



SADSCONnect at the Atlanta Conference.

This October 1 & 2 we will have special sessions for kids and teens at our International Conference in Atlanta. All youth, ages 9-18, affected by SADS, or who know a loved one with a SADS disorder are invited to participate. There will be kid friendly presentations from our world experts on SADS, special teen sessions, CPR training, fun activities and art projects, and a chance to help create a SADS Foundation video.

Don't miss this opportunity to meet others, share stories, create friendships, and have a lot of fun!

If you have questions or comments, please contact Anne Maurer: anne@SADS.org or 1-800-STOP SAD.

5th International SADS Foundation Conference

Preventing Unexpected Sudden Death in the Young

October 1-2, 2011 • Atlanta, GA
Marriott Buckhead Hotel



Top 10 reasons to attend the conference

1. To learn the most cutting-edge information available from world renowned experts on SADS conditions
2. To find out what ALL the treatment options are for SADS conditions
3. To see where the future of treating SADS is heading and what your care might look like down the road.
4. To meet other families living and thriving with SADS
5. To visit the healing wall to pay respect to those who have passed away
6. To give voice to your experience in a community that understands
7. To help create and strengthen the SADS community; more voices get more attention, greater awareness and more research to change the future of SADS conditions
8. To be inspired by the individuals who have volunteered and/or raised money for SADS, for research, and for their communities in the most creative of ways.
9. To hear what legislative action is being taken to benefit those with SADS
10. To see what research is being done and how you can help.

Healing Wall

Take advantage of this wonderful opportunity to honor and/or remember your loved one. For just \$10, your loved one's picture/photo will be placed on SADS Healing Wall and you'll have a keepsake to take home. The Healing Wall will be available for viewing all weekend, with a special ceremony on Saturday. To view the past Healing Walls: www.StopSADS.org.

Happy Birthday SADS!

The SADS Foundation is turning 20, and you are invited to a gala celebration on October 1st in Atlanta, Georgia as part of the 5th annual SADS International Conference. Join the founders of the SADS Foundation, **Dr. Michael Vincent** and **Katherine Timothy**, and world renowned SADS experts, Dr. Michael Ackerman, Dr. Silvia Priori, and Dr. Robert Campbell (just to name a few), as we raise a toast to the work of the SADS Foundation.

We will be honoring volunteers, highlighting families and remembering those lost to SADS—while celebrating the progress that is being made every day. This is a special anniversary you won't want to miss!

Conference registration deadline coming up!

September 1, 2011 is the deadline for the ½ price conference rate. Send in your registration now or register online!

SADS Scientific Advisor, Dr. Sami Viskin, Highlighted for Breakthrough Research

4/22/2011

Dr. Sami Viskin of Tel Aviv University's Sackler Faculty of Medicine has recently published research in the Journal of The American College of Cardiology regarding screening for Long QT Syndrome. Dr. Viskin developed a special test called the "Viskin Test" to better recognize patients with a higher risk of sudden cardiac arrest.



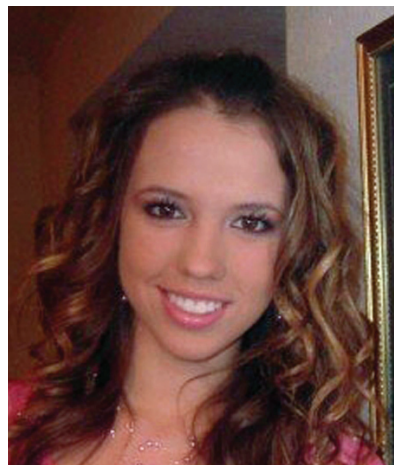
"Current screening methods offer no real therapeutic value, because very few people who experience arrhythmias, up to 20 percent of the population, will ever die from sudden death," Dr. Viskin says. "Young people who suddenly faint for no reason, have dizzy spells or have a family history of LQTS are very good potential candidates for this new test."

In response to brisk standing, both the LQTS patients and the control subjects showed similar heart rate acceleration. But Dr. Viskin discovered that the QT interval in LQTS patients increased significantly.

"This test adds diagnostic value. And the beauty of the test," Dr. Viskin adds, "is that it's easily done at the patient's bedside. It eliminates the need for more expensive IV tests and more strenuous exercise tests."

Pedigree Project Intern

We are excited about our new intern, Kara Evans, who is working with us on the Pedigree Project this summer. Kara recently graduated from Brigham Young University with a B.S. in Public Health. Kara has been passionate about health ever since she was young and hopes to assist others achieve their optimal health and ultimately help to save lives. Kara enjoys running, hiking, traveling, and spending time with her family. She is excited to be joining the SADS Foundation as an intern and be involved in their great work.



Volunteer Hotline

Volunteers are the lifeline of the SADS Foundation and help us carry out our mission every single day. The information generated by volunteers is also vital to helping SADS maintain funding. We know you're busy and we appreciate all your hard work. We want to make it easier for you to let us know what you're doing in your communities with the "Volunteer Hotline". Just call 800-STOP-SAD and dial extension 117 or ask for the volunteer hotline where you can leave a quick message about your activities. Thank you for your continued dedication to saving lives!

SADS Scientific Advisor Featured on XM Radio Program!

In addition to serving on the SADS medical advisory board, Dr. Dan Roden is professor of medicine and pharmacology and assistant vice-chancellor for personalized medicine at Vanderbilt University School of Medicine. Recently he spoke about the use of genetic testing in diagnosing and treating Long QT Syndrome and other heritable channelopathies on the ReachMD XM Radio program. There has been much debate about genetic testing and its application as a decision-making tool for physicians in choosing appropriate medical therapies. Dr. Roden explains that the concept of personalized medicine goes beyond genetics; it is also about meeting a patient's goals and individual needs. Visit www.StopSADS.org to listen to the program or download the podcast.



Anne Joins SADS Team

I am very honored to have joined the SADS team providing the Family Support piece of such a strong and passionate organization. I am looking forward to meeting and reaching out to the families who have been affected with a SADS disorder. I am so impressed by the supportive and active community I have already met, and am excited to meet more of you. I come from a mental health background, focused on grief, loss and trauma, especially in children and families. I am a licensed counselor and graduated with a Masters degree in Existential-Phenomenological Psychology from Seattle University. I was born and raised in Salt Lake City, Utah and am happy to have returned home after living in the Pacific Northwest for over 5 years. Outside of work I am usually hiking with my dog, baking cookies, and trying to get better at playing the banjo.



October is Sudden Cardiac Arrest (SCA) Awareness Month!

Sudden cardiac arrest occurs when the electrical system in the heart suddenly stops working. Did you know every two minutes a person passes away from SCA—that is more than breast cancer, lung cancer, and AIDS! Congress has appointed October as national sudden cardiac arrest (SCA) awareness month to help raise awareness of this issue.

The SADS Foundation is a founding member of the Sudden Cardiac Arrest Coalition—a group of non-profit organizations passionate about preventing SCA deaths through legislative initiatives that lead to greater public awareness, research, and access to life-saving

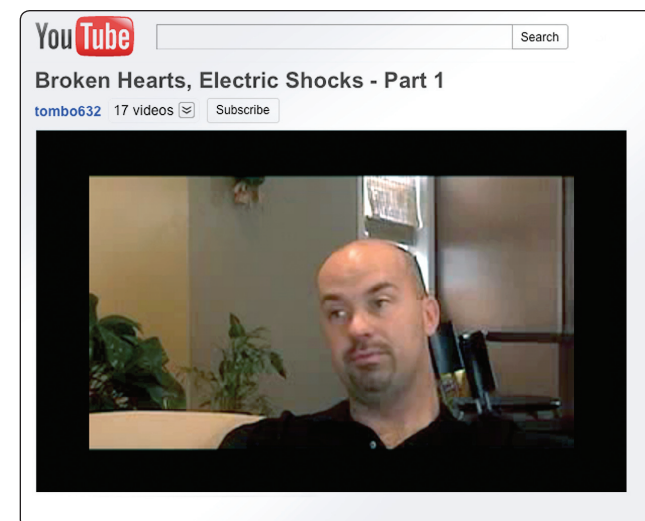


therapies. One of the goals of the Coalition is to ensure all high school graduates in this country are required to have training in CPR/AED emergency response. We encourage you to spread the word and help your community learn the importance of CPR/AED training this October. We'll have special awareness materials for October—be sure to sign up for SADS e-newsletter so you don't miss out!

Also, check out the SCA Coalition website www.StopCardiacArrest.org and Facebook page for other ways you can participate this October.

YouTube Videos: Getting the Message Heard

Recently, we've added a section to the library on our website for YouTube Videos. These videos are a great way to help increase public awareness and knowledge of SADS conditions. SADS volunteers have been using the videos when giving presentations to school groups, public meetings, sports teams, etc. The list continues to grow as we have videos on CPR, AEDs, and other great public service announcements. We're especially excited to feature the heart-warming documentary about coping with long QT syndrome, "Broken Hearts, Electric Shocks" by director/producer and SADS member, Tom Sutch. Check out these videos today! www.StopSADS.org/Library/Videos.



Keeping Hearts Beating: SADS Safe Schools

It's that time of year again—SADS Safe Schools! Every year the month of September is dedicated to keeping kids safe at school. This year we have an exciting line-up of awareness tools for September including new presentations and videos, a new poster about CPR and AEDs as well as a "back to school kit". The school kit includes important information for school nurses as well as fun awareness pieces for students of all ages. It is important that every school is aware of SADS conditions and knows how to properly respond in the case of an emergency. Help us keep children safe at school by ordering a school kit today: www.StopSADS.org.



If you are a school nurse and would like to get involved with SADS Safe Schools and other school-directed awareness efforts, please contact Adrienne Butterwick at Adrienne@sads.org or call 800-STOP-SAD.

Dr. Mike Ackerman and Lucatuorto Family Featured in ABC News Story

ABC News saw a story recently published in the United Kingdom's Daily Mail about a young girl who suddenly passed away in Wales and decided to run a follow-up. ABC reporter, Laura Salahi, contacted the SADS Foundation and spoke with Alice Lara who provided some information as well as contacts for a physician expert and an affected family: Dr. Mike Ackerman and the Lucatuorto family.

The story features quotes from SADS Board President, Dr. Mike Ackerman, and new Board member Anthony Lucatuorto, whose daughter Annie has been diagnosed with Long QT Syndrome. Read the story on our website: www.StopSADS.org.

Be the first to hear the latest and greatest! Sign up for SADS e-newsletters www.StopSADS.org/signup.

Heart Beaters

Mariah Weaver

Mariah Weaver is a sixteen year-old living and thriving with Long QT Syndrome in Montana. She's a remarkable young girl who has been very active in raising awareness in both Wyoming and Montana. She was kind enough to share this drawing and a little bit about her experience living and thriving with LQTS. You can read more stories like Mariah's or share your own story on our website at www.StopSADS.org.



"In art the hand can never execute anything higher than the heart can inspire"

—Ralph Waldo Emerson

"My name is Mariah and I am sixteen years old. I was diagnosed with Long QT Syndrome a couple of days after turning 15. This summer after I turn 17, it will be two years since I was diagnosed. I was tested and diagnosed with this disease after they found out that my father had it. I was immediately put on a Beta Blocker to help my heart. In my family I have a

brother and sister but I was the only one who inherited it. After all this had happened there were not words that could describe how I felt. So I would draw. When I would draw, the uneasiness and the fear that I felt would disappear. I used lines and curves to tell a story, a story about being alive. The story I want to draw is about being brave and alive even though I have this disease and it scares me sometimes. So, I call this drawing 'Letting Go'."

—Mariah Weaver

Help with Research and Protect Your Extended Family, Too

The SADS Pedigree Project is an online registry that can help you track your family tree and also provide valuable research data to the scientific community that works with the SADS Foundation.

The SADS Pedigree Project contains extremely valuable information for researchers. You could help them determine which medications can be used for asthma or how to diagnose your baby before he/she is born or many other vital research questions. By providing your information in the Pedigree Project you will strengthen the scientific databank. All your information (and your family's) is confidential and will not be made available for research without your consent.

It is our hope that this Project will save many hundreds of lives—but we need your help to reach out to your family and to participate in research!

Register today for the SADS Pedigree Project at www.StopSADS.org.

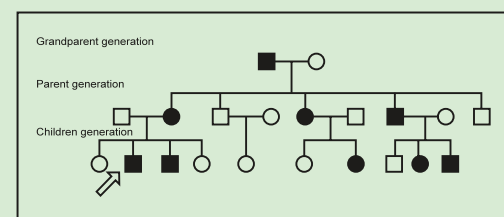
Ricky Trietley

Nineteen year old Ricky Trietley and his family are making a big difference in their home town of Allegany, New York. This Spring their local paper wrote a story about Ricky and their fundraising and awareness efforts. Ricky was diagnosed with Long QT Syndrome last summer after he fainted while exercising one day. Since then he has had an ICD implanted and is attending the University of Pittsburgh. The Trietley family has now raised over \$4,000 for SADS life-saving programs!



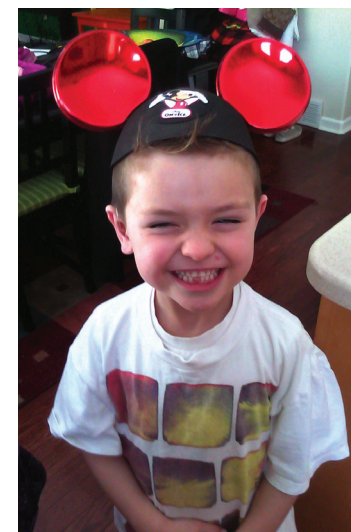
Order a SADS Pedigree Kit Today

The Pedigree Kit provides all the forms and instructions you will need to get started with your medical family tree—either by filling out the information or going online to complete. You can get your **SADS Pedigree Kit** online at www.StopSADS.org or from Anne Maurer at anne@sads.org or 800-786-7723.



Cache Miller Turns 6!

Family and friends of Cache Miller were literally bouncing off the walls at Cache's 6th birthday party at Jump Around Utah in Salt Lake City. Mom, Melissa Miller, organized a fun-filled fund-raiser in honor of Cache, raising nearly \$600 for this year's Climb to Conquer SADS. Cache was born with two Long QT genetic mutations—which is called Jervell Lang-Nielsen Syndrome. When Cache was 2 1/2 years old he was diagnosed with severe to profound deafness. This is a part of Jervell Lang-Nielsen Syndrome. Although his ability to speak is a challenge for him, he does not let anything stop him from living his life. The Miller Family will be represented by climber Brad Herr, who carried their personalized banner to the top of Mt. Rainier. Happy birthday, Cache! www.firstgiving.com and search for "valiant hearts."



Organize a School Fundraiser

We know it's still summertime, but it's never too early to start putting together a fund-raiser/awareness raiser for the SADS Foundation at your school. We have families who have amazing ideas about ways to get schools involved, both in raising awareness, and collecting money for the SADS Foundation. Trends in philanthropy show that the younger children are when they start becoming aware of the need to support important charities, the more likely they are to be philanthropists for life. We love our young philanthropists, and value their contributions tremendously.

Our Families and Friends are Among the Most Creative People We Know!

Every day, we get calls at the SADS Foundation from someone who has a new idea or wants to put together a fund-raiser for us. And you know what we say? Bring it on! We're here to support you. This year, we've seen the addition of a wine-tasting event in New Jersey in memory of Stephanie Mejias, a Triathlon in North Carolina in memory of Abbey Wambach, and even a good ol' Blue Grass concert featuring Carl Jackson at the Bluebird Café in Nashville in August in memory of Robbie Kaas. Be creative—have fun—and know that every dollar raised goes toward the life-saving work of the SADS Foundation.



Please contact Laura at Laura@sads.org for the updated Fund-Raising kit and other information about how to get your community and the media involved.

Where's Bob? Come online to find out!

Be sure to find out where our very own Bob DeVries (Where's Bob?) is going to be this year. Last year, Bob toured all 30 ballparks in the USA, raising awareness and funds for the SADS Foundation. This year, he's not hitting all 30, but he's going to several, and would love to have you join him. Go online, order your "Where's Bob?" T-shirt and come represent the SADS Foundation.

Celebrate Wayne and Conquer SADS

On a beautiful night in Atlanta (June 3), friends and family of Wayne Sawyer flooded into Smith's Olde Bar for a night of music, silent auctions, love and support for Shannon Kiss and her daughter Lily. Shannon Kiss worked tirelessly to assemble one of the most astonishing silent auctions to date! For the first time, auction items were photographed and put on facebook to encourage on-line bidding as well. A groundbreaking move in utilizing social media to increase philanthropy! Way to go, Shannon—it was fantastic, and we're looking forward to the 3rd annual Celebrate Wayne and Conquer SADS next June.



Go To Bat! – State Farm selects the SADS Foundation To Play!

State Farm has partnered with Major League Baseball to sponsor the Go To Bat program, and this year they have chosen the SADS Foundation to participate. All you do is go online and register to play a simple online game for the chance to help win a weekly donation of \$18,000 for the SADS Foundation and a trip to the World Series for two. The charity with the highest score at the end of each of 10 weeks, wins! Last year, State Farm donated over \$200,000 to several lucky charities.

Join in the fun, and Go To Bat! for the SADS Foundation: www.StopSADS.org and click Go To Bat.



SADS First Medical E-newsletter

The first volume of our new Medical E-newsletter was distributed via email last week and received a very positive response from readers. Medical E-newsletters will focus on innovative and up to date medical information surrounding SADS conditions and will feature an “Ask the Experts” article discussing hot topics that are relevant to our medical community. Medical e-newsletters will alternate with an expanded version of our literature review, a service that our healthcare community has valued tremendously. If you have topics that you would like to submit for Ask the Experts, please send your ideas to Christine at Christine@sads.org.

You can access the Medical E.newsletter at www.StopSADS.org – click the “For Professionals” tab.

New Guidelines on Genetic Testing for Heritable Arrhythmias

At the Heart Rhythm Society’s 32nd Annual Scientific Sessions, an expert panel of physicians and researchers, co-chaired by Michael Ackerman MD, Ph.D and Silvia Priori MD, Ph.D, presented new guidelines for genetic testing of SADS conditions. These guidelines are the beginning of a long-term look at genetic testing recommendations and best practices. The guidelines contain detailed recommendations for six channelopathies, five cardiomyopathies, out-of-hospital cardiac arrest survivors, and post-mortem testing in sudden death cases. Other elements of the guidelines include the need for proper evaluation of genetic tests via counseling by either the physician or a genetic counselor and the need for a more thorough investigation into sudden death in young people. This paper will be published later this summer.

New Study Identifies LQTS Risk

Risk for Life-Threatening Cardiac Events in Patients with Genotype-Confirmed Long QT Syndrome (LQTS) and Normal-Range Corrected QT Intervals (QTc).

This study was designed to identify risk factors for life-threatening events in patients with LQTS with normal QTc intervals. Genotype-confirmed patients with normal QTc intervals make up about 25% of the LQTS population. Genetic data, including

information regarding mutation characteristics, can identify those at increased risk in this overall lower-risk LQTS subgroup.

Visit www.StopSADS.org to see the complete study and the full literature review for the 4th Quarter 2010. Wish you would have heard about this sooner? Sign up for SADS e-newsletters to hear it first! www.StopSADS.org.

Help SADS Reach Medical Examiners and Coroners

Having a knowledgeable ME/Coroner is the key to having genetic material that will be preserved correctly for use later to determine whether the young person died of a SADS condition. We need your help to provide medical examiners and coroners around the country with this important information!

Here’s how you can help NOW:

1. **Find** the contact information for your local medical examiner/coroner via Google, your state health department, etc. We can help you get started; just give us a call or email Adrienne@sads.org.
2. **Send** the contact information to Adrienne@sads.org (or call 800-786-7723) so that we’ll have it on file when we need it.
3. **Visit** the local office with the SADS ME/Coroner Information Kit so that they will have the tools they need when a young person dies suddenly.

Working together we can help families who have suffered a loss find answers and support in their time of need.

Summer Swimming!

We hope you are all having a fun and safe summer! We know many of you have concerns about what activities are safe, and what should be avoided during the summer vacation. It is always best to follow your doctor’s advice, but we have included some facts and tips about one popular activity, swimming.

There are still many unanswered questions about swimming and how it can trigger an episode. Here are our recommendations for swimming safety:

- Always swim with a buddy who knows CPR.



- Consider carrying an AED with you to the pool or beach or make sure your pool has an AED on site.
- Make sure someone with you has a cell phone with service at all times.
- Consult with your Doctor about your type of LQTS and water. We know that with LQTS type 1 you should be especially careful in the water.
- If you do not let your child swim, be sure to explain why you are making that choice to keep them safe. And make sure they don’t feel like they are being punished or that it is their fault. Provide alternative activities that are fun, healthy and interactive for your child in place of swimming.

Enrolling Research Studies

Diagnosing LQTS in Utero

Bettina Cuneo, M.D., The Heart Institute for Children and Advocate Health Care in Chicago, IL is heading a fantastic study to increase our knowledge of the heart before birth. They can now diagnose LQTS before birth using a non-invasive test, called a magnetocardiogram that presents no danger to the mother or fetus; it does not use radiation like CT scans or x-rays. The optimal time is at 22-26 weeks of gestation.

Research in Philadelphia

Adults ages 18 years or older with a diagnosis of Long QT Syndrome (LQTS) are wanted for participation in a study about quality of life, thoughts, feelings, and behaviors relating to medical care, and emotional and social aspects of living with LQTS. Participation is ANONYMOUS. Participants will receive a \$10 gift card to a national retail store when questionnaires are returned. This study is led by Stephanie Felgoise, Ph.D., ABPP at the Philadelphia College of Osteopathic Medicine (PCOM).

Northern California Women with ICDs

Women ages 18 to 40 are needed to participate in a confidential study exploring the experiences of young women with an ICD. Participants will share their ICD story and contribute to a better understanding of the female ICD experience, which helps health care providers better meet your needs. Upon study completion, participants will receive a \$15 gift card. Researcher is Erin McKnew, M.A. at the Wright Institute in Berkeley.

Check www.StopSADS.org/Research and our enewsletters for new studies (a CPVT study is coming) and contact Anne at Anne@sads.org if you’re interested in participating.

SADS Young Investigator Award Winners Announced

The SADS Foundation was in San Francisco May 2-7, 2011 for the 32nd Annual Heart Rhythm Society Scientific Sessions. The meetings began with the SADS co-sponsored Pediatric and Congenital Electrophysiology Society (PACES) pre-conference seminar on cardiac channelopathies and sudden death.

The award in the basic science category went to Ahmad Amin of The Academic Medical Center of Amsterdam for his paper titled “Functional Variants in the 3’ Untranslated Region of the KCNQ1-Encoded Kv7.1 Potassium Channel Strongly Modify Disease Severity in Patients with Type 1 Long QT Syndrome”. The award for translational/clinical science category went to Peter Aziz of The Children’s Hospital of Philadelphia for his paper titled

“Genotype and Mutation Site Specific QT Adaptation during Exercise, Recovery and Postural Changes in Children with LQTS.” Congratulations to both winners for their outstanding efforts in cardiac channelopathy research.



Advocacy Update

SADS Foundation endorses and supports:

- Josh Miller HEARTS Act (H.R. 1377) re-introduced by Congresswoman Betty Sutton of Ohio again this year; establishes grants to place AEDs and train staff in schools across the country.
- Rural and Community Access to Emergency Devices Program: restore funding to this program.
- Teaching Children to Save Lives Act of 2011 being drafted by Congresswoman Lois Capps would ensure all students receive CPR/AED training prior to graduation.

Other activities:

- Joined the Coalition for Health Funding by signing onto a letter to ensure funding for public health programs.
- Participated in the annual Genetics Day on the Hill this past June in Washington, D.C.
- Continuing our leadership role in the Sudden Cardiac Arrest Coalition. One of our legislative/regulatory goals for 2011 is to support a system for Sudden Cardiac Arrest (SCA) surveillance to make SCA a reportable condition.

We will be watching these bills closely and will let you know when and how you can help. Keep up-to-date by getting e-newsletters and Action Alerts: www.StopSADS.org/signup

Capitol Hill Study Shows Importance of Electronic Communications by Constituents

According to a recent study, *Communicating with Congress: Perceptions of Citizen Advocacy on Capitol Hill* emails are effective with legislators. This study shows that the content is the most important factor when contacting representatives. By giving a personal message and voicing your opinion, you are leaving a lasting impression. So, keep up the good work and thank you to all our wonderful advocates for your dedicated efforts this season! Read more about this study: www.StopSADS.org/Advocacy.



Unique Gift Benefits SADS Foundation

Special jewelry you can personalize in memory or in honor of your loved one—and benefit the SADS Foundation at the same time. Our friends at Metal Pressions and Andreas Argentinis loved the help and advice they got from the SADS Foundation. Now they have agreed to donate 25% of all SADS sales back to our life-saving programs! www.StopSADS.org (click “Get Involved” tab)



SADS International

The SADS Foundation is proud to announce the first International SADS Booth at the Heart Rhythm Society's Annual Scientific Sessions in May, 2011. Check out the new “country flags” tab at the top of our web pages to view SADS groups in other countries.



Upcoming Events

Medical Seminars

Nashville, TN Aug. 18

Tolosky Saratoga Springs Races

Saratoga Springs, NY - Aug. 14

SADS Benefit Concert at the Bluebird Café

Nashville, TN - Aug. 18

SADS Safe Schools Month

September

Medical Seminars

San Antonio & Austin, TX - Sep. 7-8

6th Annual Ryan Weidler Golf Tournament

Norristown, PA - Aug. 8

“Where’s Bob?” in NYC

Cubs vs. Mets - Sep. 11

6th Annual Christie’s Heartoferfest

Ballston Lake, NY - Sep. 17

14th Annual Layton Oktoberfest

Colorado Springs, CO - Sep. 17

Medical Seminars

Connecticut & New York City - Sept. 23 & 24

“Tri” for Abbey Triathlon in memory of Abbey Wambach

Rockville, SC - Sep. 24

Sudden Cardiac Arrest Association

Minneapolis, MN - Sept. 23-25

SCA Awareness Month

October

SADS International Conference

Atlanta, GA - Oct. 1-2

SADS Family Seminar with NYU

New York, NY - Oct. 22

SPARQ  www



E-Newsletter Sign-Up

It's back-to-school season, are you ready? Click the code to see the SADS back-to-school checklist and make sure you're prepared. Don't forget September is SADS Safe Schools month—order a free kit for your child's school today!