Spring Issue 2012
Supporting families. Saving lives.

SADS Celebrates
20 YEARS OF SAVING LIVES

To celebrate the 20th Anniversary of the Sudden Arrhythmia Death Syndrome (SADS) Foundation, we have planned an entire year of exciting activities! Dr. Michael Vincent, the founder of SADS, has taped a special message and is asking families from the past 20 years to get in touch with us and tell how they’re doing.

www.StopSADS.org/20th-Anniversary

Throughout the year we will feature birthday messages from individuals who have made a difference for the SADS Foundation in the past 20 years. We want to hear from you, too! Send in a short (less than 2 minutes) video wishing the SADS Foundation a happy birthday. Your video will be on SADS YouTube Channel and our website. They will also all premiere at the SADS Foundation 6th International Conference in Salt Lake City, Utah on October 12-14, 2012.

20 simple ways to celebrate the 20th Anniversary of SADS

1. Share your story on the SADS website
2. Order a free red kit to distribute in your community, class, office, etc.
3. Talk to your extended family about your SADS condition
4. Send “No Ball at All” invitations to all your friends
5. Tell us about volunteering for SADS and receive a pin
6. Give a presentation about SADS
7. Learn CPR or organize a group to learn CPR
8. Order your “Family History Kit”
9. Participate in a research study
10. Tell your story to your local paper
11. Sponsor a climber for Climb to Conquer SADS
12. Take a picture of an AED in your area with “Flat Bob”
13. Sign up for a SADS volunteer training to fine-tune your skills
14. Make a YouTube video to wish SADS a happy birthday
15. Participate in the youth poster contest this June
16. Attend the SADS 6th International Conference in Salt Lake City
17. Make a monthly pledge to the SADS Foundation
18. Attend a SADS event in your community
19. Enroll in SADS pedigree project
20. Recruit your schools for SADS Safe Schools Month

6th International SADS Foundation Conference:
Preventing Unexpected Sudden Death in the Young

October 12-14, 2012
Salt Lake City Marriott University Park Hotel
480 Wukara Way
Salt Lake City, Utah

Who should attend:
Electrophysiologists, pediatric cardiologists, pediatric electrophysiologists, cardiologists, nurses, nurse practitioners, school nurses, physician assistants, families living with a cardiac rhythm disorder (IDDs, Brugada, ARVD, HCM, etc.), families with a history of sudden unexplained death of a young person and anyone who has a special interest in cardiac rhythm disorders that predispose children and young adults to sudden cardiac death

Celebrating 20 Years of the SADS Foundation

SADSConnect at the International Conference:
Calling All Young People (ages 9 to 18)

Join us for the chance to meet and talk with peers, learn about your condition and how to care for yourself—for your whole life, AND fun outings and activities. Every year kids love attending and making lasting friendships. Don’t miss out!

New! Friday Sessions and Reception with Experts

Come early and see the sights with your family. Our hotel is close to the zoo, new history museum, Pioneer Park, botanical gardens and lots more. Plus, there is a free shuttle to downtown Salt Lake City.

Sessions will kick off on Friday afternoon with a SADS Ambassador training. Special groups (ICDs, Grief, Parenting Issues) will meet from 3-5 pm.

Then, meet and mingle with SADS families and our expert speakers at a reception Friday evening.
Check www.StopSADS.org for breaking news!

Conference Scholarships

SADS is offering a limited amount of need-based scholarships to help you get here! For information and an application visit www.StopSADS.org/SADS-International-Conferences.
SADS Goes Red in SLC

On February 3rd, 2012, volunteers joined SADS staff members for a special Utah edition of National Go Red Day. The day began at the SADS office with a mini advocacy training and refreshments and then we took to the state capitol sporting our SADS Red T-shirts! This year, the SADS Foundation continues to encourage CPR training in all high school curriculums as a graduation requirement.

Quick Poll Results: Drugs-to-Avoid List

Thank you to everyone who participated in the quick poll about the drugs-to-avoid list. Here are some of the quick poll results:

• 92% of participants reported checking the list for updates 1-2 times each year.
• 94% of participants reported having been prescribed a medication on the list of drugs to avoid.
• Most participants report the list as being helpful, but are also interested in a list of medications acceptable for patients with LQTS/Brugada syndrome to use.

If you have any questions about either the list of drugs-to-avoid or about this poll, please contact Anne Mauer at Anne@sads.org or 800-STOP-SAD. Also, it’s not too late to share your story about the drugs-to-avoid at www.StopSADS.org Drugs to Avoid page.

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SADS Red Kits a Huge Success!

The month of February was National Heart Month. We again promoted the overwhelmingly successful SADS Red Kits from 2011, adding new cards targeting pediatricians and emergency departments. We are proud to announce that this year we have had the largest number of volunteers ever! Over 1,500 SADS Red Kits have been distributed across the US for so far this year. We’ll be continuing to distribute kits throughout the year to order yours now. Thanks to everyone who participated in National Heart Month, you are truly making a difference in your community!

Genetic Counseling Essential to Understanding SADS Conditions

Heather MacLeod, M.S. G.C. - SADS Scientific Advisor

Getting a SADS diagnosis, or finding yourself at risk for one, is a confusing and often scary experience, but genetic counselors are specifically trained to support and educate your family through the process. Genetic counselors’ role in the evaluation of SADS conditions is to carefully review and document your personal and family history, discuss how a condition is inherited in a family, and explain the process and potential implications of genetic testing. Meeting with a genetic counselor does not mean you automatically have genetic testing: rather, the meeting gives you the opportunity to learn and decide whether genetic testing is right for you. The process of genetic counseling involves creating a 3-generation family tree for you and your medical providers, which results in a better understanding of how the condition may be inherited in your family and identifies which other relatives may be at risk. Your genetic counselor will also give you recommendations, based on your family history and/or genetic test results, for screening tests that will help protect your health.

Several cardiology organizations recommend genetic counseling for all patients and relatives with familial heart disease. This has improved insurance coverage for genetic counseling and testing. In October 2011, Cigna released a progressive policy update that requires genetic counseling prior to genetic testing for long QT syndrome. This new policy emphasizes the importance of a careful discussion about the genetic testing process that helps families be better prepared for the terms of diagnosis, screening, and treatment, and implications for the rest of the family.

A growing number of genetic counselors are specializing in cardiovascular disease and are experts in SADS conditions. Visit the National Society of Genetic Counselors site (www.nsgc.org) to find a cardiac genetic counselor in your area, or schedule an appointment for genetic counseling via telephone at 800-975-4819.

Highly Voted Nonprofit

Visit greatnonprofits.org to share your story about the drugs-to-avoid at Anne@sads.org or 800-STOP-SAD. Also, it’s not too late to share your story about the drugs-to-avoid at www.StopSADS.org Drugs to Avoid page.
In our last newsletter we had a story and a picture of little Lee Ciciarelli, a young boy with Timothy's syndrome. An Amish mother in Pennsylvania picked up the newsletter and she finally found an answer to an 8 year old question. Her son, Mahlon, had been genetically tested for a few syndromes, including Andersen Tawil, but always tested negative. He had gone into 2:1 heart block when under anesthesia for surgery to correct his syndactyly, or webbed fingers—a trait common in all Timothy’s Syndrome patients. He also had some episodes of falling over and seizures from low blood sugar. Mahlon’s family and doctors did not know what else to do—but knew something was not right with him. Once his mom, Esther, saw the picture of Lee in the newsletter she knew she was not alone and had found her answer. “The physical similarities were uncanny! I was so excited!”

Esther wasted no time and called the SADS Foundation right away; she wanted to speak to Mary Ann Cicirelli, Lee’s mom. The SADS Foundation had just received an email from Mary Ann THAT DAY, asking for any help she could talk to who also had a diagnosis of Timothy’s Syndrome. They quickly got them in touch and they were able to share their stories. “I wanted all this time to find someone! I finally have someone to talk to!” said Esther, with joy in her voice.

Timothy’s Syndrome is an extremely rare form of Long QT Syndrome. People with Timothy’s often have an extremely prolonged QTc, and syndactyly (webbed toes and fingers). The SADS Foundation, along with Katherine Timothy, is excited to be developing a much larger and comprehensive program for Timothy’s Syndrome—stay tuned to see how we grow!

Family Support

Brayden’s Buddy Golf Tournament – Phoenix, AZ

On a balmy, November Phoenix day, Claudia Tambone held her first ever ‘Brayden’s Buddy Golf Tournament’, bringing in nearly $10,000 in donations to the SADS Foundation.

Brayden Tambone is a happy and healthy kid who has Long QT. His parents started Brayden’s Buddy saying, “why wait if we can help save lives now?” They decided to start Brayden’s Buddy to save lives by donating AEDs to schools, get teachers CPR trained and support the life-saving work of the SADS Foundation. Thank you Claudia, Brian and Brayden for your amazing support!

Warning Signs for Timothy Syndrome

• Syndactyly (webbing of fingers and toes)
• Prolonged QTc
• Slow heart rate in the fetus or newborn
• 2:1 AV Block at birth or in vitro

Matching Gifts

One of the easiest ways to raise money for the SADS Foundation is to see if your company does ‘matching gifts’. Take, for instance, a recent donor who turned a $3,000 personal donation into $6,000 by having her company match her gift. We have friends around the world who fill out the simple form to double their money. Please visit www.StopSADS.org for a list of companies that do matching gifts. If your company isn’t one of them, ask them to start!

Heart Beaters

Every newsletter we feature an outstanding young person who is living and THRIVING with a SADS condition. They could have pulled off an awesome fundraiser, won the class spelling bee, created a science project about SADS, or anything else they are proud of. If you have someone to nominate for a HeartBeater, send it in right away! Please send submission, with a picture, to Anne@SADS.org.

SADSConnect Poster Contest: “SADS - What is it?”

Hey Kid! SADS is hosting our second poster contest and will begin taking submissions in June. Our last contest was incredibly successful. This year we are going even BIGGER! Create a poster with the theme “SADS: What is it?” We hope to make a poster you can take to your schools, doctors, the mall, anywhere you go that might need a little more awareness about the warning signs of SADS. We also will use the artwork for our new Kids brochure! The contest is open to all youth up to age 19. Besides the fame of being on SADS materials, you will win a special gift card! Begin drawing today and watch the SADSConnect website and enewsletter for more information or contact Anne@sads.org.

Development

Texas Events for SADS

A new tune floated above Salted Texas this February as former Metropolitan Opera star (and aunt to Brett Anderson who passed away from Long QT) performed a brilliant benefit concert for the SADS Foundation. Brett’s mom, Cathy Simon, was in attendance at this beautiful event. Thank you, Carol Willingham, for sharing your talents with us.

The Brian Price Jambalaya in Dallas, TX was a huge success bringing hundreds of Shelton School kids out on the gym floor to learn the warning signs of SADS while showing off their mad jumprope skills! Thanks, as always, to Kathy Martin and Betty Gladstein for your great efforts!

Brittany’s Trees for the 20th Anniversary of the SADS Foundation

Some stories get better each year, and a perfect example of that is the “Brittany’s Trees” event. Started several years ago with a hopeful 30 trees, this year the team in Carol Stream, IL surpassed their goal of 1,000 trees, were featured on Fox News and donated more than $11,000 to the SADS Foundation!

This year, we want YOU to host a Brittany’s Trees in your community. As part of our 20th Anniversary, we want to have at least 20 communities involved. We have a detailed guide for this event—watch the videos to see the real thing! Contact Laura to ask how: Laura@sads.org or 800-STOP SAD.

No Ball

The 18th Annual No Ball at All campaign for the SADS Foundation is featuring beautiful Abby Wambach who passed away at age 9 due to a misdiagnosed SADS condition. When you get your invitation, take a moment and tally up what you’d spend on a gown, a tux, flowers, tickets to a Ball, etc. and instead, hug your family and mail us a check. To receive additional invitations to send to your family and friends, just e-mail laura@sads.org.
Community Responds in Lancaster, Ohio

On Friday, February 10th and February 11th, the Lancaster community got the message from the folks at the Fairfield Medical Center. The Fairfield Medical Center hosted Dr. Michael Ackerman at their facility on Friday for a CME program, “The Vanilla Paint vs. Sudden Death Warning Sign,” with approximately 200 healthcare providers in attendance. We then met with the fantasti- tic committee chaired by Bob Williams as they discussed their plans for the future. On Saturday, we participated in a community event with over 100 community members including teachers, coaches, athletic directors, school nurses, parents, community members and more, entitled “Sudden Cardiac Arrest in Youth: What Every Parent Should Know.” Local physicians Dr. Gordon Snider and Dr. Douglas Pope joined Dr. Ackerman to lecture about warning signs and community involvement. Alice Lara spoke about the SADS Foundation and Clint Birkole, whose daughter survived a cardiac arrest and Matty Morrison, who also survived, told their story and helped encourage the community to get involved. Bob Williams and his team arranged for tons of media coverage including a radio program, a local NBC program interview and flyers and newsletter articles galore. Weren’t we thankful Bob and his Fairfield Medical Center committee enough? We’ll definitely be working with Fairfield again—stay tuned.

SADS Presents & Exhibits at the 2012 HRS Scientific Sessions

The SADS team will join leading experts in the field of cardiac arrhythmias and SADS conditions in Boston this May at the 2012 Heart Rhythm Society Scientific Sessions. The 33rd annual event will take place from May 9-12 and will showcase the latest science, discovery and innovation that are essential to quality care for patients. On May 9th, The SADS Foundation will partner with the Pediatric & Congenital Electrophysiology Society (PACES) to sponsor a pre-conference event entitled “Sudden Cardiac Death and the Rest of the Family.” Speakers will include several of our scientific advisors and Alice Lara, President and CEO, will also speak about the SADS Foundation’s resources for physicians and families. During the Scientific Sessions, the SADS Foundation will have 2 booth spaces in the exhibit hall (SADS US and SADS International) where we will distribute our materials and launch our “Flat Bob” campaign. We will also be hosting meetings of the SADS Scientific Advisors and the National Society of Genetic Counselors Cardiac Sig group. And, on Sat., May 12th, we’ll hold a family community meeting titled “Living and Thriving with the Risk of Sudden Cardiac Death” (FREE) featuring Dr. Susan Ehrhardt Michael Ackerman, Dr. Sam Sears and Dr. Kevin Heslin.

Published Research

RHCs Safe for ICD Patients

New research from Dr. Henry Halperin and a team at Johns Hopkins University indicates that patients with ICDs can now safely undergo magnetic resonance imaging (MRI) in models manufactured after 1998. Patients should then follow up within six months after having an MRI to have their device inspected.

New Way to Test Asymptomatic Family Members

New research shows that measuring the QTc after an exercise stress test is a good way to diagnose LQTS in family members.

Few Follow AHA Recommended Guidelines for Pre-Sports Participation Exams

A new study shows that less than 6% of physicians fully follow the national AHA guidelines. Of the more than 1,100 family doctors and pediatricians surveyed, less than half of the physicians and only 6% of athletic directors were even aware of these guidelines. Please visit www.StopSADS.org to view our Risk Assessment Form recommended for pre-participation sports exams, as well as regular childhood checkups.

Insurance Help and New Study

Med Ed Events – December 2011

The SADS Foundation is aware of the challenges you sometimes have obtaining health insurance and getting insurance to cover AEDs, genetic testing, etc. This problem has come up more frequently over the last 6 months and we are concerned. The SADS Foundation supports any legislation that makes insurance easier to obtain for our patients and increases benefits and reimbursements. We are also pleased to be sponsoring an upcoming study of the insurance system in the US and Canada. Visit www.StopSADS.org. Research page

If you have a specific concern about insurance, or want to share tips and advice for others, please contact Annie at Annie@sads.org or 800-STOP-SADS.

Medical Education Programs — SADS on the Road

Please contact Christine Fontaine at Christine@Sads.org if you want us to come to your area. Check www.StopSADS.org for upcoming seminars.

Cleveland and Lancaster, OH

Thanks to Dr. Ariz (Cleveland Clinic) and Bob Williams, RN (Fairfield Medical Center) for helping organize these events and to Transgenomic, Inc. and Boston Scientific for their unrestricted educational grants.

SADS Conditions Highlighted at Philadelphia District School Nurse Meeting

A special thank you to Jackie Henderson, RN, and Karen Simmons, RN from the Children’s Hospital of Philadelphia for speaking—again—on SADS Foundation’s behalf. For more information on school nurse resources, check www.StopSADS.org.

Advocacy Update: 2012 Focus

• Sustaining federal funding for the Rural and Community Access to Emergency Devices Program
• Chaining the national Sudden Cardiac Arrest Coalition (SCAC)
• Encouraging removal of language from AED cabins saying the use is intended for trained personnel only
• Supporting a new registry of sudden cardiac deaths in young people
• Sponsoring H.R. 1191: Teaching Children to Save Lives Act (Capps-Ca)
• Continuing support for the Josh Miller HEARTS Act (Sutton- & Brown- )
• Continuing support for the HEARTS Act of 2011/H.R. 36251 (Pallone-NJ)
• Supporting Good Samaritan Legislation including the Cardiac Arrest Survival Act of 2011 (Olson-TX)
• Continuing to participate in the Annual National Sudden Cardiac Arrest Awareness Month of October

Be sure to keep your eye out for action alerts so you can help us maximize our impact and make a difference for SADS patients and families nationwide!

Research Update

• Evaluating Young Women's Experiences with ICDs: study complete As Erin said, “Without the SADS Foundation, I am cer- tain I would not have been able to find the young women who took part in my study.”
• Empiric Quinidine for Asymptomatic Brugada Syndrome

This study is trying to determine if Quinidine will reduce the long-term risk of arrhythmic events in asymptomatic Brugada Syndrome.

• ICD Sports Safety Registry

will publish results soon! An abstract describing data on the 2-year results have been accepted for a poster (Opening Clinical Trial, and will be presented in early May at the Heart Rhythm Society meeting in Boston. Of the North American participants, half were “self-enrolled”, and the majority of these had heard about the registry from agencies like the SADS Foundation. Thanks to our SADS families for contributing valuable information to this research project!

For more information about these studies—and others (CPVT Study, etc.) and how you can participate, contact Anne Maurer, Director of Family Support at Anne@sads.org or 800-STOP-SADS.For more information about these studies—and others (CPVT Study, the ICD Sports Registry, etc.).
New Resource for School Nurses!

The SADS Foundation has been working with Linda Khalil of the NY Statewide School Health Services Center on an educational webinar for School Nurses about cardiac disease and risk prevention. We’re proud to announce the completion of this valuable tool which can be found on the SADS website under the “For Professionals” tab.

Celebrate 20 Years of the SADS Foundation

Pledge $20 each month to help us continue our work! Contact Laura@sads.org or donate online today: just check the box that says “Make this a sustaining gift (automatically repeat every month)”

SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research

To encourage the next generation of researchers in SADS conditions, the Sudden Arrhythmia Death Syndromes (SADS) Foundation is awarding the Fifth Annual SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research. Mr. Cleveland, a Texas philanthropist, and his widow, Sally Cleveland, have made this award possible through a generous gift to the SADS Foundation.

Upcoming Events

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<td>Heart and Soul Benefit Concert</td>
<td>May 19, 2012</td>
<td>San Diego, CA</td>
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<td>SADS Family Meeting</td>
<td>May 19, 2012</td>
<td>Washington, DC</td>
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<td>Community CPR Day</td>
<td>May 19, 2012</td>
<td>Lancaster, OH</td>
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<td>National EMS Week</td>
<td>May 20-26, 2012</td>
<td>Nationwide</td>
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<td>Spring Lake 5 Marathon</td>
<td>May 26, 2012</td>
<td>New Jersey</td>
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<td>Celebrate Wayne and Conquer SADS</td>
<td>June 1, 2012</td>
<td>Atlanta, GA</td>
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<td>(Wayne Sawyer)</td>
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<td>HCMA’s 15th Annual Meeting</td>
<td>June 1-3, 2012</td>
<td>Florham Park, NJ</td>
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<td>CPR/AED Week:</td>
<td>June 1-7, 2012</td>
<td>Nationwide</td>
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<td>Kick-Ball Fundraiser in</td>
<td>June 30, 2012</td>
<td>Springfield, NJ</td>
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<td>Memory of Stephanie Mejias</td>
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<td>Where’s Bob? Rays vs. Orioles</td>
<td>August 5, 2012</td>
<td>Tampa Bay, FL</td>
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<td>- Nationals vs. Marlins</td>
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