



SADS 2010 Awareness Campaign: Keeping Hearts Beating

The SADS Foundation staff has been working hard on a new, year-long awareness campaign for 2010. In the past, the SADS awareness campaigns have been once a year for about 6 weeks. In 2010, raising awareness of SADS conditions will be our top priority and the campaign will last the entire year. The campaign slogan is **"Keeping Hearts Beating"** and will be featured on our new posters and other materials. Watch for **Keeping Hearts Beating** wristbands--coming soon! Each quarter we will focus on different groups.

Quarter one will focus on community buildings and spaces. A new poster has been designed and volunteers will be asked to "blanket" their community with posters and information. New media prompts will also

be provided for volunteers to submit in order to get articles in community newsletters.

The focus for the second quarter is sports and athletics. The poster for this quarter will feature risk assessment and AED information and will be placed in gymnasiums, recreation centers, etc. Also during the second quarter, the SADS Foundation will issue an official letter to use to advocate that risk assessment questions be added to sports screenings. The letter will be distributed to youth athletic organizations.

The third quarter is the annual SADS Safe Schools campaign. This year, we will be focusing more on school nurses and plan to exhibit at the National Association of School Nurses annual conference in Chicago in late July.

The fourth quarter will focus on medical professional education. The new poster will be taken to community health clinics, emergency rooms, after-hours clinics, and physician's offices. A door-knocking campaign is being planned for this quarter to correspond with Sudden Cardiac Arrest Awareness month in October.

Don't miss out! Help SADS boost awareness in your community.

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Keeping Hearts Beating Q1: Community Buildings and Spaces

What can you do to raise awareness of SADS conditions in your community? Glad you asked!

We need volunteers to take posters to local spaces such as:

- Public libraries
- Amusement parks
- Shopping centers
- Community centers
- Grocery stores
- Minority group center
- Churches
- Anywhere in your community!

We also have new media prompts for volunteers to use to get an article printed in their community newsletters. These are just a few of the events we have planned for the first quarter. To find out more or sign up to volunteer e-mail Adrienne at adrienne@sads.org or call 1-800-STOP-SAD (1-800-786-7723). Awareness alerts will be sent out via e-mail with different events and volunteer activities that you don't want to miss!

Have you ever fainted?

Thousands of kids die each year because their heart suddenly stops beating—what can YOU do?

- You can be a hero—know the signs and SAVE A LIFE!
- Learn CPR
- Complete a cardiac risk assessment form (visit www.stopSADS.org)
- Ensure your school has an automated external defibrillator (AED) and KNOW WHERE IT IS!

1-800-STOP-SAD www.StopSADS.org
Find us on Facebook today!

If you or anyone you know has experienced any of the following, see a doctor:

- Family history of unexpected, unexplained sudden death in a person under 50.
- Fainting (syncope) or seizure during exercise, excitement or startle.
- Consistent or unusual chest pain and/or shortness of breath during exercise.

SADS FOUNDATION

Find Your Local Network Contact

Join your local group to advance awareness and advocacy for SADS conditions! Check our website (www.StopSADS.org) to see if your state has a Local Network Contact (LN). These volunteers will help facilitate an opportunity for families to network, implement local awareness activities, and/or help facilitate learning from each others' successes. There is strength in numbers!

If your local contact is not listed, contact Adrienne at adrienne@sads.org.

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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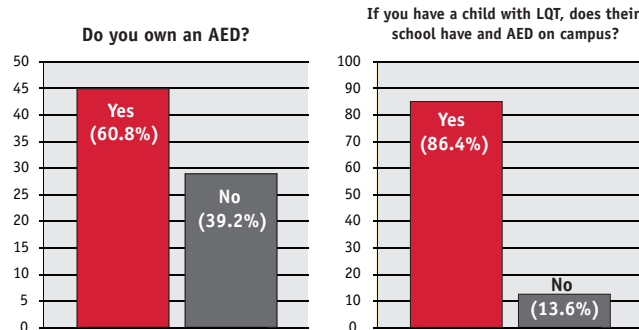
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Advocacy

AED Survey Results Are In!

Thank you to everyone who participated in October's AED Survey. We received some valuable information about what people are currently doing in the realm of AEDs. Below are some highlights from the survey. A complete summary of results can be found on our website www.StopSADS.org.



SADS and H1N1: A Mini Report

From SADS E-newsletter

Throughout the months of November and December 2009, patients and families have been asked to inform the SADS Foundation of their experiences with H1N1. In early December, SADS Quick Poll (on our website) asked questions about H1N1 and 52 families responded. Of all responses from all venues, approximately 41% of people received the H1N1 vaccine, 30% contracted H1N1 and 29% took Tamiflu.

No one has reported having any adverse reactions to the H1N1 flu vaccine or Tamiflu. The people who contracted H1N1 did not report any serious complications as a result of having a SADS condition.

Check the thread on the SADS website Discussion Board (www.StopSADS.org) to find out what others are experiencing and post your experiences.

Medical Examiner/Coroner Outreach Campaign

We are excited about our newly expanded outreach campaign to Medical Examiners and Coroners. Our goals for this campaign continue to be:

1. Support the grieving family
2. Get the living family members diagnosed/tested and treated before another event
3. Determine why the death occurred

We have revised and updated our information sheet for MEs and have a short letter that can be emailed or faxed. We are also actively contacting the local ME/Coroner when we hear of a death.

When the sudden, unexplained death of a young person occurs, we are encouraging the local ME/coroner to contact us for help with tissue/blood samples and family referral. We can even help with genetic testing, if needed.

By the fall of 2010, we hope to have the official Guidelines for SCA in the Young completed. We are working with the National Society of Genetic Counselors and the National Association of Medical Examiners to develop the guidelines.

You can help!

If you hear of (or read about) the sudden death of a young person (under age 50) in your community, call or email Adrienne (1-800-STOP SAD or adrienne@sads.org).

Visit our website (www.StopSADS.org) and take the latest SADS Quick Poll! Check the website or your next e-newsletter for the newest Quick Poll. It's a fun way to stay connected and helps us collect information to better serve you!

SADS Safe Schools Volunteer Spotlight: Diane Raynor and Kristen Kraunelis

Diane Raynor of Robbinsville, New Jersey signed up to distribute materials this September for the SADS Safe Schools campaign. Not only did she distribute materials to pharmacies, schools, and libraries, she was successful in speaking at a PTA meeting! Diane presented a SADS video and spoke about her personal experiences with SADS along with handing out materials to the 75 attendees at St. Gregory the Great. Way to go, Diane!

We'd also like to thank St. Gregory the Great for their generous donation to the SADS Foundation in lieu of their Sub for Santa program this holiday season. We appreciate your support!

Another congratulations goes to Kristen Kraunelis, a nurse in Exeter, New Hampshire. Kristen was diagnosed with LongQT Syndrome at age 17 after passing out at her high school prom. "This is why

I think it's so important for people who work in schools and with children to be familiar with SADS". Kristen distributed the most materials for SADS Safe Schools this year! Not only did she spread the word in her own state, but her outreach extended to three other states: Florida, Massachusetts, and even Hawaii! Thanks for all your hard work, Kristen!

Thanks to everyone for their dedication and hard work! Get involved and help spread awareness of SADS by e-mailing Adrienne at adrienne@sads.org or call 1-800-786-7723.



Kristen Kraunelis



Diane Raynor and St. Gregory the Great Principal, Mrs. Joan Pramberger.

SADS in the News

SADS Foundation patient and volunteer, *Marissa Smith*, contacted her local television affiliate and got her family's story aired on television as well as in her local newspaper. Thanks to Marissa for using her family's story to raise awareness about SADS conditions!

Melanie Stichler's story about her experience surviving sudden cardiac arrest was covered by her local newspaper. You can read the story on our website at <http://www.sads.org/index.php/Family-Stories-Healing-Wall/Against-All-Odds.html>

CBS News, The Early Show: "Genetic Diagnosis Breakthrough"
"Doctors can now study family history and genetic testing to determine a patient's risk of disease."

Aired: September 30, 2009 6:49 AM EST

Thanks to all the volunteers who contacted their local media in Arizona, Arkansas, California, Pennsylvania, Minnesota, Missouri, New York, Washington D.C., and Tennessee.

With your help, we can save lives!

Awareness

Tips for Volunteers

When you volunteer for SADS (or any other nonprofit organization) you can deduct your expenses on your income taxes. You can't deduct the cost of your time but you can deduct any out-of-pocket expenses, car expenses, meals, special uniform expenses, etc. The IRS says that you can deduct the cost of gas and oil that are directly related to giving the service. Or, you can deduct \$0.14/mile. You can't deduct general repair and maintenance.

So keep track of any miles you spend as a volunteer for SADS (taking brochures to schools, staffing a booth at a health fair, etc.) and add it up at the end of the year. I find it easiest to keep track on my day-planner, listing the miles traveled, the activity and the organization. You should also keep receipts for any materials you purchase for your volunteer work—listing the activity and the organization. If you want more information about this, we have added a link to the IRS documents on our website (www.StopSADS.org) or you can get Publication #526 from the IRS.

So, start recording!!

The NBC affiliate in Philadelphia aired a story about LQT Syndrome and the options for treatments.

The CBS Morning Show kicked off their segment, "What's In Your Genes?" with a segment on the advances genetic testing has made for treatment of diseases like Long QT Syndrome. The story featured SADS Board chair, Dr. Michael Ackerman of the Mayo Clinic.

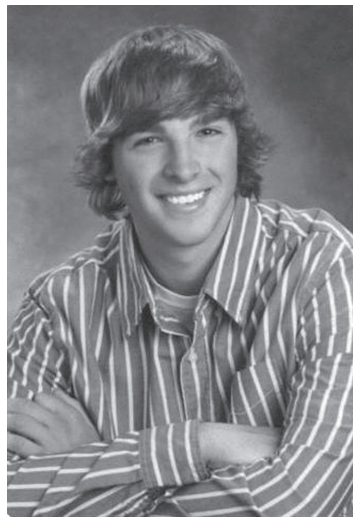
Good Morning America spotlighted professional dancer, Jessica Martineau's, decision to keep dancing despite being diagnosed with LQT Syndrome at age 25 and Dr. Sylvia Priori stressed the importance of genetic testing in determining which type of LQT a patient has in order to provide the best medical treatments.

You can view all of the videos on our website at sads.org/index.php/Table/SADS-in-the-Media/

Finally, a video, featuring Dr. Michael Ackerman, is available for medical providers answering FAQs about genetic testing. You can watch the video on our website at: <http://www.sads.org/index.php/Home-Page/Medical-Professional-Education.html>

Family tragedy saves a life.

Barbara Krzenski, a new friend to the SADS Foundation writes: "I lost my son, Jordan Tucker, unexpectedly 11/15/2008, just five days after his 18th birthday. Jordan was a healthy, happy and well-loved boy. He had just begun his senior year at Esko High School and was looking forward to graduation, he was an honor student and planned to attend college and play soccer in the fall of 2009. He was a gifted soccer player. Jordan had been named to the all-conference team and had just played in the all-star game the night of November 5, 2009. The night he passed away was his average Friday night; he was out hunting, did some homework then met up with some friends at his favorite restaurant for appetizers. About midnight he came home, put his leftovers in the fridge, smiled at me and said goodnight, he was planning to get



up and go hunting the next day. When he did not come down for lunch the next day, I panicked; he normally slept in on Saturdays, but not much past noon. I ran up to find him in his own bed, unresponsive, he had passed away early in the morning the doctors told me, it was too late to try CPR or to revive him." Jordan died of a previously undetected SADS condition. One month after Jordan passed away, a friend had an 'episode'

at basketball practice. Coaches thought it was an asthma attack but this boy had just been to Jordan's funeral. He went in and had an EKG, it was found he had Wolfe Parkinson White (a SADS condition), he had the surgery to correct it and was back on the court playing that same season. He credits Jordan to saving his life. Getting the word out does save lives.

Heart Beater

Matthew Purvis was diagnosed with Long QT Syndrome at the tender age of seven. He had an ICD implanted at age 14 (just one year after his mother had her own ICD implanted). Matt decided to get an ICD because that was the only way his Electrophysiologist would allow him to



race road bicycles. After the implant, Matt was able to race competitively and eventually made it to the semi-professional level.

Because of his condition and implanted ICD, Matt thought he wanted to design defibrillators. Therefore, he went to school to get a B.S. in Biomedical Engineering at UC-Irvine, where he was also president of the cycling club for two years. He completed a summer field internship with Medtronic after his junior year, and changed his mind about actually designing the devices; instead, realizing he wanted to work with the patients and physicians directly.

After finishing his degree, he began working full time for Medtronic as a clinical specialist. Matt interacts with device patients daily in follow-up clinics, where

2009 ARVD Family Seminar

The ARVD Program at Johns Hopkins invites you to attend the 10th annual ARVD Family Seminar on Saturday, May 2, 2009 at Johns Hopkins Hospital in Baltimore, Maryland featuring Dr. Frank Marcus. Dr. Marcus will provide an update on the NIH sponsored study, Multidisciplinary Study of Right Ventricular Dysplasia, as well as discuss changes in the diagnostic criteria.

To register for the seminar, please complete the registration form available at www.arvd.com/conf_info and return it to Crystal Tichnell by fax: 443-609-4061 or email ctichnell@jhmi.edu.

he checks and programs devices, as well as in the actual implants, where he tests the leads and devices.

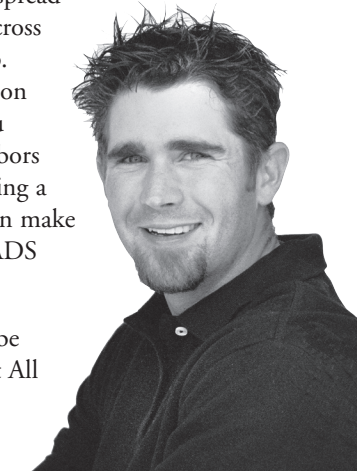
Matt is now 23 and married. He and his wife, Beverly, ride their tandem road bike together nearly everyday. Matt is extremely happy to be leading an active, normal life in spite of LQTS!



No Ball at All—2010

This February, join us and participate in our No Ball at All campaign. Denise Falzon (MI) is serving as National Chairman, and Jackie Kaas-Vines (CA) is serving as Honorary Chairman. Denise and Jackie are teaming up with the SADS Foundation to spread the word of SADS awareness across the country – and you can help. Simply call the SADS Foundation and request invitations that you can send to your friends, neighbors and co-workers. Instead of buying a ticket to a fancy Ball, people can make a life-saving donation to the SADS Foundation.

Robbie Kaas (1977-2005) will be featured in the 2010 No Ball at All campaign.



This artwork was created by Sonya Rogers, a 13-year-old girl from Colorado who was diagnosed with Long QT Syndrome in July 2009. Sonya is an honor-roll student at a school for gifted students who loves math, art, manga, and anime. She often creates amigurami, drawings, sculptures, and paintings for her friends and family. Sonya is a shining example of living and thriving with Long QT.



Brittany's Trees

Five years ago, the neighbors in Carol Stream, IL started an event where they sold trees in honor of Brittany Valene who died from Long QT. The first year, they sold 22 trees, and contributed the proceeds to the SADS Foundation in Brittany's honor. The event has continued to grow, and this holiday season, they sold more than 600! The streets were aglow with memories and love for Brittany and all children who have passed away from SADS conditions.



New Corporate Sponsor

The SADS Foundation would like to recognize a new corporate sponsor: the law firm of Brownstein Hyatt Farber Schreck made a holiday contribution in honor of an employee with two children with Long QT. Amy Venturi – Director of Community Relations and Karma, says: "At Brownstein giving back is in our DNA. We are proud to support our communities. Because life isn't about who you know, but what you do."

**Brownstein | Hyatt
Farber | Schreck**

We are pleased to support the SADS Foundation."

SADS On-line Store

Coming soon! Visit our on-line store for exclusive SADS Foundation items!



I be able to purchase SADS stbands, pens and pins - rfect to hand out at school community events. We will so have beautiful, unique :welry for that special :meone for Valentines Day, other's Day or any other :cial occasion.

Get involved

Get involved and sponsor a climber for the SADS Foundation's 4th annual Climb to Conquer SADS! July 7-11 in 2010 at Mt. Rainier, WA.

Sarah Musgrove, a mom who raised over \$800 for Climb 2009 after her husband and kids were diagnosed with Long QT wrote: "It is so important that more doctors and families are aware of SADS and the symptoms to look for and that is exactly what the SADS Foundation is all about. A donation to the SADS could help to save a child's life through awareness."

For more information, visit Climb to Conquer SADS on our website, or e-mail Laura@sads.org.



The Musgrove boys

Living with a SADS Condition

For the child and the whole family, having a SADS condition changes your life. As parents of children with a SADS condition, we know that this may change your family's life but it needn't become your family's life.

Young children may not understand the changes and restrictions that a SADS diagnosis brings to their life. Common reactions among children include a feeling they are being punished for disobedience, feelings of shame or guilt and a fear of death.

These reactions may prompt your child to act with hostility toward you, feeling that somehow you have failed him or her. Because children think their parents are all-powerful, your child may believe you can make the SADS condition go away.

One of your most important jobs the parent of a child with SADS is to supervise, encourage and foster the independence your child needs to successfully manage

their SADS condition. Try to avoid being overprotective. Overly protective parents undermine a child's self-esteem.

Self-care is the key to the development of a child's independence and self-esteem. You must get your child involved in self-care as soon as he or she is able to master self-management tasks and is emotionally ready.

Adolescence is a tough time for your child—and you. Teens are constantly changing and working toward independence. Understanding and recognizing the limits of your control are key elements in helping your teenager with a SADS condition work through the challenges of adolescence. Areas of special importance are:

- **Understand the Need for Control.** Teens want to be masters of their own lives. They want to define their own identities. To accomplish these objectives, they have to keep testing their limits. You

can help show how they can use the discipline and control of their condition to gain strength and mastery in other parts of their lives.

- **Recognize the Limits of Your Control.** Be realistic. Accept the fact that you can't watch over your teen every minute of the day. You, too, have to learn that it's your child's condition, not yours.

You're not alone in your struggle, and there's no reason to feel alone. Get involved in a support group. Your child will benefit from talking with other young people with a SADS condition, and you will benefit from sharing information and insights with other parents who know the pitfalls, frustrations, and anxieties of a life with SADS.

Adapted from information produced by the Juvenile Diabetes Research Foundation International.

SADS Foundation's Position on Screening to Prevent Sudden Death

Each year, several thousand infants, children, adolescents, and young adults die suddenly and unexpectedly. For most, a meticulous medico-legal autopsy will identify the cause. In about one-third of these tragic sudden deaths, the "killer" eludes detection and the death is classified as "autopsy-negative sudden unexplained death." The SADS-related genetic heart diseases of long QT syndrome (LQTS), catecholaminergic polymorphic ventricular tachycardia (CPVT), Brugada syndrome (BrS), and short QT syndrome (SQTS) are the likely cause of death in many of these cases. These heart conditions (also known as "cardiac channelopathies") affect about 1 in 1000 people and are highly treatable.

So, can we screen for these channelopathies and thereby prevent tragic occurrences of sudden death? The answer is "yes." In fact, we are screening for these diseases and indeed sudden deaths have been prevented. At the SADS Foundation, we recognize that perhaps 50% of the sudden death victims had preceding "warning signs." Proper recognition of such warning signs could reduce the number of sudden deaths significantly overnight. Accordingly, the SADS Foundation strongly advocates for SCREENING programs (general health exams, pre-sports participation physicals) that would probe for the presence of such "warning signs" as exercise- or auditory-triggered fainting/seizures and family history of premature sudden death < 40 years of age or unexplained accidents/drownings. The SADS Foundation is also actively involved in trying to decrease the "knowledge gap" that exists among health professionals by increasing the awareness of and respect for the cardiac channelopathies.

For the other 50% where the sudden cardiac arrest was truly the individual's and their family's first event, there are only two ways to prevent their tragedy – rapid access to automatic external defibrillators (AEDs) allowing immediate life-saving therapy and universal electrocardiographic (ECG) screening. The SADS Foundation fully supports school-based and community-based CPR and AED programs. Whether at the airport or at the athletic field, lives are being saved by effective bystander response.

In terms of ECG screening, this is a very complex issue. The SADS Foundation strongly believes that a common, potentially lethal and highly treatable condition like LQTS deserves screening to be able to diagnose and treat it before an event occurs. However, not every patient would present with a diagnostic ECC and currently, there are serious technical and logistical challenges that preclude the use of ECG as a robust tool for universal ECG screening. Because of this, the SADS Foundation advocates for research funding to enable the appropriate scientific and "real world" studies that are necessary to determine most effective and efficient methods of ECG screening for LQTS. Our patients and families deserve such a concerted effort.

The bottom line – the SADS Foundation's position on screening to prevent sudden death is "Yes we should, Yes we already are, Yes we need to do it better, and Yes we need to study it to do it right".

Participating in Research Studies

You may want to participate in research—or enroll your child in a research study. Or, you may have concerns about research participation. We have an article that can help you decide whether or not to participate in a research project. It will tell you why it is important to think about this decision carefully.

Informed consent

When researchers seek your consent, they are asking for your voluntary agreement to take part in a test, procedure, or research study. Informed consent means more than signing a written or printed consent form. To

be informed, you need to know about benefits and risks of the research and how it may affect you, your family, and society.

If you think you do not have enough information to make an informed decision, or there is something you do not understand, ask questions. Keep asking questions until you do understand the project.

For the complete article, including questions to ask before participating in a research study, see our website at www.StopSADS.org or contact Adrienne (800-Stop SAD) and she will mail you a copy.

ICD Sports Safety Registry: Enroll Now!

The goal of this research project is to determine the safety of sports for individuals with implantable cardioverter-defibrillators (ICDs). Whether sports are safe for individuals with ICDs is currently unknown. The guidelines now recommend that ICD patients refrain from participation in any competitive sports more vigorous than golf or bowling. We know people with ICDs are participating in vigorous and even competitive sports, despite these guidelines. The ICD Sports Registry is currently enrolling individuals, age 10-60 years old, who have made the decision to participate in competitive sports at any level. We want to obtain information to determine the safety and/or risks of sports participation. Contact SADS (1-800-Stop SAD or sads@sads.org) if you want to enroll.

SADS Foundation Young Investigator Award

To encourage the next generation of researchers in SADS conditions, the Sudden Arrhythmia Death Syndromes (SADS) Foundation is announcing the Third Annual SADS Foundation Young Investigator Award in Cardiac Channelopathies. 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 12th at the Heart Rhythm Society Scientific Sessions. It will recognize outstanding, original academic work in the field of cardiac channelopathies.

WWW.StopSADS.org for more information or call 1-800-Stop SAD or email sads@sads.org

New Research Study—Babies

LQTS has been successfully detected and treated in utero, and because of the detection, several asymptomatic youngsters under age 5 have been found to also have a mutation. If you are pregnant and willing to be a part of this study, please let Adrienne know (adrienne@sads.org or 1-800-Stop SADS)

Also watch for our new web page describing current research projects that you can join. Research saves lives.



We also met with leaders of the genetic testing companies (GeneDx and PGx Health) to learn about some of the exciting new things they are offering (see our website for information: www.StopSADS.org). And Boston Scientific discussed working with us on our Pedigree Project and our new Awareness Campaign.

Dr. Etheridge, the Vice President of our Board, met with leaders in this field to discuss genetic testing advances and she also met with a researcher from Chicago about her exciting new research with pregnant women (see article pg. 7 or www.StopSADS.org).



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Coming Events in 2010

Parent Heart Watch Annual Conference

Arlington, TX –
January 15-18

Family and Physician Seminars

Los Angeles, CA –
January 28-30

Physician Seminars

Nashville, TN -
February 10-11

Brian Price Jump-A-Thon – Volunteer Event

Dallas, TX –
February 12

Brianna Badger's Starry Night Gala – Volunteer Event

Denver, CO –
February 27

Family Seminar

Cincinnati, OH –
May 1

No Ball At All

Watch for your fancy invitation to this exclusive “non-event” in February. Email Laura (laura@sads.org) if you want to make sure you're on the list. Save the money you would spend on a dress, sitter, etc. and help SADS save lives.

Be the first to know!

Don't miss out on current research, disease information (H1N1, ICD issues) etc.! Send your e-mail address to adrienne@sads.org to join our e-newsletter mailing list! Or, you can check www.StopSADS.org for the past e.newsletters. Or, you can receive a hard copy by calling 1-800-STOP-SAD (1-800-786-7723).

Online Pedigree Questionnaire Coming Soon!

- Fill out a questionnaire about your condition (or your child's). Your participation will help advance knowledge, understanding, and research about SADS conditions!
- Help family members get screened by emailing Help Sheets automatically to them.
- Learn from other “patients like you”.

This will help save lives by finding at risk individuals!



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