



SADS Connect Youth and Teen Track

NEW at this year's SADS International Conference: by popular request SADSConnect will be hosting two separate tracks—one for youth over the age of 13 and one for youth under 13. These two tracks will be full of fun and information as usual, but the different age groups will benefit from sessions more closely tailored to their specific concerns. Don't delay—register today to reserve your child a spot in one of these youth programs!



7th Annual SADS International Conference

It's time to start making plans to join us for the 7th annual SADS Foundation International Conference in Columbus, OH on November 1-3! Ask anyone who has attended one before, they're worth the trip. Families will be able to interact with the world's experts, ask questions, and learn the latest and greatest about their particular SADS condition.

Full CME Day for Healthcare Professionals

New this year will be a full day of CME accredited courses for medical professionals

in partnership with the Ohio State University on Friday, November 1st. This will offer a unique opportunity to hear from internationally recognized specialists who focus on cardiac arrhythmias and to interact with other colleagues diagnosing and treating SADS conditions. This course will allow participants to ask questions of the world's experts on cardiac channelopathies and cardiomyopathies.

Register now and take a look at our impressive speakers and the innovative topics for 2013 at www.StopSADS.org.



Pedigree Project Has Grown Up!

Introducing SIRCh: SADS International Registry of Channelopathies

The Pedigree Project was started as a way to collect data from SADS members about their conditions and treatment, and to help them begin the process of informing their extended families about the risk of the mutation in their genetics. With the help of the NIH Office of Rare Diseases Research (ORDR) in collaboration with PatientCrossroads, Children Hospital of Philadelphia and WebMD, we have streamlined our database for our patients and will be sharing research data to help manage rare diseases on a global scale. Scientists and researchers all over the world will be able to

use the SIRCh Registry to help them complete important studies on Long QT, Brugada Syndrome, CPVT and other arrhythmias.

To log in to our new registry and begin participating in this lifesaving research, go to www.StopSADS.org and click on SIRCh to enter your data. If you have participated in the Pedigree Project in the past (over 500 of you did!), please log back in to update your info with SIRCh. For questions, contact Anne@sads.org or 1-800-StopSAD.



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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Thank You and Farewell

January 31st was my last day as the Awareness and Volunteer Director at the SADS Foundation. While working to finish my Master's in Public Health, I have chosen to pursue an opportunity in the private research sector.

Thank you, all of you, for sharing your amazing stories, talents and gifts with me and the SADS Foundation. My experience here has been truly unforgettable and I am a much better person for having known and worked with all of you. As I will always be an advocate for heart conditions, I hope to see you all again someday, in the meantime, take care.

With Love,

Adrienne Butterwick

Awareness.....



Me with my puppy, Nina, and Flat Bob.

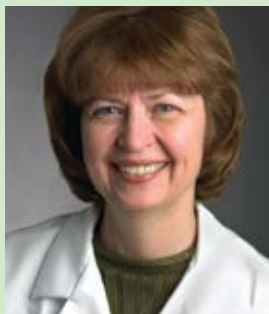
SADS Advisor, Dr. Charles Antzelevitch Presents Keynote Lecture

Dr. Charles Antzelevitch, Executive Director and Director of Research of the Cardiac Research Institute (CRI) at Masonic Medical Research Laboratory (MMRL) was honored with an invitation to present the Keynote Lecture



at the annual meeting of the Japanese Society of Electrocardiology. The symposium, attended by over 1,000 cardiologists, electrophysiologists and scientists from throughout Japan was held in Chiba, Japan on Oct. 12 and 13.

Please join us in congratulating SADS Scientific Advisor Dr. Victoria L. Vetter, who was awarded the prestigious Edward S. Cooper M.D. Award at the American Heart Association's Philadelphia's annual Heart Ball.



The Board of Directors and staff of the SADS Foundation want to thank Jackie Kaas-Vines for her wonderful service as the Board Treasurer. Jackie, we love you and miss you already!

Joanna Bewick, SADS Treasurer

Joanna Bewick is a portfolio manager in the Global Asset Allocation Group of Fidelity Management & Research Company (FMRC), the investment advisor for Fidelity Investments' family of mutual funds. She has been with the company since 1997 and lives in Boston, MA.



In addition to her financial background, Joanna has been an active volunteer for the SADS Foundation. Along with her sister-in-law Jodi, she has raised both awareness and funds. She is a certified SADS Ambassador having gone through the Ambassador training program this past October.

Ms. Bewick is honored to serve on the Board of the SADS Foundation and wholeheartedly supports and believes in their mission to raise awareness of heart rhythm abnormalities, support families and save lives.

New SADS Youth Advisor

The SADS Connect youth program would like to welcome Sarah Carlson as our new Youth Advisor.

Sarah is 19 years old and attends Arizona State University. She is a criminal justice and criminology major and is hoping to be in the FBI some day. Sarah lost her mother to LQTS and was subsequently tested and has LQTS types 1 and 3. She recently had an ICD implanted and now is training for a marathon and her favorite activity is hiking. Sarah is an optimistic and friendly young woman who wants to lend a hand to help other young people who are going through their own struggles and successes with SADS conditions. "Even though my life is definitely different than most college kids, I know that these events in my life changed me for the better. I am a very outgoing and kind girl and I would really love to talk to and give support to other teens and children who are going through the same, and similar things."

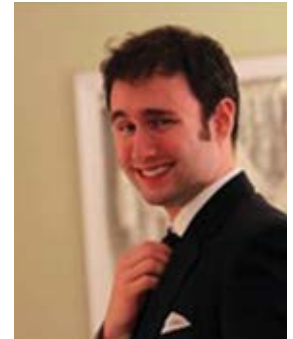


Grapefruit and Beta Blockers do not mix!

Grapefruit juice and the fruit itself is associated with increased side effects and complications when taken with certain medications. It can disrupt the way your body breaks down absorbs your medication and, more seriously, it can also increase your risk for adverse events when combined with certain drugs. According to a new article: Grapefruit-medication interactions: Forbidden fruit or avoidable consequences? by David G. Bailey, George Dresser and J. Malcolm O. Arnold, grapefruit when mixed with certain medications can increase the risk of Torsades de Pointe. In the past the SADS Foundation has recommended that you avoid consuming anything more than a small amount of grapefruit flesh or juice.

An Outstanding Volunteer

SADS Foundation would like to give a special thanks to Greg Totero for his amazing work helping us make our website beautiful and better! Greg is a diligent volunteer who generously donates his time and expertise going behind the scenes of StopSADS.org. Thanks Greg!



SADS Goes Virtual for National Heart Month

This year, we decided to make our National Heart Month campaign a totally virtual one! Not only are you saving trees, but it's much more efficient as you get the information you need and can get started right away. Hundreds of volunteers flooded their social media networks with messages and information about SADS conditions, warning signs and the importance of CPR and AEDs. Also a part of this month's activities was the Sudden Cardiac Arrest Coalition (SCAC) tool kit. This tool kit was used to encourage newsletter articles about SCA as well as specific items relating to Members of Congress.



As part of a larger initiative, the SCAC will be presenting a petition which has reached over 10,000 signatures, demanding AEDs and CPR be included in school curricula. Stay tuned for details on the SCAC and other important legislative issues.

SADS and Snyder Community Heart Watch

Keeping Kids Safe in Ohio

The Snyder Community Heart Watch is a group of dedicated and passionate health professionals at Fairfield Medical Center in Lancaster, Ohio. A few years ago they became very active with a colleague's daughter collapsed and was revived with CPR and an AED. Ever since then, the group has taken the task of raising awareness very seriously and has been working on an accreditation



program specifically to keep children safe at school. The program is up and running and was pleased to award the first Heart Safe School Accreditation to West Elementary School of Lancaster, Ohio.

A special thanks to Bob Williams and his talented team, the Snyder Community Heart Watch for all their hard work and dedication to this issue. We are very excited to expand this program even further as we move into SADS Safe Schools season this upcoming August and September.

Introducing the SADS Ambassadors

At the 2012 International Conference the SADS Foundation was proud to train over 40 new SADS Ambassadors on all the ins and outs of volunteering for SADS. These amazing individuals have all shown great dedication and efforts to the mission of saving young lives and we are pleased to have them now listed on our website. If you need some advice on volunteering, or have questions about events in your area, please check them out!

Also- if you are interested in becoming a SADS Ambassador and want to dedicate a few hours a month to raising awareness and supporting families for SADS, please plan to attend our 2nd Ambassador training to be held on Friday, November 1st at our 7th Annual International Conference being held in Columbus, Ohio.

In Loving Memory of Dwayne Chow

1981-2012

Dwayne was the beacon of light in our family. He was ambitious yet well-grounded; at a young age, he already had clear plans on how he would build his own business and ultimately give back to the community through charity. He grew up in Hong Kong and later moved to New York, where he graduated from New York University.

Although he lived on his own, on the night of 25 June 2012, Dwayne came home to our family house after dinner and spent some quality time chatting to me, his father and his sister, as we often do as a family before bedtime. He was going on holiday with his sister and his friends in two days' time and was happy and cheerful. We said our goodnights, and I remember giving him a big hug and saying "I love you" before leaving his bedroom.

On the morning of 26 June 2012, Dwayne never woke up, passing at the young age of 31. It was as heartbreaking as it was bewildering for everyone. As far as we knew, Dwayne was in good health and he had exhibited no symptoms of any diseases or any adverse health conditions. He led a happy and healthy lifestyle, was active and sporty, and he kept a good diet. In a split

second and for no discernible explanation, we lost someone so dear to our hearts and so important and irreplaceable in our lives. I held my son in my arms, cradling him like a baby, and all the years of memories flashed across my mind. The loss was indescribable and the pain was piercing, because his departure was so sudden and the finality of death was so absolute.

An autopsy was performed and no cause of death was identified. Genetic testing was conducted on Dwayne's heart tissue, and as a result we now understand that Dwayne had Brugada syndrome, one of the causes of SADS.

Throughout the past few months, whilst I grieve the sudden death of my dear son Dwayne, I also increasingly feel the purpose and significance of raising broader awareness of SADS in the Hong Kong community. In order to save lives and prevent similar tragedies from happening to other families, I believe much more can be done to support SADS research and generate public awareness.



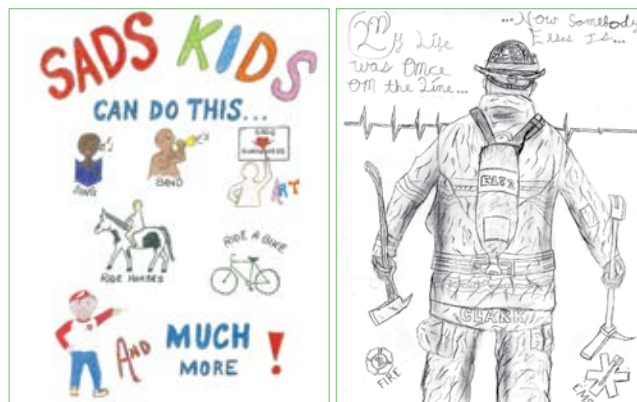
Dwayne's life was filled with hope and joy. We were, and will always be, so proud of him – his genuine nature, his soft spoken ways, his quiet assurance, his big smile, his zest to live life to the fullest and, most of all, his deep love and care for his family and friends. I hope that SADS Hong Kong Foundation can be Dwayne's legacy for the community, to which he had always wanted to contribute. I am so grateful to the SADS Foundation for their continuous support. The SADS HK Foundation will be officially launched in June 2013.

- Shirley, mother of Dwayne

Poster Contest Winners Announced!

This year's poster contest was a huge success! We had 6 amazing winners, who submitted some beautiful drawings which will be used on our website and in materials to raise awareness of SADS conditions! Congratulations to the top two winners:

Michael Clark from Edgewood, Kentucky and **Morgan McArthur** from Abilene, Texas.



NYU

SADS Foundation will be teaming up again with the NYU Cardiovascular Genetics team to host another Family Support Seminar in September, 2013. These well attended seminars provide the very latest in research on SADS conditions, treatment options, medical device info, and a chance to meet local families from the East Coast who have SADS conditions, just like you. Keep an eye out on our website and eNews for registration to open in July.

Roadmap

The SADS Foundation has created a handy document to help you cross off all the steps you need to take to ensure an accurate diagnosis, proper treatment, and a long happy life living and thriving with a SADS condition. The SADS Foundation works with people during all stages of their diagnosis, and we almost always find



at least one step that still needs to be completed on their path. Check out this tool and see if you and your family have every step checked off!

Have you gotten your copy of the roadmap? Visit StopSads.org.

Lemonade for Long QT

"Hi, I'm Lexie. I am 8 years old and I have Long QT Syndrome. Long QT is a heart problem, that makes me not be able to participate in some competitive sports and games. I'm a pretty normal kid, but I can't do some things.

Anyway, can you please donate \$1.00 for a glass of lemonade? All the money we get at the end of the day will help kids and adults who have Long QT like me. It could help them buy medicine, or find a cure.

Thank you for being so generous.

Love, Lexie"

This sweet note accompanied a donation to the SADS Foundation for just over \$50.00. Isn't that incredible? You rock, Lexie!



Lexie (right) and friend Emma at their summer lemonade stand

Jumpathon 2013!

You want to know what's better than one kid jumping rope to raise awareness and funds for the SADS Foundation? 600 of them! That's right – on Valentine's Day each year, the wonderful students at the Sheldon School in Dallas, TX, don their tennis shoes and warm up to get ready to JUMP! The Brian Price Jumpathon is one of the SADS Foundation's longest running fund-raisers, and has raised hundreds of thousands of dollars over the years. Thank you, Betty Glasheen and Kathy Martin for your ongoing commitment.



Young Philanthropist Pledges Allowance to Help SADS Foundation

At the recent SADS Foundation International Conference in Salt Lake City, young Miranda Dallaird, who has Long QT and lost her mom to Long QT in 2006, made a very special pledge.

After careful deliberation, Miranda joined the ranks of the new generation of philanthropists and pledged \$25 per month to help the life-saving work of the SADS Foundation.



Thank you, Miranda, for your gift. Every dollar truly does make a difference as we continue supporting families and saving lives! You are an inspiration.



Don't Let The Cold Stop You From Planning Your Summer Fun In The Chicago Area!

Enjoy great views of the lake, the city's stellar skyline and many thousands of other cyclists celebrating two-wheeled freedom at the Bike the Drive event on the beautiful Lake Shore Drive in Chicago, May 26! You can join the fun and raise money for the SADS Foundation at the same time.

Long-time SADS Foundation supporter, Sharon Lentino, is leading the charge to get at least 20 bikers involved so the SADS Foundation will be officially recognized as a Charity Partner of this exciting event. Please contact her for more details at: lenti-no1129@comcast.net.

No Ball at All – Justin Viker

If you know the SADS Foundation, you know that for 18 years we have saved the cost of hosting a big gala event and instead throw 'No Ball at All!'. The same is true this year – honoring Justin Viker, a young man who passed away at the age of 20 due to an undiagnosed SADS condition. Want to know how you can help? It's easy. Think of a list of friends and family members that you'd like to send an 'invitation' to – send Kate@sads.org a quick e-mail with your name and the person you're doing this in honor or in memory of – and we'll send the invitations to you!



Make a Gift Through Your IRA

The White House and Congress voted this year to restore a tax incentive for older donors who give through their individual retirement accounts. The popular "charitable rollover" provision allows people aged 70-and-a-half or older to shift up to \$100,000 from an IRA to a qualified charity without having to count the money toward taxable income. To discuss your planned gift, call Sarah at 801-531-0937.

Medical Education Program a Huge Success

The 1st Annual SADS International Conference was held in London in 2002. Last year SADS sponsored over 30 medical seminars, providing education to more than 1,200 physicians and core healthcare team members nationwide and we hosted a successful 6th Annual International SADS Conference in Salt Lake City, UT.

Institutions and educational groups have begun reaching out to the SADS Foundation to bring medical education to their facilities and also to find speakers for existing programs. If you are a physician or healthcare provider who would like to see SADS bring their educational seminars to your facility in 2013, please contact Christine Rice at Christine@sads.org.

We would like to thank Transgenomic Inc., Boston Scientific, Medtronic, and St. Jude Medical for their unrestricted educational grants which made these opportunities possible.

7th Annual SADS International Conference

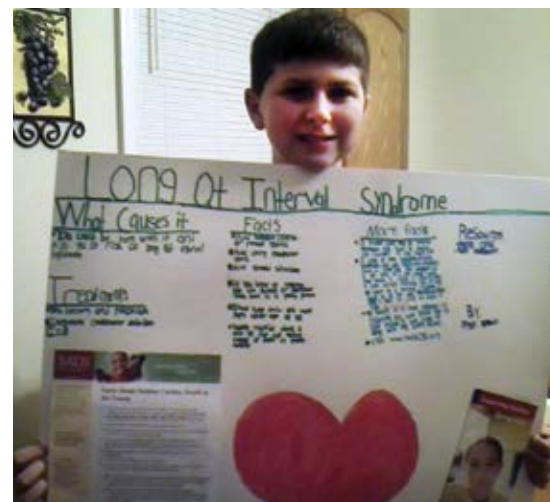
Full CME Day for Healthcare Professionals!

New this year will be a full day of CME accredited courses for medical professionals in partnership with the Ohio State University on Friday, November 1st. Additional details will be available soon, so check back on our website for more information.

Raising Awareness in Virginia!

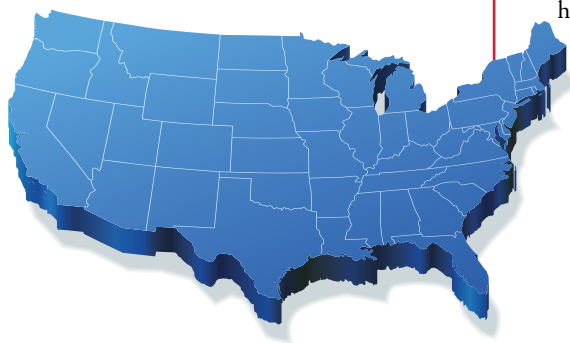
Ryan Kegley (left) of Fishersville, VA chose to do his 7th grade science fair project on Long QT Syndrome. Ryan has LQTS type 1 along with his sister, Alli. In addition to having a passion for science, Ryan also likes to play the drums, hunt, and fish. According to mom, Joy Kegley, "He learned a lot about his condition while working on the project." Not to mention, he's spreading awareness in a creative way! Way to go, Ryan!

Did your child do a school project about SADS or SADS-related issues? Send us the photo and short description and we'll feature it on the SADS Connect section of the SADS website. These stories help inspire other kids out there to help get the word out and create a great space to share ideas and other happenings.



Physician Referral Network – Now Online!

If you're seeking a doctor in your area, you can now log on to www.StopSADS.org to access our Physician Referral List. We have compiled a list of all our regional experts and electrophysiologists who treat SADS conditions, and listed them by state. Check it out to see if your doctor is listed, use it to find a referral for a second opinion, or refer you family to the list so they can go get screened by an expert! For questions and feedback- please contact Christine@sads.org.



Comparison of ICD Use for Primary vs. Secondary Prevention

In the December 2012 issue of *Circulation*, authors including SADS Scientific Advisor Dr. Arthur Wilde, et al., compare the use of an ICD for primary vs. secondary prevention in their article entitled *The ICD for Primary Prevention in Patients with Inherited Cardiac Diseases: Indications, Utilization and Outcome. A Comparison with Secondary Prevention*. The authors concluded guidelines on ICD implantation in patients with inherited cardiac diseases have been derived from observational trials.

They demonstrated that for some inherited diseases the efficacy of ICDs contrasts with the amount of harm, and that the

factors that formed the indication for ICD implantation do not relate to the occurrence of appropriate shocks.

This does not imply that ICDs should not be implanted in those patients, because the severity of SCD might outweigh the burden of ICD related complications. The absolute risk of ICD related complications outweighs the mere chance of any appropriate shock in BrS, LQTS and, so far, in DPP6. In patients with ICDs implanted for secondary prevention, there was no such discrepancy.

CDC Announces Plans to Gather New Data on Sudden Death in the Young

According to a notice given by the CDC, "Sudden death in the young (SDY) is a tragedy that affects children and young adults of all ages, making it a critical public health concern. Development of effective screening and prevention strategies is currently limited by the lack of prospectively defined epidemiological data, including incidence rates of specific causes of death (e.g., sudden cardiac death, sudden unexplained death in epilepsy).

To address this knowledge gap, the CDC and the National Institutes of Health (NIH) are developing a program to explore and provide greater understanding of SDY by developing a surveillance system and registry that will broaden and enhance the activities of CDC's Sudden Unexpected Infant Death (SUID) Case Registry. We expect many of the infant SDY cases to be a subset of the SUID cases."

Anesthesia-related Cardiac Arrest

In the November 2012 Anesthesiology journal article entitled Case Scenario: Anesthesia-related Cardiac Arrest in a Child with Timothy Syndrome, authors, Dr. Nathan, Dr. Antzelevitch, Dr. Montenegro and Dr. Vetter discuss the risk associated with the use of anesthesia in Long QT patients. Anesthesia is a known trigger for arrhythmias in Timothy Syndrome patients and the authors give a detailed account of a 9 month old child who underwent complications during a surgical procedure. The importance of an individualized anesthesia care plans is highlighted as well as the need for involvement of their electrophysiologist for all LQTS patients who will undergo a surgical procedure using anesthesia.

If you have an LQTS patient who will be undergoing a surgical procedure using anesthesia, please contact the SADS Foundation for a copy of this important article and share it with your anesthesiologist as you work together on your patient's care plan

Additions to the Drugs to Avoid List

On December 30, 2012, the FDA approved a new drug for the treatment of multi-drug resistant tuberculosis, bedaquiline (Brand name Sirturo®). Because the FDA-approved label includes a black box warning that it can cause QT prolongation, it's been added to the list of drugs with "possible risk of torsades de pointes".

Based upon the analysis of emerging evidence reporting QT prolongation, olanzapine has also been added to the list of drugs with "possible risk of torsades de pointes". The most common brand name is Zyprexa®, but others include Zidis®, Relprevv®, Olzapin®, Zalasta®, Zolafren®, Zypradhera®, and Ofertav.

For patients with congenital Long QT syndrome (CLQTS), recommend that, unless no other option is feasible, drugs on any of the QT drugs lists should be avoided. For this reason, bedaquiline also included on list of Drugs to be Avoided by CLQTS Patients.



Thanks to Scott Dailard- Secretary of the SADS Foundation Board, for representing the SADS Foundation at the reception to welcome Dr. Gary Gibbons as the new Director of the NHLBI.

Advocacy Update

NHLBI and CDC Announce Plans for a Registry of Sudden Death in the Young

Sudden cardiac death in the young (SCDY) is a tragedy that affects children and young adults of all ages, making it a critical public health concern. Development of effective screening and prevention strategies is currently limited by the lack of prospectively defined epidemiological data, including incidence rates and etiology (e.g., sudden cardiac death, sudden unexplained death in epilepsy). To address this knowledge gap, the National Heart Lung and Blood Institute (NHLBI) at NIH anticipates initiating a two-phase program to explore and provide greater understanding of SCDY. This will include a surveillance system and registry as well as DNA samples and will ultimately support scientific research. For more information: alice@sads.org or www.StopSADS.org.

CPR With Chest Compressions Alone Show Better Outcomes

In the 2013 Circulation article entitled Chest Compression Alone Cardiopulmonary Resuscitation Is Associated With Better Long-Term Survival Compared with Standard Cardiopulmonary Resuscitation, the authors findings provide strong support for long-term mortality benefit of dispatcher CPR instruction strategy consisting of chest compression alone rather than chest compression plus rescue breathing among adult patients cardiac arrest



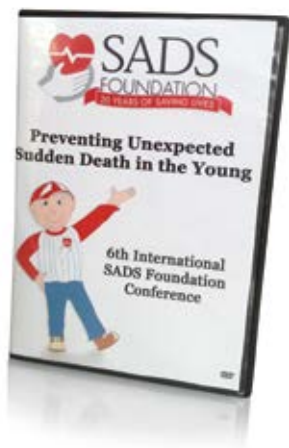
requiring dispatcher assistance. Emergency dispatchers have a vital role in resuscitation, and community stakeholders should leverage this important role to increase early arrest recognition and effective layperson CPR and, in turn, improve survival following cardiac arrest. Bystanders can proceed with the chest compression alone approach with the appreciation that this strategy on average provides optimal long-term survival benefit.

Sudden Cardiac Arrest Coalition (SCAC) Petition Gathers 10,000+ Signatures!

What a great way to start Heart Month! We met our goal of 10,000 signatures on our AED petition! A HUGE thank you to everyone who signed and shared with family and friends. This month we will be sharing the petition with elected officials and policymakers and asking them to fund programs that get AEDs into schools and public places. Our message is strengthened by your support!

Check www.StopSADS.org for the newsletter
to find links to the full articles and other
information from this newsletter.

SADS Foundation's International Conference DVD Nominated for a Grammy!



Oh just kidding. But if you are looking for hours of information straight from the world experts in Long QT and other SADS conditions, it is a definite must-see. You can order your complete set of all of the talks presented at the Conference for just \$49.95 + shipping. Visit our website at www.StopSADS.org and visit our on-line shop.

Upcoming Events

May 8-11 - Heart Rhythm Society Annual Conference - Denver, CO

May 12 - BA 5K in honor of Brian Anderson - Sewell, NJ

May 25 - Spring Lake 5 Run - Spring Lake, NJ

May 26 - Bike the Drive - Chicago, IL

June 1 - Celebrate Wayne in honor of Wayne Sawyer - Atlanta, GA

June 7 - Green Rive 5K Run in honor of Keith Young - Green River, WY

July 21 - SADS Charity Booth in honor of Christie Tolosky - Saratoga Springs, NY

July 22 - Ryan Weidler Golf Tournamen - Lansdale, PA

7th International SADS Foundation Conference:

November 1-3, 2013
Columbus Ohio