



New Awareness/Prevention Program

Is Your Child At Risk?

for sudden cardiac death

The SADS Foundation focus for Awareness/Prevention in 2006 is to promote our new Risk Assessment Form (www.sads.org to see the full form). This form is based on the physical assessment form recommended by the American Academy of Pediatrics and the American Medical Association. Parents, working with their children's physician, should complete this form for each child every few years, between preschool and high school graduation, and before participating in organized sports.

We will be using this form for the new school nurse campaign, which will begin in March and will continue in September. (Be sure you get SADS e.News for more information).

What you can do

1. Make sure the nurses in your school district know about this campaign & are participating.
2. Assist the nurses and school district to implement the campaign.
3. Whether or not your school nurse is participating, ask your school or child's sports association to make this questionnaire mandatory for all kids before they participate in any active sport.

Eventually, we would like all states to mandate some form of this questionnaire be used for all kids before entering school and every few years through high school.

For more information, call 1-800-STOP SAD (www.sads.org). And remember to let us know your progress and if you are successful with your school or sports association.

You may save a child's life!

School Nurse Campaign

This campaign will begin in March with a press release to all national/ regional school nurse associations for inclusion in their newsletters & list-serves. By December 31, 2006 we will have 150 nurses in 34 states participating.

School Nurse Campaign Objectives:

1. Mandated use of the risk assessment form for all students (or at the very least all sports physicals)
2. Place an article in the school (&/or PTA) paper and give a presentation to the PTA.
3. SADS warning signs posters in every school
4. Educate all teachers & coaches in schools
5. Presentation to other school nurses



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

From the Executive Director



It seemed like 2005 just raced by—with much done but much still on our “wish list”. We had several fantastic volunteer efforts in 2005: a school nurse campaign that exceeded our wildest expectations; a

media alert—via SADS e.News—with over 40 SADS volunteers contacting their local media; several informative family seminars and a fantastic International Conference in Chicago that were staffed by volunteers and SADS Awareness Month in September made effective by the large number of volunteers.

We also saw efforts made over the past 3-4 years start to make a difference: 1) we formed a coalition with several other nonprofits to plan a national “sudden death in the young” awareness campaign and we taped 2 professional PSAs for this; 2) we became a “Patient Link” organization with Medtronic Foundation which will allow us to apply for grant funds for SADS’ programs and 3) we worked with many other groups on a variety of advocacy campaigns—from genetic nondiscrimination to research funding for the NIH to the Teague Ryan Act.

Knowledge of SADS conditions has continued to grow and change. Many more physicians are aware of these conditions and some real inroads have been made in screening—especially for athletes. The field of genetics is growing so rapidly! Issues like genetic discrimination are getting increasing attention and procedures such as genetic testing and autopsies that incorporate genetics are now becoming more widely available. Knowing your family health history is more and more important for all of us as a tool to improve our health.

As so many changes are taking place, SADS has worked to “fine-tune” our programs to respond to the needs and challenges of the next few years. Our priorities for 2006 include:

SADS Awareness and Prevention Programs

- School nurse campaign: we’re really excited about this campaign that will use our new risk assessment form. We plan to begin in February—see the article on page 1.
- SADS Awareness Month in September: we want to obtain state proclamations, an article in a national women’s magazine and local media stories

- National awareness campaign pilot in the fall with the Sudden Cardiac Arrest in the Young Coalition

- Continue to collect family stories and respond to local news events

SADS Support Programs

- Kids programming—to continue and further develop this, utilizing a website and online groups
- Family Seminars in Atlanta (March) & Boston (May)
- Networking—revise & expand to include an online adult community
- Hotline, newsletters, e.newsletters, quarterly research literature review
- Website—continue to make more material available & make the site easier to navigate

Medical Education Program

- Advocate the use of the Risk Assessment Form for all children
- Continue to work with school nurses via presentations and materials
- Plan a new campaign targeting Medical Examiners (coroners)
- Literature review of newly published research for SADS’ members

Advocacy & Research Programs

- Continue to “advertise” ways for you to participate in research & open studies
- Continue to let you know of current research findings, new diagnostic and/or treatment options, etc.
- Advocate for specific legislation important to our families like: like insurance questions, genetic discrimination, financial assistance, AEDs, ICDs, etc. & ask you help
- Explore the need for (& financing for) convening scientists to solve a particular problem and/or to determine the next direction in research (i.e. scientific conference).

As volunteers and donors, we will be looking to you for help to move these projects off the drafting board and into reality.

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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Volunteers support SADS!

Each year a number of enthusiastic SADS Foundation volunteers organize community events to raise funds that help make SADS Foundation education, support and awareness programs possible. Not-to-be-missed events in the last 6 months of 2005 included the Brian Abell Memorial Run in eastern Pennsylvania, the Brian Falzon Memorial Road Rally just north of Detroit, Michigan, the Octoberfest put together by Bill and Sally Layton just outside of Denver,

Colorado, a hog and corn roast at the Almendinger family farm in central Ohio, bracelets sold in memory of Brittany Valene, and the Widmann Quilt Raffle. Altogether, these events raised nearly \$30,000 for Foundation programs. Go team!



Left and center: Layton Octoberfest. Far right: Brian Falzon Memorial Road Rally

Doubling Dollars

Many large corporations will match employee donations to the SADS Foundation. Over the past year, the following businesses have doubled employees' gifts:

Allstate Insurance
CNA Surety
ConocoPhillips
Fund American
GlaxoSmithKline
International Paper
Leo Burnett Company
Microsoft
PG&E Corporation
Starbucks
TAP Pharmaceutical Products
Tenet Healthcare

SmartGiving: Making Gifts of stock

Often donors can save money on their income taxes by donating stock that has appreciated in value, rather than donating cash. If a stock you own has increased in value, and is sold to generate cash for a donation, capital gains tax must usually be

paid, decreasing the value of the charitable deduction. Paying tax on the capital gain can be avoided if the stock, rather than the cash, is donated to the nonprofit organization. Of course, you should talk to your own tax preparer to make sure this type of donation makes good sense for your situation.



Brian Abell Memorial Run

To make a stock donation to the SADS Foundation, please contact Sarah Marsden at 800/531-0941 or sarah@sads.org. She can give you the simple instructions that your broker will need to move a security from your brokerage account to ours. **Please let us know when you transfer stock.** When we receive stock, there no record of where it came from. So if we don't know it's coming, we can't thank you as much as we'd like!

Brian Anderson

My son, Brian Anderson, age 21, died suddenly this year on Mother's Day morning one week after his birthday. We talked several times that day and he sounded happy and full of life. He was with friends who witnessed his death. They said he was laughing one minute and dropped to the ground the next – he seemed to have died very soon after, before they reached the hospital. Brian was a happy, healthy boy, who was never sick with even a cold. He was truly a blessing to all that knew him. Brian touched so many lives with his warm personality, his willingness to help others, and his sense of humor. He had a love of life and wanted everyone around him to be happy. Brian loved his family and friends very deeply. Brian was attending Villanova University and was a hard working student,

he completed an Electrical Engineering Degree in three years! He was preparing to graduate in two weeks — first in his class, Summa Cum Laude. I accepted his diploma for him at graduation. We were all so proud to hear his name announced with the other graduates. Brian accepted a prestigious job at MIT-Lincoln Labs in Boston.



Brian was about to begin the next chapter of his life. He just bought a new car, found an apartment in Boston, and had a garage full of furniture and belongings already to go! Brian was so special, that on his desk at school his friends found a Mother's Day card already written out to his mother. He hand wrote a note and at the end said, "You are the best mom and a good friend to me." Brian is greatly missed by all of us and he'll be in our hearts forever. As I told him each day – "You are my Blessing from God" So far, we have no cause for his death. My husband and younger son have been through genetic testing, and nothing has shown to be a cause of Brian's death. Currently, Dr. Ackerman is studying Brian's DNA in his Mayo Clinic Laboratory, we pray for an answer.

4th International SADS Foundation Conference

More than 80 people attended the SADS Foundation conference in Chicago last October to hear SADS experts, genetic counselors, public health nurses, and Familion and Philips HeartStart representatives discussing anything and everything about hereditary channelopathies. The meetings provided a lot of information for families new to a SADS diagnosis, and opportunities for those who have lived with SADS conditions for some time to share stories, ask questions of the experts, get tips about AEDs in schools & family genetics and learn from each other. For the second year, the conference included a Teen Track, organized by teens (with SADS) for their peers. These meetings offered youth their own opportunities to make friends, ask the medical experts their own questions, and share their SADS experiences.



A crack team of volunteers made this conference run smoothly! We thank Denise Falzon, Diane and Steve Horowitz, Julie and Kellie Kotraba, Sharon Lentino, Matt Purvis, Colleen Kausak, Susan Todd Valene, Eliana London, Jim and Dorothy Renner, Nancy Adams for their time, energy, smarts and commitment.

For four years now this conference has covered topics that staff, cardiologists, and patients feel is critical to recently diagnosed families. The next SADS conference is scheduled for the summer of 2007, and we would like your input about format and topics. Would you like more advanced medical topics? More social time? More suggestions about how to spread information in your community? Please email your suggestions to sads@sads.org or call us at 800/786-7723.

Updates to the QT Drugs List

The University of Arizona CERT is an independent academic center whose mission is to improve therapeutic outcome and reduce adverse events caused by drug interactions, especially those affecting women. The educational material developed for the site is reviewed by the University of Arizona CERT directors and consultants. We are physicians, pharmacists, and scientists. Our basic and clinical research, as well as educational efforts, are in this important area of therapeutics.

These drugs have been added to the list:

- Clozapine

A few notes about the Lists:

Drugs are listed with up to 2 common brand names. There are many more brand names for some of the common drugs, such as pseudoephedrine and erythromycin. It is also important to look at the list of active drugs in medicines that contain a combination of drugs such as Zyrtec-D®, which contains pseudoephedrine.

This means that you must look up each ingredient of the drug to see if it is on this list. Also, remember that herbal remedies are medicines, too and may contain ingredients that could prolong your QT interval.

Stories

Please send us your stories! We will put stories of any length online at <http://sads.org/stories/index.htm>. Stories of 300-400 words we can publish for our Healing Wall. Don't forget a picture! We will share them with everyone.

A difference in our lives

Sharon Lentino's Story

The year was 1973 and I was 9 years old. I was taking swimming lessons at New Trier High School. I was in the shallow end and I sank to the bottom of the pool. Luckily the lifeguards were able to get me out and back into consciousness. They thought I had hyperventilated. Two weeks later while in the deep end, once again I was pulled from the swimming pool. I came back to consciousness on my own but not without scaring a few lifeguards. I was taken to the doctors and was seen by a neurologist who put me on Dilantin. He had seen some tiny abnormalities on my brain wave test (EEG).

In 1975 I was taken off of Dilantin in hopes that everything was okay. In 1976, mothers day, I became weak while swimming and was sick with flu like symptoms for a couple days. In September of the same year I had another episode in the pool. Episodes like this continued to occur. January 1977 while running and July 1979 diving in the pool continuously. In July my father had quite enough of this and wanted some answers. He had an ambulance take me to the Children's hospital in Cincinnati, Ohio where we were currently living. My Dad was onto something, as you will find out later. He had both the cardiologist and the neurologist review my case. They found nothing in the EEG or the ECG and decided it could be syncope or a seizure. With that they put me back on medicine—this time Phenobarbital.

I continued on medicine until my sophomore year of college (1983) where the doctor felt I could have outgrown the seizures and that my brain was fully developed. In 1984 my father passed away and this really changed my life. In the fall I returned to

school being episode and medicine free. However this did not last long. In September while running stairs at Volleyball practice I passed out. Again I was taken to the hospital, nothing was discovered and I was released.

I week or so later I was still feeling very tired and not myself. I was sent to a neurologist with no concurrent findings but he felt maybe a 24hr Holter was a good idea. I was told to run the stairs that evening in hope of getting an episode on tape. Well I did not pass out but I became very weak and sick. I returned the Holter to the doctor's office and they said they would call me with results. I was called on a Sunday, "do not walk up flights of stairs or go running please lay low". They have finally caught my arrhythmia on tape. I went to a specialist, Dr. Thomas Bump, and he diagnosed me with Long QT syndrome. It's been ten years since my first syncope and I'm lucky to be alive.



2005 - I am now 41 years old have been episode free for 21 years. I take Nadalol (Corgard) daily and can lead a pretty normal life. I have been married for 16 years and have three children, Mary is 12 and in

seventh grade, Anne 10 and in fourth grade and James is 6 and in Kindergarten. My daughters have Long QT Syndrome are involved in fun activities such as Cheerleading, Tap and band.

We have become involved with SADS and this Foundation has allowed us to meet others who have this livable but life threatening disease. I try and let my children know the severity of our disease but I also want them to live life and love living it each day. To all those at SADS I thank you for all your hard work. You have made a difference in our lives and made us more aware of what our disease is all about.

SADSConnect

People under 20 have heart disease, too! If you are interested in meeting other young people with Long QT, cardiomyopathy, arrhythmias or other SADS conditions, you should join **SADSConnect**- a yahoo group for kids. Through **SADSConnect**, you will receive and share support, feedback and information. At **SADSConnect**, you will connect with teens that are going through what you are going through—you will learn that you are not alone. To join today, go to: <http://health.groups.yahoo.com/group/sadsconnect/>

SADS Seminar in Dallas

Thanks to SADS volunteer Barbara Butcher and her family for arranging the SADS Family Seminar in Dallas last November. I also want to thank Dr. Scott, Liz Brantley, RN and staff of Children's for all their hard work. The room was great and I think all participants learned a great deal about living with their condition. Dr. Ackerman gave a fantastic presentation and he and Dr. Scott answered participant's very thoughtful questions. Liz had even arranged for a Spanish interpreter for any families more comfortable in this language. I hope everyone got all their questions answered—I certainly learned some things from participants.

I also had the honor, during the American Heart Association meetings, to visit the Shelton School and Kathy Martin and the other volunteers who do such a great job holding a Jump-a-Thon for SADS every February. What a fantastic school!

Jackie Renfrow's Story

I had no idea what Long QT Syndrome was until May 2003. I was 3 years too late to save my son and 10 months too late to save my daughter! My Mom was taken to the hospital for what we thought was an anxiety attack; she was having rapid heart rhythm and fainting spells. She was diagnosed with Long QT, a rare and hereditary heart disorder that can only be found when you are alive. This doesn't show up in autopsies. It is commonly misdiagnosed as epilepsy.

My son, Jimmy, died in his sleep April 15, 2000 leaving behind a wife and a baby, Alexis, who will never know her Daddy. My daughter, Chrissy, died on July 25, 2002 in her sleep also suffering from a seizure and left behind an eight month old baby, Jessica, who will never know her Mommy. Now that we are aware of Long QT, my grandchildren can be treated for it as well as other family members and myself. A simple EKG could help save someone's life.



Above: daughter Chrissy; below, son Jimmy and his daughter Alexis

I have been working since 2003 to make people in my community aware of this treatable condition. I have been on seven TV programs—including our ABC Affiliate, CBS Affiliate and CNN. I have been in eleven newspaper articles and also told my story on the radio. I am working on a book about my story that will include the SADS Foundation. I have some commitment from three TV stations to help with the book promotion. My goal is to get on national TV—you can touch so many lives with this story.

I have Long QT, too, as well as my two grandchildren.

If I help to save one life, it's all worth it. I know my children would want to help save others.

SADS Volunteers Succeed in AED Legislation in State

In May of 2005 the House of Representatives in the State of Oregon passed HB 3482, a bill that directs the Oregon Department of Education to seek private donations, federal funding, and foundation grants to pay for placing automatic external defibrillators (AEDs) in schools.

The bill was introduced in 2003 by Rep. Mark Hass and is dedicated to the memory of Graeme Jones, a 12-year old boy who died from sudden cardiac arrest on October 22, 2000. Four lifeguards and two physicians, one a cardiac surgeon, tried to resuscitate him at the southwest community center where he had attended a swim party. They did everything possible to save him, but lacking an AED, they failed.

The issue came up again when a Grant High School basketball player died in February. Eddie Barnett collapsed while playing in a high school basketball game. He had a known heart condition but an AED was not present at the game.

Eddie's mother, Christeen Johnson has fought to increase awareness of the need for AEDs in schools, Hass said. "I want to thank Christeen Johnson and Blair Jones for their courage and their help", Hass said. "They could have easily shielded themselves from

public view while grieving for their children and everyone would have understood. But they choose to stand up and move forward to help others."

The bill also updates the current "good Samaritan" law that deals with AEDs and removes liability from schools as long as they store and maintain the devices responsibly. Under this new bill, large health clubs must also keep AEDs onsite.

SADS Awareness Month a Success

Thanks to the 33 volunteers in 16 states who participated in SADS Awareness Month, held in September 2005.

SADS Volunteers distributed :

716 SADS brochures	242 coach packets
343 posters	215 nurse packets
431 teachers packets	386 LQT brochures

Congratulations to all who participated!

Spokane Crew Conducts Large School Nurse Campaign

Kathy Conlin, RN, Dr. Chris Anderson and Doreen Hock ran an extensive awareness campaign for school nurses last spring.



Inspired by our article in the SADS newsletter, Kathy organized the campaign and enlisted the help of Dr. Anderson. With her super drive, they personally delivered or mailed specially designed packets to nurses in

21 school districts in the Spokane, WA area. Recruiting the help of her niece who had media experience she also drafted a letter to the local newspaper and let the TV stations know.

Finally, and most impressive to the SADS staff, she designed a postcard which was included with the materials that allowed the nurses to give feedback about the campaign and also order more materials, etc. This type of follow-up is so valuable—not only for the local campaign but also for us to judge the impact of our work. Kudos to all!

ICD's: What Should Patients Expect?

Until recently, SADS has not focused on ICD issues. But, with the increasing implantation of our members and the recent difficulties with ICD performance, we have begun to take part in the discussions about the current state of the health systems that regulate pacemakers and ICDs. We will continue to expand our role in covering ICD news and in advocating for ICD patients.

We have begun a small survey of our members with ICDs. If you have a device, please complete our survey by clicking the button on our website (www.sads.org) or give us a call and let us know:

- What type of device you or your child/children have
- Have any of them ever fired?
- Have you (or you child/children) had any problems with your ICD?

New on www.sads.org

Risk Assessment Form—use this for all your kids and “spread the word” to other families.

www.sads.org/Development/main.html: Learn more about raising funds for SADS programs—& see great photos of past events

www.sads.org/enews/earchive: eNews archive

New links (www.sads.org/Links/links.html):

<http://thomas.loc.gov/>: Find out about the status of any federal legislation

www.sads.org/Links/AED.html: new links for AED resources & the SADS Foundation AED Policy

Office of Rare Diseases: Information on research studies — completed, current & planned (http://rarediseases.info.nih.gov/asp/resources/rsch_trials.asp)

PubMed: look up everything about diseases and health (<http://www.ncbi.nlm.nih.gov/entrez/dispmim.cgi?id=192500>)

Clinical Trials: everything about government-funded research, including how to participate (<http://clinicaltrials.gov/>)

GeneTests: Information about genes, diseases, clinical testing, research (<http://www.genetests.org>)

National Heart, Lungs and Blood Institute (<http://www.nhlbi.nih.gov/>)

National Library of Medicine: this is their guide for finding accurate and reliable medical resources online (<http://ghr.nlm.nih.gov/ghr/resource/evalmedinfo>)

Links to our new International partners’— China and The Netherlands— websites.

Volunteer Opportunities

We would like to again thank all of the volunteers who have generously given their time over the past year. In 2006, we are expanding our volunteer opportunities and recruiting for two part-time internships. Here are some of our current opportunities:

Office Intern – this person will assist with office duties including mailings, computer work, filing, database entry, event planning, and special projects (must live in the Salt Lake area).

Awareness Intern - this person will assist in the coordination of two medical education projects as well as SADS awareness month.

SADSCoast Moms - The role of SADSCoast mom is to ensure that all postings placed on SADSCoast are appropriate. Moms are assigned weeks in which they monitor the board periodically throughout the day.

Corporate Fundraising Liaisons - Our liaisons help staff contact local corporations to raise funds for SADS. They work closely with the Development Director to determine the best fundraising approach.

School Nurse Awareness Project Volunteers - We need the help of all our families to help contact school nurses in their area. Please see page 1 for details.

If you have any questions or would like more information, please contact Jenny at Jennifer@sads.org.

SADS Volunteer Speaks Out in Chicago

On September 2nd, 2005 SADS Volunteer Colleen Kausak and her husband attended a concert by legendary singer/songwriter James Taylor as part of Medtronic’s Keep the Beat campaign, a nationwide outreach and education program designed to raise awareness of Sudden Cardiac Arrest (SCA) and early defibrillation.

Colleen was nominated by SADS for the community champion award and was asked to speak at the pre-concert event. Colleen told her story and discussed the impact AEDs have had on her life in front of an audience of approximately 75 people. Colleen said, “It was a privilege just being able to get awareness out and be a part of that program.”

Upcoming SADS Family Seminars

March 11, 2006
from 1:00 to 3:00 p.m.
Atlanta, GA

Co-sponsored by Children's
Healthcare of Atlanta

Contact Alison Ellison directly
for directions and to "register"
alison.ellison@choa.org or
404-785-7201

May, 2006
Boston, MA

SADS e.News

Did you hear about the new device from Medic Alert? Dr. Vincent said of it, "For many years we have recommended that people enroll in some type of Medic Alert program and this is a great advance in the usefulness of this data." If you were receiving SADS e.News, you would have learned all about this in early November.

If you want to keep up-to-date on new developments, research, action alerts, SADS programs, etc.—sign up for the SADS e.News at www.sads.org or give Jenny your e.mail address at sads@sads.org or 1-800-STOP SAD.

The November eNews is available online at www.sads.org/newsletter/archive.htm

New Bracelet

We have a fabulous new bracelet for sale to benefit SADS programs. Thanks to Sue Valene for designing this in memory of her daughter, Brittany. You can order this from SADS at www.sads.org or call 1-800-STOP SAD.

