



www.stopsads.org

SADS is excited to unveil our brand new website! In an effort to provide our families with better and more comprehensive services, we've developed a new, easy-to-navigate website that will provide you with the most up-to-date information on Long QT Syndrome, Brugada Syndrome, CPVT and other SADS conditions. New special features include:

- discussion board—ask questions and chat
- submit your family stories and photos easily
- photo gallery—easily browse and upload photos of volunteer events
- download and print all SADS materials automatically
- volunteer using an online form

And lots more! Please visit us at www.stopsads.org and let us know what you think.



Saving Lives Through Family Medical History

Do you know which side of the family (your mother's or your father's) your Long QT Syndrome came from? Are there family members who might have inherited Brugada Syndrome that don't know they should be tested? The number one warning sign of SADS is having a family history of unexpected, unexplained sudden death in a young person under the age of 40. These deaths can also include sudden drownings, single car accidents or babies who die from SIDS.

Ackerman have long relied on family history to assist them in their diagnosis of inherited cardiac arrhythmias. Collecting detailed medical histories from their patients greatly aided Doctors Vincent and Keating and their colleagues in the discovery of the first chromosomal locations of genes causing an abnormally long QT interval.

Completing your family health history (or pedigree) can save lives directly. After a child is diagnosed with LQTS or any other arrhythmia, other siblings may be at risk, as well as parents, grandparents, aunts, uncles and cousins.

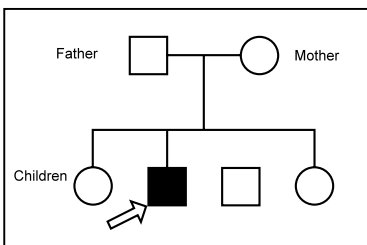
Your family pedigree can identify other family members who may be at risk but don't know about it. They should be tested with ECGs and a genetic test for these conditions so that they can get treated to prevent a tragic death.

The SADS Foundation is launching a Family Pedigree Project to create broader awareness of the importance of family history and to provide information, materials, and support to assist patients and families to identify additional family members at risk, contact their family members and urge them to have an ECG evaluation.

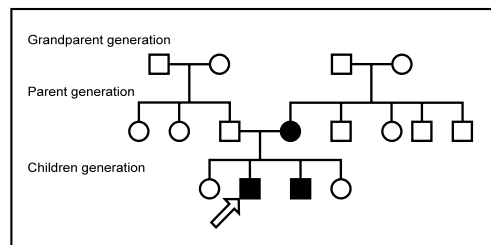
Researchers and experts like Dr. Michael Vincent and Dr. Michael

Family Pedigree Project

The Family Pedigree Project will encourage all of our SADS families to map out their own pedigrees to identify other individuals who may be at risk. Figure 1 shows how you can start your own personal pedigree or family tree with your immediate family. Squares represent males, while circles are females. Colored in circles or squares represent people with LQTS.



Unless it is known which family side—your mother's or your father's—has LQTS, both families must complete their family pedigree and have ECG evaluation and genetic testing. Figure 2 expands the pedigree to include paternal and maternal grandparents and the siblings of both parents. Once LQTS has been conclusively diagnosed on one side of the family, you



would continue to look at more generations of that side of the family and have ECG and genetic testing for those at risk.

The SADS Foundation is dedicated to saving the lives of young people genetically predisposed to sudden death due to heart rhythm abnormalities. Working together to promote the value of family histories and to prepare your family's pedigree will save lives.

The SADS Foundation is committed to supporting families and saving lives through awareness, prevention, family support, medical education, advocacy and research.



Greener Pastures

Jenny Marinovich, a wonderful employee of SADS for the past 3 years, is moving to Thailand with her husband and new baby. We will miss you, Jenny—especially at the Climb to Conquer SADS. Jenny will miss working on behalf of our great SADS families and says, “if you ever open a SADS foundation branch in Thailand—let me know.”

We also wish Chris Ferguson well on his move to Seattle. We are looking for a new Development Director so, if any of you are interested in a job in Salt Lake...

Scott Dailard



Scott Dailard is a member of the Washington, DC law firm, Dow Lohnes, PLLC, where he practices advertising, antitrust and intellectual property law. Scott counsels clients in all areas of advertising, consumer trade regulation, and antitrust and unfair competition law. He assists clients with the planning and design of national comparative advertising campaigns, sweepstakes and promotional contests, customer loyalty and rewards programs, telemarketing, e-marketing and direct mail offers, and campaigns for controversial products and services. Scott graduated from Harvard College in 1990 and received his law degree from the University of California at Berkeley in 1993. Scott’s practice focuses on major media and communications companies but he also advises several nonprofit groups, including the nation’s largest membership organization.

Scott’s late wife, Cynthia Dailard, died in December of 2006 at the age of 38 after suffering cardiac arrest as a result of previously undetected LQTS. She was a senior public policy associate at the Guttmacher Institute, a nonprofit research and advocacy group devoted to women’s sexual and reproductive health issues. Before joining Guttmacher, Mrs. Dailard was associate director for domestic policy for President Bill Clinton, legislative assistant and counsel for Sen. Olympia J. Snowe (R-Maine), and a fellow at the National Women’s Law Center.

Prior to joining the Board, Scott helped the leaders of the SADS Foundation to develop plans to pursue federal funding for a research program designed to develop reliable and cost-effective protocols for diagnosing LQTS and other congenital arrhythmia disorders in young people. Scott hopes to continue to assist the Foundation with its federal legislative objectives and to increase public awareness and media coverage of LQTS and other channelopathies that needlessly claim young lives.

Scott lives in Washington, DC with his two daughters, Miranda (5) and Julia (3).

Thanks to Board Members for Their Service

Thanks to Katherine Timothy, a founding member of the SADS Foundation (see page 5 for a lecture in Katherine’s honor) and Marjorie Currey for their fine service to SADS. I want to personally thank both of these ladies—Katherine has been such a support and resource to me and to all the staff over the years. Marjorie was my ‘sounding board’ and cheerleader this past year and helped me cope with all various tasks that the director of a small nonprofit must perform.

We will miss your sound advice on the Board but I know you will continue to support SADS and our mission.



Events for SADS 2007

Organize to help SADS raise awareness by hosting a fundraiser in your community. Many wonderful families and friends have already chosen this way to raise awareness and donations for SADS. What sorts of fundraisers can you do?

Jump-a-thon—Kathy Martin, Stephanie Weatherford, and Mary Franklin at the Shelton School in Texas

A Valentine's Starry Night Gala—Bill and Cheryl Badger in Colorado

Christie's Heartoberfest—the Tolosky family in New York

Ryan Weidler Memorial Golf Tournament—Weidler Family in Pennsylvania

Octoberfest—Bill & Sally Layton and family in Colorado/Wyoming

Besselaar Baseball Tournament—the Tina Besselaar family

Tommy Marren Memorial Beef & Beer—Jennifer Marren in Pennsylvania

Christmas Tree Candyland—Jim Guthrie in Illinois

Donner Jaime Miller Swim Meet Invitational—Sarah Sullivan and family in Indiana

Jump-a-thon—Tracy Stafford in Alaska

EBay auction for the movie PS, I Love You—the Hooper family in Tennessee & California

Adam's Night—Colleen Kausak in Illinois

Brian Anderson Memorial Run—Diane Anderson and family in New Jersey

Silpada Jewelry Sale—Brenda Tiffan in Ohio



We've also had office events, birthday parties, tennis tournaments, single runners in marathons...No need to limit yourselves, be creative! We appreciate all the support from our SADS volunteers!!

Support SADS by Trading on eBay

Windland "Wendy" Smith Rice died on May 31, 2005 of Long QT Syndrome. Although Long QT is a treatable condition, Wendy was misdiagnosed multiple times with a seizure disorder and died without treatment. Wendy's sisters, Molly and Laurie, as well as the rest of the Smith family, continue to miss her daily. Despite, or perhaps because of the pain, Laurie is now a board member for the Sudden Arrhythmia Death Syndromes (SADS) Foundation, as well as an activist for arrhythmia awareness. Molly expressed her grief through the new movie PS, I Love You, which she recently produced and dedicated to her sister, Wendy. The movie, however, stands as just one example of the several ways that members of the Smith family continue to preserve the memory of Rice's extraordinary life. The SADS Foundation has benefited from their generous donations and their active support of our efforts to save lives. Wendy was an extraordinary young woman. We don't want to lose any other young people to these treatable conditions.

Due to the efforts of this remarkable and courageous family, an auction on eBay—through MissionFish—was held in conjunction with the release of the movie "PS I Love You", and was a great success! In fact, we raised over \$7,000 in three days! Many, many thanks to all those who participated!

You, too, can hold an auction to benefit SADS—or just have a virtual garage sale. SADS is registered on MissionFish (under Sudden Arrhythmia Death Syndromes Foundation) and sellers can choose to give all proceeds of the auction to SADS or just a portion. To find out more go to www.missionfish.org or email Michelle at michelle@sads.org.

David Salisbury Legacy Circle

David Salisbury was a founding member of the SADS Foundation and served as an active member of the Board of Trustees for over 15 years. He supported SADS and Dr. Vincent with his knowledge as an outstanding attorney as well as his financial support for the programs of SADS. We miss you on the Board but will always remember your role in founding SADS!



We have named our Legacy Circle, composed of donors who give \$1,000 or more for the year, in honor of David Salisbury.

NO Ball At All

No Ball At All is the most planned for, the most attended, and the most publicized non-event around! But even though this is technically a "non-event", SADS is asking for real donations! The SADS Foundation is run, in major part, by volunteer contributions. Please help us meet the needs of families with SADS conditions across the nation! We can only do this through your generous support. Thank you for helping us build our SADS network and community!!

Donate to No Ball At All:
<http://sads.org/Development/NoBall.html>
 Send invitations to your friends and family:
alyson@sads.org

No Ball
Cover Art



Brianna's Story

Brianna Demi Badger was the beautiful 3-1/2 year old daughter of Bill and Cheryl Badger and big sister to Liam Badger. On April 20th 2005, she was rushed to Children's Hospital in Denver after experiencing a serious unexplained seizure. She was with her mom, Cheryl, and emergency medical support arrived quickly. She was resuscitated and given CPR and was taken to the emergency room by ambulance. The pediatric cardiologist at Children's determined that she had Long QT Syndrome. Brianna stayed on a ventilator and received medication to stabilize her blood pressure and heart rhythm. Unfortunately, her little body just wasn't able to meet the demands needed and Brianna passed away at 12:13 a.m. on Tuesday, April 25 2005. "No one

knew that this fainting episode would lead to such tragedy," said Cheryl.

After Brianna's passing, her parents dedicated a new playground in the Denver area in her honor to help educate others about her deadly condition. "It's helpful for us to just ease our pain a little bit" Cheryl said.

After Brianna's diagnosis, the family tried to get their insurance company to pay for genetic testing so that Liam, Brianna's younger brother, could be diagnosed and protected—but to no avail. Liam has yearly EKG's and shows no signs of LQT. And since Bill and Cheryl wanted Liam to grow up surrounded by lots of loving family they

just had another baby, Landon, who had an EKG in the hospital at birth and does not show Long QT syndrome on subsequent tests.

"Life will never be back to normal," says Brianna's father, Bill, "you don't learn to live with it but you learn to live around it." They wanted to make something positive out of Brianna's death, so the family hosts a gala in her memory each year, called the Starry Night Gala, to benefit the SADS Foundation. This year's event was held on January 28, 2008 in Denver, Colorado and raised \$30,000 for SADS programs. As Bill says "it gives the family something positive out of something negative".

Help SADS Climb to Save More Lives

Support Dr. Chris (and the climbers) with a donation "sads.org/Climb/donate.html."

Attend the family seminars beginning July 10th "sads.org/Climb/seminar.html" Spread the word about Climb to Conquer SADS & the John Roskelley special climb by taking posters to outdoor and climb stores around the country "sads.org/Climb/Roskelley.html"



You can also help Nancy Adams, Julie Kotraba and Susan Guzetta plan the family activities—t-shirts, food, games, etc. email michelle@sads.org



P.S. Check out the new pictures of the climbers in the ice caves and also, Dr. Chris's climb journal from last year. "sads.org/Climb/Climb_6_23_07/index.htm"

Teen Sessions (Ages 10 to 18)

- Lifesavers: CPR with an AED
- Taking Charge: Tools for Teens
- LQTS: Unravel the Unknown?
- The Pulse: Q & A

Experts to Speak:

- Dr. Michael Ackerman, Mayo Clinic
- Dr. Susan Etheridge, Primary Children's Hospital
- Physicians from Seattle Children's Hospital

Family Vacation Fun

- Hike with the climbers
- BBQ with SADS
- Swimming, biking, horseback riding
- Party with climbers

Submit Your Stories

You can now submit your own stories—with pictures—of your family, your children, yourself. Telling your story is often a great help to others experiencing similar things. We would love to publish any stories on our new website: Visit new.sads.org, click on Patient & Family Services and Family Stories.



Reaching Out on Behalf of SADS Patients

The SADS Foundation interacts with many nonprofit organizations and companies to share information about SADS and to identify additional good resources for patients and their families. Through government and industry contacts, SADS also strives to keep informed of research, medical advances and new technology that could assist those living with cardiac arrhythmias. In a recent trip to Minneapolis, SADS executive director, Alice Lara and board member Denise Falzon met with two cardiac industry leaders, Boston Scientific and Medtronic, to learn more about their current patient-focused efforts. While visiting

the Boston Scientific headquarters, Alice and Denise toured their ICD manufacturing plant and patient call center. Boston Scientific's call center provides 24/7 live one-on-one support for patients with ICDs. Alice and Denise were very impressed with the level of professionalism, commitment and caring the call center staff showed. It was also interesting to hear about Boston Scientific's new patient management system that allows physicians to check a patient's ICD remotely through a home monitoring device.

The meeting with Medtronic focused on

the SADS Foundation's partnership with Medtronic's charitable foundation that supports patient education and public awareness activities in the United States and around the world.

SADS continues to develop partnerships with other organizations like Parent Heart Watch (Alice attended their conference in Seattle) and has meetings scheduled this spring in Chicago during the American Academy of Cardiology annual conference and at the Heart Rhythm's scientific sessions in San Francisco to explore other opportunities.

SADS Foundation Annual Lecture at PACES

In Honor of Katherine Timothy

We are excited to partner with the Pediatric and Congenital Electrophysiology Society (PACES) to present a lecture at the PACES Annual Meeting, in conjunction with the annual Heart Rhythm Society meeting. We are pleased to sponsor this lecture in honor of Katherine Timothy. Katherine was a founding member of the SADS Foundation and has served on our Board of Trustees since the beginning. Katherine was a pioneer in studying the genetics of heritable arrhythmias. Initially working with Dr. Vincent and then with Dr. Keating, she played a huge role in advancing our understanding of the most common heritable arrhythmia syndrome, Long QT Syndrome. Through her meticulous work with families and family pedigree studies, Katherine was instrumental in connecting symptoms, researchers and families that enabled us to learn so much about SADS conditions.

Care Plans for SADS Kids in School

Whether your child is the social butterfly, the class clown, the heartthrob, or the human brain, you need to know that he/she is protected at school. If an emergency occurs, who knows about your child's condition? Is there a plan in place if your child has an episode?

School nurses use Care Plans for kids who have a medical condition to help them keep your kids safe in school. Emergency

Health Plans help school nurses, school professionals and emergency personnel in your community know what to do for your child in case of an emergency. These can be used in conjunction with or instead of a 504 Plan (see article page x).

With help from a task force of school nurses, physicians and, especially, the expertise and time of Alison Ellison (Project SAVE), we have developed the first two care

What is a 504 Plan and why do I need one?

The federal government has established a mechanism for children with health issues. Under this act, the school must make "reasonable accommodations" your child's health issues. A 504 plan is developed—with input from you and your child's doctor—that spells out all the things that must be done in order to keep your child health and safe at school.

If your child has been diagnosed by a physician with a SADS condition (examples include but are not limited to: Brugada Syndrome, Wolff-Parkinson-White syndrome, Long QT Syndrome, Short QT, CPVT), they should have a plan at school. SADS recommends that (1) your school should have an automated external defibrillator (AED) available on school grounds and also on field trips for your child and (2) your child's teachers and coaches should be trained in CPR. These are reasonable accommodations that may save your child's life if he or she goes into Sudden Cardiac Arrest (SCA).

The AED must be available with a trained responder within three to five minutes of your child collapsing and the AED electrodes being placed on your child. Three minutes is the preferred time lapse. The school district is responsible for purchasing the AED, maintaining it, making it publicly accessible and having staff trained to use it.

A 504 Plan may be requested by asking for a hearing for a Section 504 Plan for your child at your school district.

Our new website www.stopsads.org will have sample 504 plans and more information and help.

plans—one for kids with an ICD and one for kids with Long QT Syndrome. These will be available soon on our new www.stopsads.org for you, and your school nurse, to download and use. Make sure that no matter what your child's niche in school, he/she can be safe and healthy. Please let SADS know how you use the materials!

SADS Heart Beaters

So many SADS families around the country are showing us how they live and thrive with Long QT and other conditions. They have overcome challenges, like living with an ICD, and have gone on to live in the most fulfilling way they know how. We want to applaud them and let you know about some of their great successes.

SADS Receives \$3,000 and Has 3 Runners in the Race

Last fall, SADS had three athletes in the Medtronic Twin Cities Marathon or the Medtronic TC 10 Mile in Minneapolis and St. Paul. The Medtronic Global Heroes program sponsored them and donated \$1,000 for each runner.

- Courtney Sprissler (from Raleigh, NC) who received her ICD while running for UNC-Chapel Hill in college,
- Erin McGann (from Vancouver, BC) who had a baby the same year she got her ICD and runs "to show my daughter

there are no barriers to what she can do and to show the importance of staying fit and healthy"

- James Todd (from Port Haywood, VA) a fire-fighter and medic
- Matt Purvis: A SADS patient and semi-pro cyclist, is beating the odds with the help of his ICD. Diagnosed with Long QT Syndrome when he was just 9, Matt set his sights on making his and others' lives better—even when dealing with a SADS condition. Upon graduating from college, Matt has decided to take a job with Medtronic and work on improving ICD's.
- Jacqueline Williamson: Jacqueline attends Pickerington Central High School in Ohio and for her senior project, worked for 6 months researching sudden cardiac



death syndromes, focusing primarily on Long QT syndrome, which her brother, Zach, and good friend, Andy, both have. She wrote a letter to the editor titled, "Early Diagnosis of Long QT Syndrome is Crucial" and gave a presentation to staff, students and community members which included an explanation of Long QT Syndrome with pictures and stories, the importance of sports participation physicals and AED's in schools.

SADS Heart Beater Stories about Living and Thriving with SADS

You can now submit your own stories—with pictures—of your family, your children, yourself. We would love to publish any stories on our new website: www.StopSads.org

SADS Kids Safer in School

Our volunteers have been working tirelessly to make SADS kids safer in schools and we've had some fantastic success as of late:

Teresa Bencie has worked tirelessly for several years to increase awareness in her Florida community. With the help and support of Dr. Jorge McCormack, Teresa has been able to become a strong voice and advocate in her community and school district. organize two Some of her activities include: organizing two SADS seminars, forming a SADS support group and working on legislation to require CPR for teachers. She and Dr. McCormack, have also done a program on Spanish TV and a major interview for ABC TV as well as a story in a new school district publication for parents. Way to go, Teresa!

Clyde and Kathy Tanner let us know about the great work of Faith Jones, a District Nurse for the Temecula Unified School District, on behalf of their son Daniel. She went to bat for Daniel and other LQT kids by heading up a campaign to put AED's in every school in the district. Thanks Faith!



SADS Awareness Month 2007

Preparing Nurses and Staff to keep SADS Kids Safer in School

Thanks to the generous support of Boston Scientific and, of course, all of our pro-active volunteers, last year's Awareness Month was a big success! Not only did we surpass our goal of reaching people in 38 states, but we well-exceeded the number of schools that received SADS information. Approximately 108 schools received information because of your efforts!! In fact, almost 5,000 packets were taken to schools, physicians' offices, PTA meetings, and given out at school nurse conferences. We still can't believe the feedback...our office was literally a mad house with receiving requests and sending out materials! Please don't let us get lazy during the month of September ever again!!! We hope to outdo ourselves yet again this year, so please begin training now!

You can still get materials for your school and we're still speaking and distributing packets at school nurse conferences. For more information contact alyson@sads.org or visit www.StopSads.org.

Advocacy Corner

The Genetic Information Nondiscrimination Act (S.358), GINA, is still stalled in the Senate by a “hold” placed by Senator Coburn. We must push GINA to success in the Senate for it to become law. With Senator Coburn’s hold on the bill, our best alternative is to get GINA on the Senate floor for a vote. Senator Reid, the Senate Majority Leader can make this happen, but only if he hears about how important GINA is to all Americans. As of our print date, we are asking people to contact Senator Reid. The language of GINA was also added to H.R.1424 which passed the house but has not been brought up in the Senate. Things are changing fast! To help us pass GINA, go to our website for the most current status and instructions: stopsads.org

SADS also strongly supports the passage of the Josh Miller Helping Everyone Access Responsive Treatment in Schools Act of 2007” (H.R.4926) which would establish a federal grant program to allow schools nationwide to purchase automated external defibrillators (AEDs) and require that grant-recipients integrate access to the AED as part of the school’s emergency response plan.

More research dollars for the NIH: Senators Specter (R-PA) and Harkin (D-IA) offered an amendment to the Senate FY09 Budget Resolution that would provide significant new funding for the NIH. We faxed letters to our Utah Senators urging them to support this amendment and

encouraged you to contact your senators to explain what SADS is, how it impacts you and your family, and how important research is to saving lives.

The SADS Foundation supports legislation, like the HEARTS Act and GINA, that will keep our families healthy and safe as well as increased funding for research. To get involved, sign up for our e.newsletter and check our website for updates.

Insurance and SADS Conditions

As a newly diagnosed person, trying to deal with your insurance company on top of everything else can be overwhelming. You’ve sent us your questions, answers, headaches and successes when it comes to insurance, and we’ve developed a new program to help relieve some of that stress. The SADS Foundation Insurance Task Force is getting underway, and will be regularly meeting to assess the insurance focused needs of the SADS community and to assist us in fulfilling those needs. The task force will do what we can to advocate for and support SADS families as they make their way

through the maze of genetic testing, AED purchase, ICD implantation, moving out of your parents home for college and the other life-changing decisions that have insurance consequences. Please visit our new discussion board at StopSads.org to give and get help with insurance questions—to keep yourself and your family safe and thriving.

SADS Foundation Young Investigator Award in Cardiac Channelopathies

The Sudden Arrhythmia Death Syndromes (SADS) Foundation would like to encourage the next generation of researchers in SADS conditions. Therefore, we are announcing the First Annual SADS Foundation Young Investigator Award in Cardiac Channelopathies.

Submission DEADLINE, April 22, 2008

Award:

- \$500 to the recipient
- \$1,250 to the institution to offset the cost of the annual meeting
- Recognition with a SADS Foundation YIA plaque

The Award will be administered by the Pediatric and Congenital EP Society (PACES), and will be presented at the annual PACES evening meeting, Wednesday May 14th at HRS.

Awards Committee:

J. Philip Saul, MD, Medical University of South Carolina, Chair

Michael Ackerman, MD, PhD, Mayo Clinic

Robert Hamilton, MD, University of Toronto

For complete criteria and instructions visit StopSads.org, email Michelle@sads.org or call 801-531-0937.

www.StopSADS.org

NEW!! discussion board—ask questions and chat with other SADS affected people & with experts. Topics include: ICDs, insurance, medical questions, parent to parent, teen chat AND SADS Board members will host and take questions/comments.