit www.StopSADS.org or contact adrienne@sads.org.

DC Family Meeting a Huge Success!

SADS volunteer and ICD patient Andy Golden along with Sandra Yesnowitz and SADS Board Member, Scott Dailard, spearheaded a fantastic and successful family meeting in Washington DC on May 19th. This meeting brought together people from the surrounding area to discuss their conditions—person to person, family to family. They shared lunch and spent the afternoon telling stories and discussing future activities—such as teaching a CPR class to the community. For more information on how to run a support group in your area, please contact Anne Maurer at Anne@sads.org or call 800-STOP-SAD.



Andy Golden

SADS Connect Youth Track

This is a great opportunity to meet other kids who are living with SADS conditions, and their brothers and sisters. We have lots of activities, arts and crafts, outside adventures, conversations, and information sessions about SADS conditions planned. Expect to get all of your questions answered, and have fun at the same time!

Last year kids made great friendships and had an amazing time, and this year will be even better. Registration is 50% off now through September 1st—we hope you can make it!

Visit new SADS Blog: stopsads.wordpress.com/

Special Thanks to our Fund Raising Families!

We want to take a moment and recognize the outstanding efforts of so many of our SADS families as they put together amazing events—raising both awareness and funds for the SADS Foundation. Here are a few highlights:

Kickball Tournament in honor of
Stephanie Mejias – NJ

Celebrate Wayne and Climb to Conquer
SADS – Wayne Sawyer – GA

Run for Ryan – Ryan Lopynski – VA

CPR Awareness Day – Fairfield, OH

Benefit Concert and Toy Drive –
Sabrina Keller – CA

Spring Lake 5 Marathon – Michele Dugan
and Mike Culver – NJ

Ellen Thalheimer event – GA

Keith L. Young 5-K – Green River, WY

3rd Annual Celebrate Wayne and Conquer SADS a Giant Success!

Quickly becoming one of Atlanta's hottest tickets, Shannon Kiss orchestrated and held another incredible fundraiser at Smiths Olde Bar in Atlanta this June, raising over \$17,000 in memory of her husband Wayne. When thanked by Dr. Ackerman, Shannon replied "It was my pleasure. My husband's memory, my daughter's future and your amazing organization deserve it and much more." Thank you, Shannon!



Families Support the Climb to Conquer SADS

More families than ever sponsored this year's Climb to Conquer SADS! From Amanda Koch's daughters' brownie troop to Dan Alatorre's Face Book group, dozens of folks raised money and awareness for the 6th annual Climb to Conquer SADS. The families' flags flew high in Montana this August!



Social Media Brings SADS Families Together

Before the Internet and social media giants like Facebook, Twitter, Linked-in and Pinterest, many families affected by SADS conditions never knew another person who had the same or similar condition and often dealt with a sense of isolation.

Those days are over—and now a close-knit global community is forming! Take for instance Oyvind Warhuus, a Norwegian man who lost his brother to Long QT and has it himself. He writes a weekly missive in a SADS Facebook group. One of these short stories inspired Indiana native Jasmine Wylie to create an original piece of art to go with it! Jump on our website today to view this piece of part! www.StopSADS

Memorial Funds

We have hundreds of stories of loved ones who have passed away due to SADS conditions. Each year, there are special days that families want to remember, and share with their loved ones. The SADS Foundation would like to help. Let us know the special days you'd like to remember, and we will send a reminder to those who have donated in honor of your loved one in the past. The money raised through these funds is used for the life-saving work of the SADS Foundation.

Donate to SADS through Workplace Giving Campaigns

You can donate to SADS through your United Way campaign or the Federal Campaign at work. Just write in the SADS Foundation as your charity of choice for United Way or look for our CFC name: Children's Heart Syndromes & Death Prevention Foundation (CFC # 56112).

SADS Foundation Responds to Sudden Death

The SADS Foundation responds to the sudden death of children and young adults all over the country that we hear about through the media, SADS families and SADS physicians. We are proud of the success of this program and want you to know that we're here to help when you see a sudden, tragic death in your community.

Partnering with the Pediatric & Congenital Electrophysiology Society (PACES), we sponsored a symposium at Heart Rhythm Society's Scientific Sessions: Sudden Cardiac Death (SCD) and the Rest of the Family. The room was packed and the questions were great. PACES plans to issue guidelines next year for evaluating families in the case of a sudden death (SDRP-Sudden Death Response Plan).

Please join our efforts and let us know about SCD cases in your community. With your help, we can act quickly during the first critical hours to contact medical examiners and support the family and the community.

Fifth Annual SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research Winners

Basic Science: Nicole Boczek, a Ph.D. student at the Mayo Clinic Graduate School (mentor, Michael Ackerman, M.D., Ph.D) Translational Science: Michela Faggioni, M.D., a Research Fellow from Vanderbilt University Medical Center (mentor, Bjorn Knollmann, M.D.) A special thank you to Dr. Charles Berul and the PACES evaluation committee.



Dr. Ackerman, Michela Faggioni, Nicole Boczek, Bjorn Knollmann

Drugs to Avoid List Update

FDA announced that preliminary results from a recently completed clinical study suggest that a 32 mg single intravenous dose of ondansetron (Zofran, ondansetron hydrochloride, and generics) may prolong the QT interval. It has been moved to the list known to cause a cardiac event and should be avoided by patients diagnosed with Long QT Syndrome.

Brugada Drugs Website Update

The www.BrugadaDrugs.org website has two new sections: an extensive (more than 1,500) list of brand names for drugs on the "to avoid" or the "drugs to preferably avoid" and a Frequently Asked Questions (FAQ) page with answers to questions from physicians and families. This is an invaluable site for those with Brugada Syndrome and health professionals—with over 65,000 visits from 158 countries in the past 3 years.

SADS Reaches Goal for Medical Education Challenge!

Your response to the SADS Foundation's medical education program fund raising appeal last spring was terrific! We met our \$30,000 goal and are busy organizing physician seminars around the country this year.

Educating physicians to recognize, diagnose and treat SADS conditions is a major focus for the SADS Foundation. Thank you to everyone who has made a financial contribution to this life-saving effort! **You can donate to the SADS Medical Education Program by visiting www.StopSADS.org.**

The SADS Foundation's Pedigree Project Receives NIH Grant!

The SADS Foundation has been selected to be one of 30 organizations receiving a special grant from the National Institute of Health (NIH) to update and enhance the SADS Foundation's Pedigree Project as part of a collaborative disease registry tool for furthering genetic research. This will help advance knowledge of SADS conditions and bring a better understanding of genetic diseases altogether. The SADS team will be revamping the Project with help from the NIH and asking all our families to sign up or make sure their data is accurate. This information will be directly used in research!

SADS Scientific Advisors Meet

SADS experts from around the world met in Boston to discuss new information on channelopathies, approved the SADS research agenda, and updated our Screening Policy. Led by Dr. Michael Ackerman, the meeting was very productive and led to the formation of a task force to update our policy on screening.



More HRS (Heart Rhythm Society) 2012 Successes!

SADS Hosts Lunch for Cardiac Genetic Counselors at HRS

New for us this year at HRS was a fantastic lunch meeting with the National Society of Genetic Counselors (NSGC) Cardiac SIG group. Watch for unique and collaborative projects in the future from this amazing group.

First Ever PACES Consensus Document:

PACES/HRS Expert Consensus Statement on the Management of the Asymptomatic Young Patient with a Wolff-Parkinson-White (WPW, Ventricular Preexcitation) Electrocardiographic Pattern.

Presented at the Heart Rhythm Society's Scientific Sessions, it provides first-of-its-kind clinical practice guidelines on the evaluation and management of asymptomatic young patients with WPW. For a summary of the findings and a link to the paper, visit www.StopSADS.org/Library.

Fetal Heart Rate/ Gestational Age Predicts LQTS – HRS Poster

Jason Mitchell, MD, D. Woodrow Benson, MD, Ph.D., Susan Etheridge, MD, Janette Strasburger, MD and Bettina Cuneo, MD presented a poster at this year's HRS meeting entitled "Shades of Bradycardia: Fetal Heart Rate Predictors of Long QT Syndrome." With the help of the SADS Foundation they collected data from 547 normal fetuses as well as 42 fetuses with LQTS. Their data concluded that there are "Shades of Bradycardia" in the fetal LQTS population. The use of gestational age along with fetal heart rate improves the diagnosis of LQTS in the fetus from 15% to 66% as compared to FHR only. These findings should improve the detection of LQTS in fetuses at all gestational ages.

Improving Survival Rates with CPR Over the Phone

We know that sudden cardiac arrest (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.

Dispatcher coaching will also empower bystanders to take action. People need to know that they won't hurt someone if they haven't had a class but, by just pushing hard and fast in the middle of the victim's chest, they may save a life.

Be sure to visit www.StopSADS.org/CPR for information and resources regarding this important issue!

ICD Registry Data: ICD Not a Complete Barrier to Playing Sports

372 competitive athletes were followed during a 3-year period with no deaths or adverse events reported. Dr. Rachel Lampert from Yale University led a special, late-breaking clinical trials session at HRS to discuss the results of this multinational registry. The registry enrolled athletes who had been competitive prior to receiving an ICD and then returned to their sport post-implantation. Some participants did, in fact, receive shocks during participation; however, no shock related deaths or injuries were reported.

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

We received the Great Non Profits 2012 Children and Families Award! To submit your review of the SADS Foundation or read the excellent reviews we've received, visit www.greatnonprofits.org and search for the SADS Foundation.

GREAT★Nonprofits

"Where's Bob?" Florida and NYC!

Bob DeVries, inspiration for "Where's Bob?" and "Flat Bob" will be at the Tampa Bay Rays game on August 5 and at the New York Mets game on September 21 (also NYU Family Seminar Sept. 22)! Bring your family out to the game and have your photo taken with the "real" Bob. For information, ticket prices, and T-shirts, call the SADS Foundation at 801-531-0937.

For more upcoming events: www.StopSADS.org calendar.



SADSConnect Poster Contest!

This summer the SADS Foundation is running a poster design contest for kids!

The poster theme is "Did you know kids with SADS can do this?" And we need your great ideas. The winner of the contest will have their artwork turned into an actual SADS Foundation poster that will go to schools all over the country, and they will also be awarded a gift card.

Go to www.StopSADS.org to see previous posters, contest entries, and to submit your own.

The winner will be announced at the SADS 6th International Conference in Salt Lake City, October 12-14. (You don't have to be present to win!)

