



Light Up Your Neighborhood for the SADS Foundation

Brittany's Trees is a neighborhood tradition (and now a nationally-recognized event) that began in 2005 celebrating the holidays in memory of Brittany Valene who died of Long QT Syndrome.



Each holiday when you drive through the Carol Stream neighborhood in Illinois between Thanksgiving and Christmas you will see the streets lined with glowing Christmas trees representing Brittany's char-

acter. Family and friends come together each year on the Saturday following Thanksgiving. The morning begins with volunteers surrounded by hundreds of Christmas trees, warming up with some hot chocolate

and coordinating the day's festivities. Volunteers then split up into teams and go from house to house delivering trees, stringing lights and spreading the holiday spirit to all of those who kindheartedly participate.



What began with 30 trees in one neighborhood, last year grew to 1,500 lighted trees lining the streets of Carol Stream and surrounding towns, raising more than \$30,000.00 for the SADS Foundation. While Brittany's Trees has been growing by leaps and bounds, the SADS Foundation also has been expanding our programs to serve more families, educate more medical professionals, and bring awareness to more schools about SADS conditions. The support we receive from Brittany's Trees as our largest volunteer fund raiser is invaluable and it is an event that can be established in your area in honor of someone you love.

With a pilot program already in place, we can offer you a step-by-step, how-to directions to start a "Brittany's Trees" in your hometown. Please contact Jan Murphy at 801-531-0937 or jan@sads.org for further information and to receive a manual. Additionally, Jim Guthrie and Tony Valene who will be celebrating the 10th anniversary of Brittany's Trees this upcoming year are always happy to offer advice.

Catch the Spirit!



SIRCh Registry is Live!

It is time to get on board and REGISTER with SIRCh (SADS International Registry of Channelopathies)! By registering a profile and sharing information about your experience with SADS you will provide critically-needed demographic, quality-of-life, family history, and other information that will help researchers increase

understanding of what it means to live with these conditions and create life saving treatments. It will improve our ability to notify you of research studies you may qualify for and be interested in participating in.

Because we respect and value your privacy, only de-identified (anonymous) information will be available. Your participation is entirely voluntary and your individual information is kept completely confidential. You're always in charge of the information you provide.

REGISTERING in SIRCh will help us better understand and improve the lives of the people and families all over the world living with SADS. You can join SIRCh at www.StopSADS.org/SIRCh.

REGISTER AND WIN

REGISTER in SIRCh by June 14 and have your name entered in a drawing to WIN one of 3 prizes: one \$250 VISA card; two \$125 VISA cards!

(Complete registration required in order to qualify for the prize)



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

Staff Farewell

We've said goodbye recently to a number of our SADS Staff. Anne Maurer left to go into private practice and we couldn't be more excited for her next steps. Sylvie Batchelor accepted an internship with Senator Pat Jones and was hard at work during Utah's legislative session. Carol Lai, who has been with SADS almost three years, is graduating and moving to Rhode Island to take a position with Teach For America.

Staff Welcome

In August we added David Hulet and Grace Drouin to our team as Office Manager/ Program Associate and Development Assistant, respectively. Both have been hard at work improving SADS and if you didn't meet them at Annual Conference, you may have had the opportunity to correspond with them in some other way. If not, feel free to call and say hello!

We are also excited to announce the addition of Matt Siemionko to our team as Director of Family Support. With a Masters in Public Health, he can't wait to get the Family Support program to the next level of Family-Centered Care. He will be assisted by Jenny Hoggard, also a Masters in Public Health, who is coming on board as our new Family Support Coordinator. Look for their full bios coming to an e-news soon!



7th Annual SADS Foundation's International Conference 2013

The SADS Annual International Conference in Ohio on November 1-3, 2013 featured 185 attendees and three days of engaging, peer-reviewed content. We are delighted to have brought together experts from across the country to provide the most current research and clinical practice guidelines. New this year was a Friday Seminar for medical professionals. Our families had the opportunity to dive deep into questions regarding insurance and GINA, IEPS and 504s, and pregnancy and SADS by attending a small group breakout on Friday. More than a dozen reporters and editors attended the press conference for Ohio House Bill 180—a bill for Sudden Cardiac Death prevention in athletes. If you were unable to attend the conference, be sure to purchase a copy of this year's Conference DVD and be sure to attend the 8th SADS International Conference in March 2015.

Kids and Teens Track:

"It was nice to see the kids hanging out with each other and getting along so well...if you just looked at them as an outsider you would have thought they knew each other for years."

-SADS Mom

"For the first time in five years, since my cardiac arrest and diagnosis of LQTS.... I finally feel like I belong and fit in."

-Cameron K.

Healing Garden:

This year we were honored to present a healing garden decorated with beautiful quilted flowers that were personalized in memory or in honor of a loved one with a SADS condition. This beautiful memorial was on display during the conference for attendees to read each story about our families.

We also raised over \$1,400 in our quilt raffle! All proceeds go to helping the SADS Foundation save lives.

"Amazing conference with so much information."

-Ana C.

Ironically, a mutant gene brought the Goodwin family closer together

"They had to shock her?" My heart was in my mouth. Her heart had stopped about two hours after arriving at the hospital. They had to do CPR and shock her to bring her back to life. I was beside myself. I just kept saying over and over, "She arrested?" Sensing my stage four anxiety, Becky said, "She's going to be alright, mom."

Knowing that Brugada Syndrome is 50% inheritable, I knew there were members of Bill's family that were at risk. After feeling strongly urged to stop another death in the family, I spoke to Dr. Ackerman who helped me identify specific family members who needed a screening Brugada EKG, and obtained the EKG protocol from Mayo Clinic for screening sessions at my local hospital. We ended up screening 25 family members ranging in age from four months to 75 years. Of course, a negative result on an EKG does not mean a person doesn't have Brugada Syndrome. But overall, these efforts opened the door for more family members to have DNA testing and one has had a Defibrillator implanted and two more have been identified as needing them.

For more on Connie's story about the sudden cardiac arrest of her daughter and how that spurred her to have her entire family tested, please visit: www.StopSADS.org and click on Stories: Living & Thriving with SADS

Send Us Your Stories!

Send us your stories! We are looking for inspiring and heart-warming stories about our members. Has your child with CPVT done something you are really proud of? Has your family held a recent fundraiser and you want to see your pictures in print? Do you want to share a story with the SADS community about your struggles or triumphs? Please feel free to send us these stories and we will print them in our e-news, use them on our website, and share them in our newsletters. www.StopSADS.org/Share-A-Story

Did you know?



It's Never Too Early for SADS Safe School

Although the 2013 – 2014 school year is winding down, it's never too early to get a head start on keeping your child safe in school! Here are some steps to ensure your child is safe at school.

1. Develop an individualized School Health Care Plan for your child by taking our care plan to your child's physician, customizing your care plan, and working with your school health professionals using your knowledge of your child's condition.
2. To ensure that your child's Individualized School Health Care Plan is in place and working, verify that a school administrator or health professional is responsible for receiving the plan, the care plan is housed in an easily accessible area, and the school trains staff regarding the existence and implementation of individual care plans.
3. Check to see that the school has an AED, a plan for the use of the AED, and whether all appropriate staff are trained to use an AED.

For more info, please visit www.StopSADS.org/Awareness



SADS Staff with a SADS Youth



Quilt for the raffle



Ambassador Training

Heart Beater - Thomas Cramer

This past November, Thomas Cramer of Sarasota, Florida, celebrated his Bar Mitzvah at Temple Sinai. When he turned 13 years old, Thomas became accountable for his actions. Thomas studied weekly with his cantor and a tutor for five months. The theme for his celebration was A Moral Compass and for the compassion focus of the compass, Thomas raised funds for the SADS Foundation in memory of Billy Levy, a brother he never knew who died in 1998 from Long QT Syndrome.

Billy Levy was born in 1990 and would have been 10 years older than Thomas had he lived. Both boys were adopted as well as their sister Violette Levy. In 2001, Thomas was just a year



old after he arrived from Vietnam to his new home in America. Thomas has recognized the tragedy of Billy's sudden death at such a young age and because of his dedication to family chose to raise funds at his Bar Mitzvah to prevent other families from experiencing the same tragedy. All of us at the SADS Foundation are honored to be the recipient of Thomas's compassion - we thank Thomas for his generosity!

Heart Beater - Tayler Smith

Tayler Smith Completes Senior Thesis on Preventing Sudden Death in Young Athletes

Tayler Smith recently graduated from Maryville College in Tennessee where she completed her senior thesis in exercise science. Her thesis reviews screening procedures for competitive athletes and how screening procedures help prevent the incidence of sudden death in young athletes. Tayler majored in exercise science and minored in psychology and plans to attend physical therapy school. Tayler's sister passed away from a ventricular arrhythmia in 2003 and now Tayler is working hard to help others with SADS conditions.



Heart Beater - Sarah Katz

When Sarah Katz was four years old, she was having a swim lesson and fainted while swimming laps. The instructor saved Sarah and brought her to the side of the pool. The instructor thought that Sarah had experienced a seizure, but her mother Jill still had questions and took Sarah to a cardiologist. Jill's intuition was correct; Sarah was diagnosed with Long QT Syndrome, but thankfully has not had another episode.



Sarah, now 12, realizes how important it is to take care of herself by taking her beta blocker every day and eating heart healthy meals. She entered Uncle Ben's Beginner's Cooking contest to demonstrate how delicious healthy meals can be with the recipe Sarah's Delicious Heart Healthy Maple Salmon. Sarah enjoyed doing the video with her family and continues to focus on what she can do instead of what she cannot do. Be watching for a YouTube video of Sarah and her sister showing how to make scrambled eggs in a mug!

The Osterhout Family

The year 1987 brought an unexpected tragedy to the Osterhout family when their son Matt, age 17, died suddenly. As part of his regular routine, Matt had jogged from his home to work. However, minutes later he was gone. Matt's autopsy did not reveal an explanation, but his death began a journey of discovery for remaining family members.

At approximately the same time in Salt Lake City, Dr. G. Michael Vincent was beginning to study cases of sudden cardiac arrest and in the early 1990's, discovering the first Long QT mutation and founding the SADS Foundation. However, another decade went by before the Osterhout family would connect with the SADS Foundation. In 2001, the unbelievable happened again. Britni Osterhout Cooper (Matt's sister) died suddenly leaving a husband and two young daughters, Quincy and Kennedy behind. The autopsy offered no clues to the cause of death.

Suspecting the deaths of her two children were likely genetic, Pam Osterhout began her relationship with the SADS Foundation. Pam attended her first SADS conference in 2001 and learned about the diseases that could cause sudden death in the young. She learned of treatment options,



pros and cons of EKG diagnosis and the importance of documenting a family pedigree. Pam was tested for Long QT mutations but all tests were negative. A genetic answer for the Osterhout family was not yet known.

In January 2013, Kennedy, age 17, experienced a sudden cardiac arrest at school. Immediate and continuous CPR by her teachers saved her life. For the first time, the family was able to submit a sample for comprehensive genetic testing. DNA testing combined with validation by the Mayo genomics lab confirmed a diagnosis of CPVT.

Pam is the silent carrier passing it on to both of her children. Kennedy is doing well with continued beta-blocker medication and the implantation of an ICD. Her sister Quincy is protected with beta blockers. Extended family members are now being tested for the mutation. It's been a 25-year odyssey for the Osterhout family, but with the increasing expertise of the medical community and the invaluable support of the SADS Foundation, the youngest generation may move forward with their lives with knowledge and preventative treatments.

We are thankful that Pam, Kennedy and Quincy are part of our SADS family.

4th Annual Race to Keep Hearts Beating Benefit Dinner & Texas Hold 'Em Poker Tournament

May 2nd in Folsom, California

All Karie can remember saying was "What happened to him?" Race's death from Long QT Syndrome occurred suddenly during his freshman year at UNLV. Losing Race has been extremely difficult for his family and friends, but Race's life continues to be honored through the annual event held in his memory. Funds are raised for the Folsom Athletic Association, UNLV Scholarships, and the SADS Foundation. "We had never heard of SADS prior to Race's death, but if we had, we would have been empowered with the information that we needed to prevent his sudden death," says Karie. "The best that we can do now is to empower families, schools, and communities through awareness of these conditions to prevent these deaths in the future." For more information, visit www.racetokeepheartsbeating.com.



2nd Annual Devon's Beat 5k Run/Walk/Bike Ride

April 5th in Lincoln, Missouri

Jason and Angela Parrott held the first Devon's Beat last year in honor of their son to spread awareness and raise funds for the SADS Foundation and EKG screenings. Devon has Long QT 3 controlled by an ICD implanted in June 2013. This year, with his physician's approval, he may continue some of the sports and activities he had done before.

"We had no idea the amount of support we would receive or that the community would want to make it a yearly event. We raised more than \$10,000 which was given to the SADS Foundation and towards screenings for kids ages 13-18," says Angela. To learn more, message Devon's Beat Facebook page.

Planned Giving

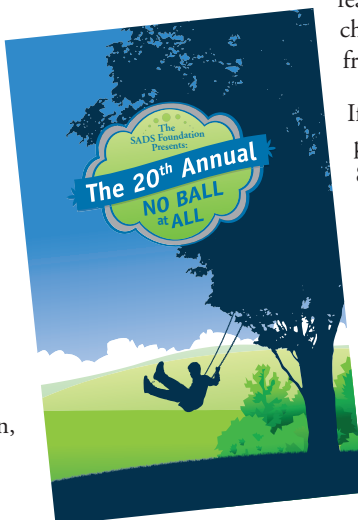
From a small local non-profit organization founded by Dr. G. Michael Vincent in 1992, the SADS Foundation has thrived. We are now recognized as a leading organization for awareness, education, research, and advocacy of all SADS conditions – which we achieve through the generosity of our friends and supporters.

When you include the SADS Foundation in your will or other planned gift, you ensure the continued progression of saving the lives of children and young adults with SADS conditions. You can create a legacy of health through your will, revocable trust, charitable trust, charitable gift annuity, life insurance, or retirement account. We invite you to contact us to discuss how to realize your philanthropic gifts at 801-531-0937.



No Ball at All – Blake and Grady Kloosterman

The SADS Foundation is celebrating the 20th Anniversary of No Ball at All! We are honoring Blake and Grady Kloosterman who came into the world with a shaky beginning, but are now thriving in spite of having Long QT symptoms. "Because of exceptional care from their medical team and compassionate expert guidance from the SADS Foundation, we have learned to make decisions for our children from knowledge instead of



fear," says Megan Kloosterman. "Our children now enjoy lives full of fun, friends, and laughter."

If you would like more information, please contact Jan Murphy at 801-531-0937 or jan@sads.org or visit www.StopSADS.org and click No Ball to donate online. Together we can support families and save lives!



Impact of genetics on the clinical management of channelopathies

Journal of the American College of Cardiology, SADS scientific advisors and authors Peter Schwartz, Michael Ackerman, Arthur Wilde, et al.

There are few areas in cardiology in which the impact of genetics and genetic testing on clinical management has been as great as in cardiac channelopathies.

This review focused on the impact of genetic discoveries on clinical management of long QT syndrome (LQTS), catecholaminergic polymorphic ventricular tachycardia (CPVT), and Brugada syndrome. For each condition, the researchers discussed to what extent genetic knowledge and clinical genetic test results modify the way cardiologists should approach and manage affected patients as well as the optimal use of genetic testing, including its potential limitations and the potential medico-legal implications when such testing is not performed. The authors highlight how important it is to understand the ways that genotype can affect clinical manifestations, risk stratification, and responses to the therapy.

For complete articles, please contact david@sads.org

Safety of Sports for Athletes with ICDs- Scientific Study

In the May, 2013 Circulation article "Safety of Sports for Athletes with Implantable Cardioverter-Defibrillators: Results of a Prospective, Multinational Registry," the authors discuss the risk of sports participation for ICD patients. Authors, including several SADS Scientific Advisors, studied a registry of 89 athletes, ages 10-60, participating in organized or high risk sports, the most popular of which being running, basketball and soccer. ICD shock data and clinical outcomes were

studied by qualified electrophysiologists. Over a median 31 month follow up, there were no deaths or resuscitated arrest or arrhythmia - or shock related injury - during sports.

This study is the first to show that many athletes with ICDs can engage in sports without physical injury or failure to terminate the arrhythmia. This data suggests that a blanket recommendation against competitive sports for all patients with ICDs may not be warranted.

Left cardiac sympathetic denervation in long QT syndrome: analysis of therapeutic nonresponders

In their Circulation Arrhythmia and Electrophysiology article entitled "Left cardiac sympathetic denervation in long QT syndrome: analysis of therapeutic nonresponders," authors Bos et al discuss left cardiac sympathetic denervation (LCSD) surgery in LQTS patients who do not respond to less invasive treatment options. Treatment options utilized included medications, device therapy, device therapy and LCSD.

Authors concluded that although there was a noticeable reduction in number of cardiac events seen after LCSD surgery, ≈50% of high-risk LQTS patients have experienced ≥1 post-LCSD breakthrough. No breakthrough events were seen in patients undergoing LCSD for betablocker intolerance. Therefore, LCSD must not be viewed as curative or as an alternative to implantable cardioverter defibrillators for high-risk patients. Prophylactic LCSD may provide another option to counter a suboptimal quality of life resulting from medication-related side effects.

Heart Safe Schools Accreditation



The Heart Safe Schools Accreditation project is gaining momentum and we couldn't be more thrilled! Together with Fairfield Medical Center's SNIDER Cardiovascular Institute and the SNIDER Community Heart Watch, the SADS Foundation is proud to announce that in addition to our first accredited school, West Elementary School, the following schools have joined the growing list by achieving their Heart Safe Schools Accreditation: Harmon Middle School, Violet Elementary School, Pickerington Elementary School and Thomas Ewing Junior High School. Thank you to each of these schools for their dedication towards protecting students in the case of a medical emergency! Way to go everyone!

The Heart Safe Schools Accreditation project was designed to be achievable, while providing the necessary measures to improve safety at our schools. We hope to have many schools and districts to thank and congratulate in the coming year!

For more information on getting your school accredited, please visit www.StopSADS.org

NASN conference – stop by our booth!

School Nurses, be the first ones to get the FREE CD with the Heart Safe School Accreditation Toolkit and Power Point! The CD has all the information you need to implement the Heart Safe School Accreditation program at your school. We look forward to seeing you at our booth at NASN on June 28 – July 1 in San Antonio, TX.

Are You the Parent of a Child Who Survived A Sudden Cardiac Arrest in the Past 3 Years?

If you have experienced having a child who survived a sudden cardiac arrest within the past three years, you are invited to participate in a research study conducted by Dr. Vicki L. Zeigler, a nurse researcher at Texas Woman's University.

The purpose of the study is to explore the experiences of parents (thoughts, feelings, and meanings) of having a child who has survived a sudden cardiac arrest in order to learn how to help families through this difficult experience.

The study will consist of an online survey and a telephone interview at a time that is convenient to you and will take approximately 1-2 hours of your time. You will receive a \$25 gift card for your completion of the interview, but you can withdraw from the study at any time.

For more information, visit:
www.StopSADS.org and click on Research.



Updates Made to Brugada Drugs List

10/14/2013

Added to Brugada Drugs to Avoid:

The drug **Lamotrigine** (an anti-epileptic drug but also used in depression and bi-polar disorders) has been added to the preferably avoid list with a class 2B recommendation. This recommendation follows recent reports in which it appears that Lamotrigine can introduce Brugada syndrome like ECG changes and can alter the results of provocation tests.



Updates Made to QTdrugs List

This is a partial list of the over 30 drugs that were added or changed on the Drugs to Avoid List in the last six months. If you receive our e-newsletters, you should have this information already.

Arformoterol (Brovana®) an inhaled bronchodilator for chronic obstructive lung disease

Dronedarone (Multaq®), a drug for the treatment of arrhythmias

Formoterol (Foradil®) and many others including combination products such as **Symbicort®**, an inhaled bronchodilator for asthma

Furosemide (Lasix®) and many others), a diuretic for edema

Hydrochlorothiazide (Hydrodiuril® and many others), a diuretic for edema

Mifepristone (Korlym® and Mifeprex®), an oral progesterone antagonist for termination of pregnancy

Norfloxacin (Noroxin® or Ambigram®), a drug for the treatment of bacterial infections

Ondansetron (Zofran® and others), a drug for the treatment or prevention of nausea and vomiting

For the full list, please visit
www.StopSADS.org and click Living with SADS.

Lamotrigine has been added to the patient letters available in many languages. You can print the updated patient letter from www.brugadadrugs.org/patient-letter/ and provide it to your patients or health care professionals.

To read more, visit <http://www.BrugadaDrugs.org>

Do You Have a Recent Emergency Room Experience to Share?

Researchers want to better understand the emergency room experiences of people living with Long QT Syndrome and their thoughts and feelings on the medical care received! Adults ages 18 years or older with a diagnosis of Long QT Syndrome (LQTS) or who have a child with LQTS, who have sought help in the emergency room in the past year are invited to participate in an online survey being conducted by researchers at the Philadelphia College of Osteopathic Medicine in collaboration with the Children's Hospital of Philadelphia. Participants will receive a \$10 gift card when the 30-minute survey is completed.

SADS Receives an Award from PCORI

The SADS Foundation is part of a Patient-Powered Research Network called "The Health eHeart Alliance: A Patient-Powered Research Network Focused on Cardiovascular Health" which received an award from PCORI. We are one of the organizations that will help to guide research topics, advocate for families with SADS conditions, and enroll patients for the new Health eHeart Network. The SADS Foundation's SIRCh Patient Registry is also a patient-centered database and will be a valuable resource.. Families with SADS conditions will benefit significantly from the collaboration between PCORI, Health eHeart Alliance and the SADS Foundation.

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

Year-End Campaign

We extend our deepest appreciation to everyone who contributed to the 2013 End of Year Campaign for the SADS Foundation. Because of the generosity of our families and supporters we ended the year by bringing in more than \$75,000 to continue to provide programs and services that will support families and bring awareness to the medical community, local schools, and public at large. **THANK YOU!**

Support Medical Education

Help us to reach \$25,000 for 2014 Medical Education programs: 20 seminars, 1000 physicians, 200 physician referrals



Get a Copy of the 2013 Conference DVD

The 2013 Conference DVD is now available for \$40.00. This informative DVD set contains the best lectures from the 2013 conference. DVDs of the CME portion are available for \$50.00. Order yours today to prepare for this year's conference! Order here: www.StopSADS.org/shop

events

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|---------------------|--|
| May 2 | Texas Hold 'em - Folsom, CA |
| May 25 | Bike the Drive – Chicago, IL |
| August 24 | A Heartbeat for Scarlett 5K – Rochester, NY |
| September 20 | 17th Annual Hanss Oktoberfest – Colorado Springs, CO |
| September 27 | Christie's Heartoberfest – Saratoga Springs, NY |

