



4th International SADS Foundation Conference:

Preventing Unexpected Sudden Death in the Young

Thursday, October 20th & Friday, October 21st

Wyndham O'Hare, Chicago, IL

This year the SADS conference looks to be even better than the past three years! We will once again have our two fantastic Long QT Syndrome experts, Dr. Michael Vincent and Dr. Michael Ackerman to answer any and all questions. In past years, attendees have said the information they received from these experts was invaluable!

“Dr. Vincent is inspirational.”

Beginning Thursday, we will have a special session to help you begin your family health history. As you know, talking with all your family members is very important so that those who have Long QT Syndrome can be treated.



All day Friday we will have special conference sessions for kids and teens (ages 10 to 18) that were such a success last year! Julie and Kelly Kotraba and Matt Purvis will again head up the planning team for this event.

New this year will be a session on the genetics of SADS conditions by Heather MacLeod, a Genetic Counselor who works with a physician researcher in Chicago. Another great new speaker, April Perry, RN, APN, M.Ed, is an expert on helping kids and parents learn to really LIVE with these potentially life-threatening conditions. We are really looking forward to her talk, “Family Coping Strategies for Sudden Arrhythmia Diagnoses and/or Experiences.”



Don't miss out on this year's Teen Session. It is a great chance to make new friends! See also the story on our new SADSConnect on page 7.

Our local Chicago volunteers have been hard at work already—planning lots of time for people to meet each other and share experiences. The people you meet at the Conference and the things you share are such a valuable part of the experience.

Cost for the sessions is \$75 for adults and \$55 for kids/teens. Watch for more information in our next E.newsletter! (sign up for the newsletter by sending Jenny your e.mail address: Jennifer@sads.org)

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

Knowing your family history can protect you and your family.

Watch for more details on the Family History Session.

Also see page 6 for more details on researching your family history.

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Legislation Update

The Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2005 H.R. 1252

The Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2005 would provide grants through the Centers for Disease Control to be used for education and screenings regarding cardiac arrhythmia syndromes. The grants would specifically be used to screen children for sudden cardiac arrhythmia syndromes, provide referrals for medical services and provide education to health professionals and the public about cardiac arrhythmia syndromes.

The language in the bill gives priority in making awards to screenings and referral programs for children who participate in, or intend to participate in, organized sports and to educational activities that are directed toward parents and health professionals.

Prior to the SADS Family Seminar, held on March 14th on Long Island, Rep. McCarthy held a press conference to announce that HR 1252 had been re-introduced into Congress and assigned to the Commerce Sub-Committee.

The SADS Foundation Family Seminar was a success. Assisted by Tom and Lynette Ryan, we were joined by the Hypertrophic Cardiomyopathy Association in marketing and planning the session. The wonderful panel of physicians, led by SADS Advisor, Dr. Robert Campbell—answered family's questions and helped.

Genetic Information Nondiscrimination Act (GINA) H.R. 1227, S. 306 was introduced into the

House on March 10th after being passed in the Senate.

The Problem: For Consumers

Your genetic information could be used to deny, limit, or cancel your health insurance.

You could face genetic discrimination in the work place.

For Researchers

Genetic discrimination fears are slowing clinical trials and decreasing the number of effective treatments being developed

For Health Professionals

Patients are refusing beneficial genetic tests due to fear of misuse of genetic information

GINA would change all this!

Fear of misuse of genetic information is preventing people from getting genetic tests done.

Refusal to utilize effective genetic tests hurts individuals, researchers, doctors, and companies. The information garnered by genetic tests helps doctors to prescribe treatments and lifestyle changes with increased success. The same information can be used by researchers to effectively create targeted drugs and develop treatments. In addition, the companies developing these important tests cannot recoup research costs and therefore are unable to invest in further development.

A majority of Americans support such legislation.

An overwhelming majority of Americans (85%) believe that if someone has a genetic test, their employer should NOT have the right to know the results. Republicans, democrats, and individuals from all racial and ethnic groups, religions, and income and education levels share this opinion. [Survey Conducted in 2002 by the Genetics and Public Policy Center, Johns Hopkins University.

What can you do to help pass this legislation?

Contact your state representatives—especially Republicans—and get them to support this legislation in this Congress. (Please let Jenny know if you contact your Representative or if you need any help. Jennifer@sads.org, 1-800-STOP SAD)

Other National Legislation AEDs in Rural America

As a member of the SCA Alliance, SADS is urging Congress to appropriate \$15 million for grants to provide AED programs in FY 2006.

NIH Funding for Research

Working with the Heart Rhythm Society and others, SADS supports keeping the NIH budget the same as in 2004 and not decreasing funding for vital research.

You can find out about all these issues—and more—on SADS' website www.sads.org. Please let Jenny know if you contact your Representative(s) or if you want to get updates e.mailed to you.

What's new at SADS?

Good Luck Gwen

Gwen Davis, the SADS Program Director, left the Foundation in April to pursue an exciting career opportunity. Both her coworkers and the numerous families whose lives she touched will miss her. Gwen is hoping to volunteer with SADS in the future, and we may even see her at the annual conference in Chicago this year. We would like to thank Gwen for all her hard work and wish her the best of luck in the future.



Jenny Joins the Foundation

I joined the SADS Foundation in March as the new Program Associate. I am excited to be part of an organization that provides so many valuable resources and programs. My background includes work in finance, public relations, event management, and program development. Though I have not had a chance to talk with many of you yet, I am already impressed with the courage and commitment of SADS members. I look forward to getting to know many more of you in the future.

Thank You

Over 80% of the funding for SADS programs come from individuals who either have SADS or know someone who does. In other words, your donations are incredibly important to providing programs that save lives from Long QT, Brugada, and other channelopathies. Without your financial support, there would be no newsletter, no public awareness/death prevention campaign, and no patient education seminars or phone support. To those of you who support our life-saving work: your ongoing generosity is paying off. Increasingly, staff hear from families that have received a SADS diagnosis, but have not had a death—almost unheard of in the SADS Foundation's early days.

Renner Dinner Dance

Almost 200 people turned out for great food and dancing at Kimberly Renner's SADS Dinner Dance near Philadelphia on March 11. Organizing this benefit qualified Kimberly to receive her Girl Scout Gold Award



this spring. Representative Curt Weldon, who is cosponsoring the Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2005 (See page 2) spoke, and the event made the news on local television stations!

Jumping for SADS

Students at the Shelton School in Dallas TX spend every February 14th jumping rope. That's after they've spent weeks distributing SADS Foundation brochures and collecting pledges from parents, friends, and neighbors. Kathy Price, and her mother, Betty Glasheen, both faculty at the school, organize the Jump-A-Thon each year to commemorate the life of Kathy's son Brian, who passed away from Long QT in 1998.



Candy gram sales!

Sharon McClellan and the 5th graders at Newman Crossing Elementary School in Newman, GA adopted the SADS Foundation as the charity to benefit from their Valentine's Day candy gram sales. Sales of heart-shaped lollipops with a note saying, "someone's thinking of you!" were brisk. Sharon took the opportunity to hand out copies of the SADS Newsletter from 2003, which featured the story of her son Billy's short, special life. What a wonderful SADS Valentine!

Volunteers use JustGiving.com to raise fund for SADS

Thanks to the steadfast volunteers who've lead us into the world of online fundraising! In the past six months volunteers Walt Allen, Kara Anglim, Jennifer Geisler, Dianne Horowitz, Heather Koffman, Cheryl Mlcoch, and Marianne Traynor have shared their SADS family stories online by creating SADS Family web pages, and then emailed friends and family to invite them to visit their page and make a donation. It's worked! To date, volunteers have raised \$3,000 online. It's secure, free and easy, so if you'd like to participate contact Sarah Marsden (sarah@sads.org) for instructions.

New SADS Research Review!

Stay up to date on new developments in SADS medicine

This month marks the debut of the SADS Foundation Quarterly Research Literature Review, delivering the most recent research abstracts to SADS Foundation supporters four times a year via email (or US Mail, if you prefer). Research articles presented in the current issue include:

- The Framingham Heart Study: QT interval is a heritable quantitative trait with evidence of linkage to chromosome 3 in a genome-wide linkage analysis
- Autonomic control of cardiac action potentials: The role of potassium channel kinetics in response to sympathetic stimulation.
- Are all sodium channel blockers created equal? Clinical-basic correlations based on observations in Brugada syndrome.
- Double SCN5A mutation underlying asymptomatic Brugada syndrome
- Recurrent cardiac events in patients with idiopathic ventricular fibrillation, excluding patients with the Brugada syndrome.

Join the SADS Family—and get the current research findings sent to you—by making a donation at www.sads.org (or mail to us). Give us your email address, or your US postal address, and note that you're interested in receiving the SADS Quarterly Research Literature Review.

Brittany's Story

Brittany Valene

February 17, 1996 – February 15, 2005

Brittany Valene was born on February 17, 1996 as a young, happy, and vibrant young lady. Over her years, Brittany made many friends and touched many lives. She was always willing to lend a helping hand, pick those up who had fallen, and smiled at everyone she made contact with.

When Brittany was three-years old, Brittany's older brother Anthony fainted at school while in gym class at the age of five-years old. After testing, it was determined that Anthony had prolong Long QT syndrome. At that point the whole family was tested to see if any other family members had the disorder. Tony (Brittany's dad) was diagnosed with Long QT, while Brittany's EKG indicated that she did not have the syndrome.

About a year later Brittany was at school and fainted in gym class. She was brought back to the pediatric cardiologist for further testing where it was determined that she had borderline Long QT Syndrome. As a course for treatment she was also prescribed 30mg of Inderal.

Over the next five years, both Brittany and Anthony had fainting spells. In both their cases most of the fainting was triggered by

physical endurance such as sports or gym class. However, one time Brittany fainted at a

soccer game when she was just getting ready to play. Never in our right mind did we think they could faint just by standing there, but it was the emotional endurance that Brittany was about to undertake that caused her to faint.

On February 15, 2005, Brittany was dropped off early at school for her Tuesday morning choir practice. She was walking into school with two of her girlfriends when she collapsed. While waiting for the paramedics to arrive, the school staff was attentive

to Brittany and encouraged her to keep breathing. Brittany took her last official breath on her own prior to the paramedics arriving at the school. Upon arrival, the paramedics began immediately working on her with a defibrillator and incubated her to get oxygen into her system to hopefully restore her heartbeat and breathing. The paramedics worked on Brittany for twenty minutes and were unable to restart her heart when she was transported to the hospital for further care. Upon arrival at the hospital, the doctors and medical staff worked on Brittany for an additional twenty-five minutes when she was pronounced dead at 8:44 am that dreadful

morning due to fatal cardiac arrhythmia.

Since Brittany's death, Anthony and Tony have both had difibrulators surgically implanted. When we inquired if Brittany would

have been a candidate for the difibrulator we were told that she would not have been since she was borderline Long QT. But now since we have a history of death in our immediate family, we have been put into another category where difibrulators are recommended. We were

also told that someone with borderline Long QT should have not had such an irregular arrhythmia as Brittany had, but as God's will Brittany died to maybe save those around her and give Anthony and Tony a second chance to have a strong life ahead of them.

Long QT impacted the way I look at life and death today. Our daughter's death has been so recent, but I feel the need to hopefully save the lives of others or help them seek appropriate medical care so that their children and families will live long and healthy lives, as that is what Brittany would have wanted.



Cubs Game Outing, August 28, 2004

SADS Family Seminars

New Orleans

Dr. Michael Ackerman, Dr. Chris Snyder and Dr. Michael Vincent talked with family members for over 2 hours at the May 3rd Seminar in New Orleans. We had family members come from Texas and Maryland to participate in this event. We would like to thank Oschner Children's for co-sponsoring this event—providing the food and facility and mailing invitations.

Philadelphia

Over 75 people RSVP'd for this special SADS Seminar. Co-sponsored by Children's Hospitals of Philadelphia with SADS Advisor Dr. Victoria Vetter, the evening consisted of presentations by experts: Victoria Vetter, M.D., Larry Rhodes, M.D., Mully Shah, MBBS, Ronn Tanel, M.D., Joshua Cooper, M.D. Afterwards, the panelists stayed late to answer the many excellent questions submitted by participants. We would like to thank CARE for also mailing invitations to this seminar to their database. We would especially like to thank CHOP for their great food, fantastic rooms and warm hospitality.

Echos from the HEART

October 21 & 22, 2005

The Marriott Resort, Ypsilanti, Michigan

An event for Young ICD recipients, their parents and special friends.

To share stories, challenges, successes and adventures, eat, dance and have a great time!

For information: Theresa (734) 936-5544 or t davidso@umich.edu

Stories

Please send us your stories (any length to put online at <http://sads.org/stories/index.htm> or 300-400 words to publish in print) with a picture. We will share them with everyone.

Saving Lives through Family Awareness

I can still remember sitting in the room at the ER, listening to the doctors tell me that I had LQTS. I was shocked. No way, it just couldn't be. I was so active. I worked at a barn during the day, rode my horses at night, and spent time with my friends on weekends. I just couldn't believe that it was true. But it was true. LQTS isn't like heart disease. You can be perfectly healthy and have it. Most of the time you don't know you have it until it's too late. I was fourteen when I was diagnosed with LQTS. It was a miracle that I even found out about it.

I can remember having fainting spells every-now-and-then when I was thirteen. One time I was running in the gym at school, and I passed out. A few hours before that, I was in class and passed out for no reason. When I woke up, I didn't know where I was or what the teacher was talking about. I didn't ever remember walking into the room. My mom took me to a neurologist, but the neurologist couldn't find anything wrong. When I was finally diagnosed with LQTS in November of '03, everything else that had happened to me made sense.

After my family and I realized how serious LQTS was, we knew that we had to contact my biological family. My adoption was closed, so I knew that it would be tough, if not impossible, to find my biological parents and sibling. I didn't know what state they were in or what their last names were or anything.



Vicki Roberts and friend.

One day my mom realized that it's possible to open adoption records if there's an illness that could be life threatening to other members of the family. We had to get Dr. Fenrich, my pediatric electrophysiologist at Texas Children's Hospital in Houston, TX, to write a letter saying that it was alright to open my adoption records. We had to take the letter to court and ask them to release the information. That simple letter changed my life forever.

While going through the records, I learned that my father died in '91. He was out in a field baling hay with his brother, stopped to rest for a minute, lit a cigarette, and died. He was thirty-one. I also

learned that I had an aunt who, at sixteen, passed away for no apparent reason.

In December of 2004, I was able to contact my biological mother for the first time. I told her about LQTS and how serious it was. After I told her about LQTS, she had an EKG done that next day. Fortunately, her EKG was perfectly normal.

I contacted as much of my biological father's side of the family as I could. I told all of them about the dangers of LQTS and that they should all have an EKG.

Ask the following questions of your child at his/her physical (especially sports physicals):

- Have you ever fainted or passed out DURING exercise, emotion or startle?
- Have you ever fainted or passed out AFTER exercise
- Have you ever had extreme shortness of breath with exercise?
- Have you ever had discomfort, pain or pressure in your chest with exercise?
- Have you ever had extreme fatigue associated with exercise (different than your friends)?
- Have you ever been diagnosed with an unexplained seizure disorder?
- Have you ever been told you have a heart murmur?
- Has any family member or relative died suddenly before age 50 (including SIDS, car accident, drowning, etc.)?
- Has any family member or relative died of heart problems before age 50?
- Are there any family members who have had unexplained fainting or seizures?

SADS AWARENESS MONTH SEPTEMBER 2005

Sudden Arrhythmia Death Syndromes Awareness Month is an annual effort to increase public awareness of potentially fatal arrhythmias.

Our vision is to decrease the frequency of sudden death in the young, support families, and to be a resource for those whose lives are impacted by cardiac arrhythmias. Volunteers throughout the U.S., Australia, Canada, the UK and other countries around the world are vital to the success of this effort.

You can make a difference and save lives through your participation in SADS Awareness Month!

Thank you!

How can I help?

Work with family, friends or local volunteers to:

- Contact the media with your story.
- Educate your community (especially schools) with SADS Foundation literature.
- Help the SADS Foundation by holding a fundraising event or making a donation.

Checklist for SADS Awareness Month

- Consider ways of participating by accessing our ideas page www.sads.org/aware04/ideas.htm
- Determine the activities in which you are interested
- Fill out the proposal form online. www.sads.org/aware04/proposal.htm
- Contact the SADS Foundation to determine the types and quantity of educational materials you will need.
- Take Action! Remember to document with photos and notes. We'd love to see those news clippings.

Family Health History: Looking into the Past for a Healthier Future

Your family health history holds key information about your past and clues to your future health. Many of your physical traits (such as eye color, hair color and height) are inherited. So, too, are risks for certain genetic conditions and health problems such as heart disease, diabetes, some cancers—Long QT Syndrome (and other SADS conditions).

Of the approximately 10,000 illnesses known to humankind, at least 3,000 leave genetic footprints.

Finding out your family history can benefit both you and your relatives...and it can be fun, too!

Family gatherings are the ideal time to begin to learn about your family health history. Older relatives are often good sources of information and starting now **may mean that you don't lose this important family memory.** Good strategies for getting relatives to share sensitive health information can be found in the article *Compiling your family medical history: Using the past to prepare for your future* on the Mayo Clinic website (www.mayoclinic.com/invoke.cfm?id=Hq01707)

You should write down the information on yourself, your brothers & sisters, your parents and your children. If you're married, you should also do your spouse's family health history. Then, go back a generation at a time and include nieces & nephews, aunts & uncles, grandparents, and cousins.

Collecting and keeping copies of medical records (including lab tests, ECGs, etc.) for you and your immediate family will allow you—or your children—to benefit from knowledge that is discovered in the future.

The Genetic Alliance has instructions for drawing your family tree (http://www.geneticalliance.org/ws_display.asp?filter=resources_family_history_family_tree) and the Surgeon General has another wonderful form with instructions (www.hhs.gov/familyhistory/downloads/MyFamilyHealthPortrait-English.pdf) and a new computerized tool to help make it fun and easy for anyone to create a sophisticated portrait of their family's health. This new tool, called "My Family Health Portrait" can be downloaded for free (<http://www.hhs.gov/familyhistory/download.html>) and installed on your own computer.

As you all know, it is very important for those with Long QT Syndrome to identify extended family members as they may be at risk for sudden cardiac arrest. We will again be holding a special Family History Session before our 4th International SADS Conference on October 20th in Chicago to help you get started. If you're interested in more information about this, just send Jenny an e.mail at Jennifer@sads.org.

Also see the story on pg. 5 about a girl who is adopted finding her family to let them know about LQTS.

School Nurse Awareness Campaign

We would like to thank everyone who contributed to the success of the School Nurse Awareness Campaign. This year, May 11th was designated as National School Nurse Day. We asked volunteers to target that day to not only commend school nurses in their community but also educate them on Long QT. We received an overwhelming response from both volunteers and school nurses. Since the publication of our Winter 2005 newsletter, we have distributed 809 packets in 35 states.

Thanks to your help we increased the ability of school nurses to identify children at risk.

We would like to again commend school nurses for their contributions to the continual development of the health and well being of our school children and youth. We look forward to working with them in the future.

While National School Nurse Day has passed, the need to educate school nurses has not. School nurse packets are still available for you to distribute in your community. Please contact Jenny at Jennifer@sads.org for more information.



Thanks to Glenda Stafford and Katie Moore (Jenny in middle) for traveling from Texas to New Orleans to help with the SADS seminar and our booth at Heart Rhythm Society.

Healing Wall

The Healing Project is one of tribute and reflection. It is a way for people to see the struggles, challenges, and successes of each family. Our families live with this illness and all of its complexities every single day. Moreover, some of our families have suffered the loss of a loved one, often too young—too soon. We feel bringing together all of our stories with pictures is a great way to honor our loved ones, and in doing so, we can support each other and begin to heal a little at a time.



Before September 23rd, 2005 please send in a photo no larger than 4x6 inches and a written story no larger than 4x6 inches (about 200 words). An email containing your photo and story would be best but hard copy is OK, too. If you have previously sent us a story for any other reason, we would be happy to include in the healing wall display, with your permission. Just let us know.

For more information, please email Jenny at jennifer@sads.org

Volunteer Opportunities at SADS!

Volunteers play a vital role in the success of all SADS programs. We would like to thank all of the volunteers who have generously given their time. There are still many volunteer opportunities available at SADS and we always welcome new volunteers. Here are some of our current projects:

Summer Awareness Campaign:

With school out, kids will be heading to camps, community centers, and summer sports leagues. This is an excellent opportunity to educate camp counselors, teachers, coaches, and all others who will be overseeing activities for kids. Packets are available to be distributed in your community.

Awareness Month:

September is SADS Awareness month. Sign up now to participate in this international event (*see article on pg 5*).

International Conference:

The International Conference is coming up on October 20th & 21st! There are plenty of opportunities to assist in the planning of the conference. We also will need assistance on the day of conference.

If you are interested in any of the above volunteer opportunities or would like more details, please contact Jenny at Jennifer@sads.org.

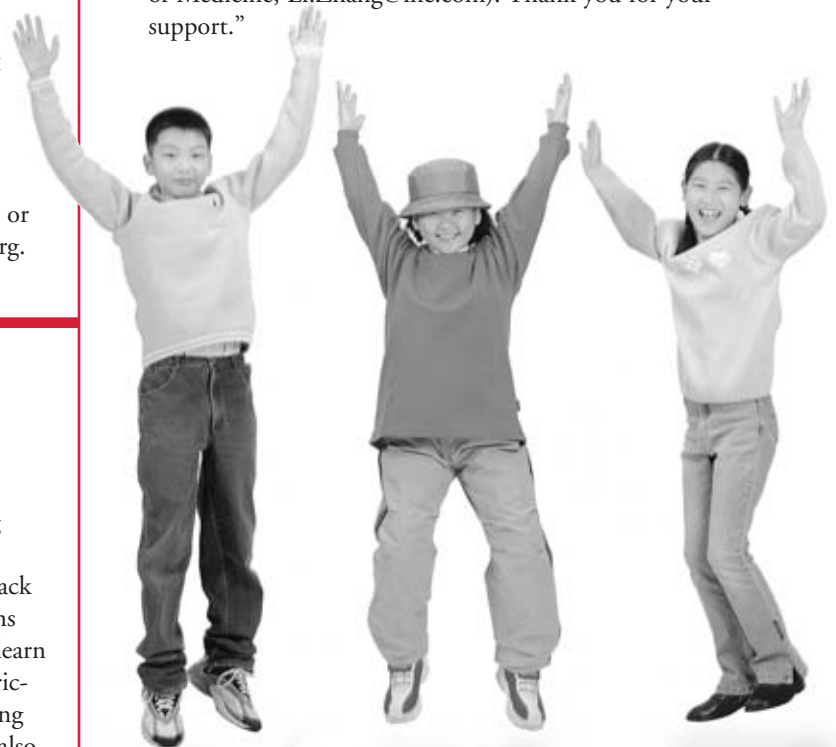
The Launch of SADSConnect - a chat group for youth

The SADS Foundation is proud to announce the launch of SADSConnect, a yahoo chat group for young people with Long QT, cardiomyopathy, arrhythmias or other SADS conditions. Through this group, youth can receive and share support, feedback and information. At SADSConnect, teens can connect with teens that are going through what they are going through—they will learn that they are not alone. They may discuss things like sports restrictions, medication side effects (weight gain, depression, etc.), living with parents who are scared and any other issues. This group is also for youth with an ICD (defibrillator) to share their experiences with others. To join, go to <http://health.groups.yahoo.com/group/sadsconnect/>. For more info, contact Jenny at Jennifer@sads.org.

Start connecting today!

Help ARVD Children

Arrhythmogenic Right Ventricular Dysplasia (ARVD) is a genetic, progressive, Sudden Death (SD) heart disease. Unfortunately, it is not rare and the first symptom can be SD. Dr. Li Zhang is conducting a research project, working together with M. Tink Long and Patricia O'Neil, the representatives of an international network of ARVD families. This study is supervised by Dr. Guy Fontaine and supported by the ARVD-forum organizers. Our goal is to identify the earliest diagnostic ECG markers, as well as the earliest symptomatic warning signs of ARVD in children. If you or someone you know has been affected by ARVD and would like to participate in this project, please contact Tink Long at tink2000@antelecom.net. or Dr. Zhang (Adjunct Asst. Professor, Univ. of Utah School of Medicine, Li.Zhang@ihc.com). Thank you for your support."



2005 SADS Family Seminars

Saturday, September 24th

SADS Canada in Ottawa, Ontario, Canada

Saturday, October 8th

SADS UK in Croxley Green, Watford, Great Britain

Thursday and Friday, October 20th & 21st

4th International SADS Foundation Conference:
Preventing Unexpected Sudden Death in the
Young Chicago, IL

Tuesday, November 15th

Dallas, TX

Enewsletter

Did you know that one of our Scientific Advisors, Dr. Vicki Vetter in Philadelphia, was interviewed for a full-page article on heart disease in children that was published in Newsweek magazine? And did you know that we helped over 40 SADS volunteers tell their story to the media as a follow-up to her article? If you didn't hear about this campaign, you must not be receiving SADS emails.

Keep up to date with the latest research, activities and seminars by giving us your email address today! Due to the cost of printing and mailing, we are planning to give you more SADS information via email and have fewer printed newsletters in the future.

Send your email address to Jennifer@sads.org. If you don't use email, let us know & we will mail you the Enewsletter.