



Talking More Than Just Turkey: Educating Your Family Could Save Their Lives

Every year, at Thanksgiving time, families gather together to eat dinner and give thanks. Why not put a little spice on this year's table and give your family a fresh helping of essential information? The Surgeon General has declared Thanksgiving to be **National Family Health History Day**. The SADS Foundation encourages families to talk with your relatives this holiday season, get their history using the questionnaires in our Pedigree Toolkit, and help them take the steps necessary to get screened. *This will save lives!*

The number one warning sign of a SADS condition is family history because these conditions are most often genetic and dominant—which means, in an average family with one person diagnosed, 50% of the other members will have the same gene! We also know that lots of these family members won't have any symptoms—or even a long QT interval—so they need to have genetic testing. When it comes to your family's lives, don't be willing to take a chance.

Getting your family's health history is as simple as talking about it, writing it down, and then sharing it. If SADS conditions run in your family a great reference source is the **Pedigree Toolkit**. This kit contains information regarding family history, risk, and testing, along with all the forms you will need to create a complete family medical history. It is easy to share

with your family members around the dinner table this holiday season. If you are interested in receiving this Toolkit, download it at www.StopSADS.org or contact Anne@SADS.org.



SADS 5th International Conference a Huge Success!

Healthcare providers and families joined us in Atlanta on October 1-2 to hear cutting edge information on SADS conditions, have questions answered by our panel of world renowned physicians, participate in the SADSCoNECT kids track, celebrate those living and thriving with SADS conditions and remember those who have been lost. A gala celebration helped usher in SADS 20th Anniversary, awards were presented for our Volunteers of the Year, two pioneers were recognized for their achievements in the field and the content presented by our esteemed speakers was top notch! We have been thrilled with the positive feedback we have been receiving from

attendees and we are confident that you will not want to miss next year's conference in Salt Lake City, Utah, October 13-14!



SADSCoNECT kids speak to the adults and experts.

5th International
SADS Foundation Conference
Generously brought to you by:



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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Awareness



Katherine Timothy and Dr. G. Michael Vincent were the key note speakers at the Gala dinner Saturday night. See their slides at www.StopSADS.org.



Katherine Timothy, SADS' Founder and keynote speaker



Shannon Kiss and Marissa Smith received Volunteer of the Year Awards at the 5th annual International SADS Conference in Atlanta. Thank you, Shannon and Marissa!



Thanks to Keron Bailey for staffing our store in Atlanta!

FDA Notice Issued for Anti-nausea Drug, Zofran

The FDA released a statement in early October addressing safety issues related to the common anti-nausea drug Zofran (ondansetron) by GlaxoSmithKline. The SADS Foundation has already advised patients with a diagnosis (or suspected family history) of Long QT Syndrome or Brugada Syndrome not to take this medication per the Arizona CERT and Brugada Drugs research lists. Based on that research, Zofran has already been packaged with a label that indicates the drug causes a prolonged QT interval.

However, the news from the FDA is especially important as the label will be amended to include a specific warning for patients with congenital Long QT Syndrome and also recommends that if administered, the patient should be monitored via EKG to ensure the patient's safety. GlaxoSmithKline has been ordered by the FDA to conduct a QT study to determine the extent of the Zofran's affect on the QT interval.



Keeping Hearts Beating: Pilot Projects in NY & UT

The New York City public school system is the largest in the world with the most diverse student population in the United States. In addition, New York State has the nation's largest college student population. This year we've taken the SADS Safe Schools campaign (developed to keep our kids safe in school) and focused on Utah and New York State.

In both Utah and New York, we've been working closely with the school nurse association and are proud to say we have given SADS life-saving information to over 500 school nurses in the state of Utah alone!

These pilot projects will utilize our existing awareness campaigns to really focus on making the whole state educated and aware of SADS warning signs and recommendations. You can still be a part of the *Keeping Hearts Beating* campaign, contact Adrienne Butterwick at Adrienne@sads.org to get started today!

New Support Group for Women over 40 with SADS Conditions

Meet other women, discuss your concerns and your experiences and help us promote research on what the qualitative experience of living with a SADS condition at this time of your life is like.

Contact Anne E. Maurer at Anne@SADS.org, 800-STOP-SAD, or find her on Facebook to join.

Add SADS to Your Blog

Personal blogs and websites are becoming more and more popular. If you mention LQTS or anything SADS-related on your blog or website, we encourage you to add a link to the SADS Foundation. It's just one more way we can spread our important message and save lives. Contact Adrienne Butterwick at Adrienne@sads.org if you'd like the SADS logo and link for your blog or website.

Thanks to all of you who are already linked to the SADS Foundation!

Coming soon for school nurses!

The SADS Foundation and Allison's Heart Foundation have been working with Drs. Priori and Cerrone and Linda Khalil, RN, the Director for the New York Statewide School Health Services Center (NYSSHSC) to create a free webinar about SADS conditions and sudden cardiac death in schools. Watch our website and newsletters for more details.

Update on Drugs to Avoid for Brugada Patients

Recently, BrugadaDrugs.org added the popular anti-seizure and bi-polar treatment medication, Oxcarbazepine (brand name Trileptal), to the list of drugs to avoid for patients with Brugada Syndrome. For a complete list of drugs to avoid, visit www.StopSADS.org

SADS Takes a Stand Against SCA on Capitol Hill

The SADS Foundation is proud to be a steering committee member of the Sudden Cardiac Arrest Coalition (SCAC). The Sudden Cardiac Arrest Coalition is comprised of more than 40 organizations passionate about preventing Sudden Cardiac Arrest (SCA) deaths through legislative initiatives that lead to greater public awareness, research, and access to life-saving therapies.

In celebration of SCA Awareness month (October), the coalition held an event "Take a Stand Against Sudden Cardiac Arrest" in the Rayburn Foyer on Capitol Hill on October 26th to raise awareness of SCA and emergency response amongst legislators and their staff members. The event was a great success and featured a fabulous line

up of speakers including Republican Rep. Phil Roe (R-TN) who acted quickly by initiating CPR on a man who collapsed nearby in the Charlotte, N.C. airport in September.

The coalition also recognized Congresswoman Lois Capps (D-CA) with an award for her out-

standing work in SCA-related legislation with the Teaching Children to Save Lives Act which will require CPR and AED certification for all high school students prior to graduation. Visit www.StopSADS.org to see photos and more updates from this exciting event on The Hill!



Heart Beaters

As you know, we just wrapped up our 5th International Conference on Oct. 2nd. We hosted a SADSCoNECT Youth Track this year and it was attended by some truly bright, talented, strong, and admirable young people. This year they took the time to share their stories, make friends, create lasting memories and learn in-depth about their conditions. See the videos they created & pictures of their two-day sessions on our website. These living and thriving youth truly inspired us all and renewed our vigor for the work the SADS Foundation does. Thank you from the bottom of our hearts!



The Beautiful Act of Giving

At the SADS Foundation's International Conference in Atlanta, Laura Wall did a fund-raising presentation for the young people attending the conference. Ideas popped up all over about ways they could make a difference – selling jewelry, doing lemonade stands, putting their 'birthday wish' on Facebook to benefit the SADS Foundation. At the end of the presentation, a shy young man who is living with Long QT approached Laura, tapped her on the arm, held up his hands with a \$1 bill and said, "This is my contribution. I want to help." It isn't the size of the gift – it's the beautiful act of giving. Thank you, Kaleb Echols.

Tri For Abbey

Athletes, friends and family of Abbey Wambach, and Triathlon enthusiasts, gathered together in Rock Hill, South Carolina for the first annual "Tri For Abbey" on September 24. Special thanks to Go Tri Sports South Carolina Triathlon Series and Set Up Events for their sponsorship of this new event. Abbey passed away at age 10 due to an undiagnosed SADS condition.



Senior Project to Support SADS

For my Senior Project I knew exactly what I wanted to do, I wanted to raise money for the SADS Foundation because I have Long QT Syndrome. My friend Brianna and I had a few ideas on how to go about doing it, but decided on running a soccer tournament because that was my favorite sport before I had to stop due to my heart condition. Unfortunately, not many people were interested so we had to go with plan b, a dodgeball tournament, which was a huge success.

On Monday May 16, 2011, the 7th and 8th graders played dodgeball; 22

students showed up, and the winner received Bruster's gift cards. Then on Thursday May 19, 2011, 44 of the 5th and 6th graders played and there was one winner who also received a Bruster's gift card. After the students all paid \$3, we sold some drinks and snacks as concessions and wristbands, and accepted donations we made a total of \$305. My goal was \$200 so I call my Senior Project a great success.

-Sloan Field
Augusta Prep



SADS Wins State Farm Go to Bat Challenge Twice!

State Farm® and Major League Baseball® (MLB) recently announced that the SADS (Sudden Arrhythmia Death Syndromes) Foundation has earned their second \$18,000 charitable donation in the State Farm Go To Bat program - an online, charitable giving initiative driven by the State Farm commitment to helping communities get to a better state, bringing the total gift to **\$36,000!**



As part of winning, two SADS Foundation fans were chosen to attend the World Series! One of the winners, Janice Barry wrote: "I am thrilled to have "won" these funds for the SADS organization having personally benefited from the work of the organization as I lost a beautiful 19-year old daughter in 2008 to undiagnosed Long QT, which we now know is present in the paternal side of the family. A cardiologist initially pointed us to your organization, and I have been a recipient of the emails and newsletters in the last few years and have found the work of the organization to be a comfort and source of valuable information."

Congratulations, Janice Barry and Gary Killingsworth and thanks to State Farm and Major League Baseball for this incredible gift!

Also, Bob DeVries of "Where's Bob?" represented the SADS Foundation at Game 3 of the World Series Saturday October 22nd in Dallas, TX. He also attended a special brunch for the winning charities. Who better to represent the SADS Foundation than our own Bob DeVries!?

Kudos to all of our friends and family members who went to bat for the SADS Foundation!

Heart of a Lion

He has the "Heart of a Lion", says uncle Omar Garriott, when referring to his little nephew, Lee Ciciarelli. Lee has Timothy Syndrome (a rare SADS condition), and has been in and out of surgery many times this fall. Omar raised over \$3,100 for the SADS Foundation in Lee's honor, participating in his first half marathon! Lee was at the SADS Foundation's International Conference and was, by far, one of the cutest guys in attendance. Thanks so much, Omar.



Climb to Conquer SADS goes to Tibet!

We just got word that Kay LeClaire has done it again. After 4 weeks in China, Kay has made the summit of Shisha Pangma. She was able to summit even with an altitude cough. She made the summit 26,289' last week, while carrying Brett Anderson's banner. Kay is the oldest woman to have summited Mt. Everest, and is proud to represent Brett's mom, Cathy, and the SADS Foundation - raising awareness and ultimately, saving lives. You can learn more about Brett by visiting his memorial page on www.StopSADS.org.



Nashville Benefit Concert

A sold-out crowd at Nashville's famous Bluebird Cafe got to enjoy the amazing talent of world-renowned song-writers, Carl Jackson, Larry Cordle and Jerry Salley in a concert that was held in honor of SADS Foundation Board member, Jackie Kaas-Vines', son Rob Kaas. Rob passed away from a SADS condition. Nearly \$4,000 was raised at this unique and fabulous concert.



Layton Oktoberfest and Tolosky Heartoberfest Grow Again!

Reports still coming in that this was a banner year for both the Layton's Oktoberfest in Colorado Springs and the Tolosky Heartoberfest in Saratoga Springs, NY! These two parties that both happened on September 17 this year, have brought in tens of thousands of dollars over the years. Not only that - but everyone leaves with information on SADS conditions! Thank you Layton and Tolosky families and supporters!

Donate your car, boat, truck, RV, jet ski or snowmobile to The SADS Foundation and receive a tax deduction!

To begin this no cost, no hassle process, contact Laura Wall at Laura@sads.org or 800-STOP-SAD.

Combined Federal Campaign

Are you a federal or state employee? If so, you know about the Combined Federal Campaign (CFC). When making your pledge, please look for the SADS Foundation under CFC # 56112 -Children's Heart Syndromes & Death Prevention Foundation (SADS Foundation). We appreciate your donation!

SADS Sponsored Seminar in Chile and a SADS Keynote Lecture in Argentina

An Arrhythmias and Sports Symposium was held in Chile on September 15th at the University of Los Andes. A special thanks to Dr. Jose Pardo for inviting SADS to sponsor this important event. SADS' wonderful volunteer, Alejandra Guerchicoff, Ph.D, CCRP, gave the keynote address at the Argentine Congress of Cardiology in October. We look forward to working with our new friends in Chile and Argentina and are excited to see the work they are doing to bring education and awareness to their medical community.



SADS Sponsors Medical Education in Nashville, Texas, New York City and Hartford, CT

In September, Dr. Michael Ackerman conducted multiple SADS medical education seminars in Austin and San Antonio, TX, New York City and Hartford, CT. And Dr. Susan Etheridge, Dr. Prince Kannankeril, Dr. Frank Fish and Dr. Dawood Darbar conducted seminars in Nashville, TN. Thank you to Boston Scientific, GeneDX and Transgenomic, Inc. for providing unrestricted grants which made these programs possible.

Please contact Christine Fontanella at Christine@sads.org if you are interested in bringing a SADS medical seminar to your area.

Does Menopause Cause an Increased Risk for Cardiac Events in LQT Patients?

The SADS Foundation has received many questions recently about menopause and LQT Syndrome. A paper published this year in *Circulation*, "Risk of Recurrent Cardiac Events After Onset of Menopause in Women With Congenital Long-QT Syndrome Types 1 and 2", provides some answers. (If you didn't see this in our Medical ENews, we have a summary in our library: www.StopSADS.org.)

SADS is continuing to assist researchers who are looking at LQTS and aging. We have started a Facebook group to allow women over 40 to discuss issues and symptoms related to menopause.

What is Your SADS Risk Profile?

In the same way that a diabetic knows their blood glucose number, SADS individuals should know the key factors that form their personal "risk profile" for the different SADS conditions. For Long QT Syndrome, for instance, you should know:

- | | |
|--|---|
| 1. your QTc number | 4. your symptom history, with particular emphasis on the length of time since the last symptom (fainting, etc.) |
| 2. the type of LQTS you have
– through genetic testing (LQTS 1, etc.) | 5. age |
| 3. where your mutation is on the gene (location, location, location) | 6. gender |

It is common to have individuals who are higher risk and those who are lower risk in the **same** family. In general, the higher your QTc number is, the higher your risk is. But, if you have the gene, you are at higher risk than a person who doesn't have the gene. That is why it's really important to get everyone in the family genetically tested to see if they have the "family gene" or not.

Knowing more about your personal risk profile—and your children's—can help you make informed decisions about treatment options (like beta blockers), exercise and activity choices. And, everyone who has a LQTS gene should be careful not to take drugs on the list of Drugs to Avoid.

Always have a copy of your medical records—including ECGs and genetic test results. This way you will have them if you need them in the future. Help educate family members about the importance of genetic testing. If a family mutation is known, it could save the life of someone in a future generation.

Stay tuned to the SADS website for more tips and upcoming articles on determining your Risk Profile: www.StopSADS.com.

Pre-Existing Conditions and Healthcare Coverage:

A Small Change for the Better in the Insurance World!

Newly announced regulations by the Department of Health and Human Services now make it easier for people with SADS conditions to access and afford the Pre-Existing Condition Insurance Plan (PCIP). This federally-mandated series of state health plans are designed to provide coverage for patients with pre-existing health conditions. The recent changes include reduced premiums and simplified eligibility standards.

PCIP varies depending on your state of residence. Visit www.PCIP.gov to find out how your state is working with the PCIP. You can also call the PCIP toll-free hotline at 866-717-5826. For a more complete summary of the PCIP: www.StopSADS.org.

Advocacy Update

Here's an update on the legislation we've been following:

- The Teaching Children to Save Lives Act of 2011 was introduced by Congresswoman Lois Capps on October 13, 2011.
- The Senate Labor, Health and Human Services Subcommittee approved its annual appropriations bill with \$2.5 million set aside to fund the Rural Access to Emergency Devices Program. Your support was especially helpful here as it was slated to be cut.
- The Josh Miller HEARTS Act (H.R. 1377)

We met with several members of Congress during our visit to Washington, D.C. in October to discuss these important bills and the issue in general. We are also working with several State bills. To be sure you are up-to-date on all the action, sign up for SADS action alerts and e-newsletters at www.StopSADS.org

SADS Foundation Featured in EP Lab Digest!

The EP Lab Digest is a publication that focuses on electrophysiology lab professionals and physicians. It has become an educational tool as well as a forum through which professionals share information about best practices, cutting edge procedures, and other relevant information to the EP community. The SADS Foundation was featured in their August edition with an article describing our vision, commitment to families, healthcare providers and communities and the actions that we take to save the lives of young people. Visit us at www.StopSADS.org (News section) to read the article.



SADS Families Participate in Research

Diagnosing LQT in Utero

As of this summer, Dr. Bettina Cuneo has completed the first portion of her study and is currently compiling the results. It will be so fantastic to standardize the new diagnostic criteria to enable physicians to diagnose LQTS before birth.

Skin Cells to Stem Cells for Research

SADS families have helped the researchers establish a LQT2 cell line and you have now helped them complete the LQT3 cell line.

These studies couldn't have happened without YOU. SADS families are making a difference for the future of people with SADS conditions.

Enrolling Studies

New NIH-Funded Clinical Trial for CPVT

People who have been diagnosed with catecholaminergic polymorphic ventricular

tachycardia (CPVT) and have an ICD, may be eligible for a new clinical trial of flecainide, an antiarrhythmic drug which may benefit patients with CPVT. The study will begin enrolling later this year and is being led by Dr. Prince Kannankeril, MD, MSCI, at Vanderbilt University Medical Center.

ICD Sports Registry

ICD Sports Registry is currently enrolling individuals, ages 10-60, who have made the decision to participate in competitive sports

The SADS Foundation is dedicated to furthering research on SADS conditions for our communities' benefit. These are the ongoing research studies that are recruiting participants. For more information visit www.StopSADS.org and click on Research or contact Anne Maurer, Director of Family Support at Anne@sads.org or 1-800-STOP SAD.

PACES Pre-HRS Symposium Announced: Sudden Cardiac Death and the Rest of the Family

SADS will again co-sponsor and participate in the PACES Pre-HRS Symposium, entitled "Sudden Cardiac Death and the Rest of the Family" Held during the Heart Rhythm Society's Annual Scientific Sessions in Boston on Tuesday, May 8th, 2012 at 2:00pm. Location and program details to follow.

Fish Oil Reduces Arrhythmias

Fish Oil (omega-3 fatty acids) has long been touted as important in improving cardiovascular health, but did you know it can help improve heart rhythm?

According to two recent articles, "Animal experiments show that fish oil can prevent sudden cardiac death or fatal arrhythmias." This is still preliminary, but the results are exciting.

As always, you should check with your electrophysiologist before taking any medication or supplement. Maybe you should start taking an Omega 3 fatty acid supplement today!



For copies of the articles, visit our library at www.StopSADS.org.



Drawing for a Quilt

Donate for a chance to have this gorgeous, hand-made, queen sized quilt in your home—for a mere \$10 per ticket. Linda Dellinger (pictured), spent countless hours creating this quilting masterpiece in honor of her daughter Stephanie and granddaughter, Sarah, who live and thrive with Long QT. Make a donation online (specify it is for an opportunity to win the quilt). Drawing will be held on December 10, and we'll ship it to you in time for the holidays!

No purchase necessary.

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

SADS Foundation Store: Get them before they sell out!

Looking for a unique gift for a friend or loved one affected by SADS? How about a SADS t-shirt (a “hot” item at the International Conference!), a holiday ornament, a monthly calendar? Visit www.StopSADS.org/Shop to order today!

Save the Date

6th International SADS Foundation Conference

October 13 & 14, 2012

Salt Lake City, UT



SADS Foundation boxed card sets

If you follow us on Facebook, you’ve seen the amazing nature photos provided by Mike Flaherty. Mike lost his dad and sister to Long QT, and is allowing us to use his photos for our new ‘SADS Foundation boxed card sets’. Sets of 10 cards, each with a breathtaking photo, will be available in the SADS Store for \$25 – just in time for holiday giving.



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