SADS FOUNDATION NEWS

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 a 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 Wakara 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 (LQTS, 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

Sudden Arrhythmia Death Syndromes Foundation
www.sads.org/Conference-2012 • 1-800 STOP SAD

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!

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!

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.

Sudden Arrhythmia Death Syndrome (SADS) Foundation
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Salt Lake City, Utah 84102
800-STOP-SAD or 801-531-0937
Fax: 801-531-0945
www.StopSADS.org

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 curricula as a graduation requirement.

Young Advocates: The Echols Family of Draper, UT

SADS Foundation Awarded Top-Rated Status on Great Nonprofits.org

The SADS Foundation has received the highest ranking status on www.greatnonprofits.org and we owe it all to you! Thank you for taking the time to post a review for the SADS Foundation on GreatNonprofits.org. Visit greatnonprofits.org/reviews/sads-sudden-arrhythmia-death-syndromes-foundation to read our reviews and post your own!

GREAT Nonprofits

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
- 54% of participants reported having been prescribed a medication on the list of drugs to avoid
- most participants reported 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 Maurer 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.

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 so far this year. We'll be continuing to distribute kits throughout the year so 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

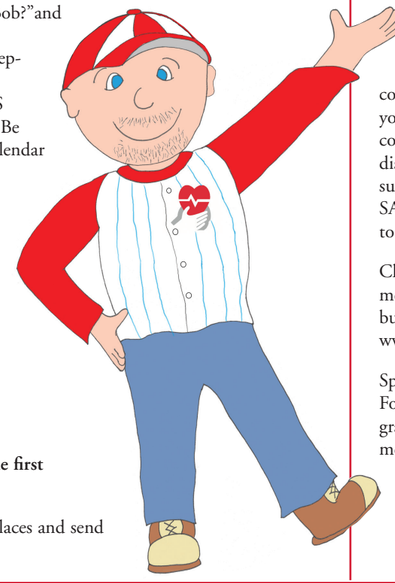
Getting a SADS diagnosis, or finding you're at risk for one, is a confusing and often scary experience, but genetic counselors are specifically trained to support and educate your family through the process. Genetic counselors' role in the evaluation of SADS conditions is to carefully review and document 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 SADS 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 diseases. 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 understand what test results will mean in 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 www.informedDNA.com or 800-975-4819.

"Where's Bob?" Is Back on the Road!

Coming off of a wildly successful year as "Where's Bob?"and attending the World Series' on behalf of the SADS Foundation at the MLB/State Farm "Go to Bat" reception, Bob DeVries has dusted off his baseball shirt and will again is touring the country, meeting SADS Families and raising awareness of SADS conditions. Be sure to visit our website to see the "Where's Bob" calendar of events and come join in the fun.



Meet Flat Bob

Our newest awareness campaign—take Flat Bob everywhere you go and take a picture with him to post on our website. You'll find Flat Bob is very helpful in raising awareness of SADS conditions.

Flat Bob Instructions

1. Print out Flat Bob: www.sads.org/Flat-Bob
2. Cut out Flat Bob
3. Take Flat Bob out on the town! **Stay tuned for the first assignment, coming in May.**

PS – Be sure to take a picture of Flat Bob in these places and send them to us (www.sads.org/Flat-Bob)!

DC Family Meeting on May 19th

This is an informal gathering for all those affected by a SADS condition. Meet other families, share your experiences and create lasting connections. At this first meeting, we'll discuss ideas/goals for future meetings such as raising awareness/advocate for SADS, or inviting medical professionals to come speak about SADS.

Children are invited and light refreshments will be served. The event is free but space is limited, so please RSVP at www.stopSADS.org.

Special thanks to Scott Dailard (SADS Foundation Board of Directors) for graciously providing his space for this meeting, as well as Andy Golden and Sandra Yesnowitz for organizing this meeting.

Ask the Experts

Wouldn't you love to ask a world-expert on Long QT and other SADS conditions a question? Here's your opportunity! In conjunction with the Mayo Clinic, the SADS Foundation is proud to announce the "Heart of the Matter–Ask the Expert" campaign. Log on to www.StopSADS.org and submit your question online. Questions are reviewed and will be answered either via video or will be posted to our 'frequently asked questions' section.

Timothy Syndrome—Connecting Through the SADS Newsletter

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 has 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 anyone she could talk to who also had a diagnosis of Timothy's Syndrome. We quickly got them in touch and they were able to share their stories. "I waited all this time to find someone! I finally have someone to talk to!" said Esther, with joy in her voice.

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

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!

SADSConnect Poster Contest: "SADS - What is it?"

Hey Kids! 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.

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.

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 AED's 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!


Dr. Mitchell Cohen & Brayden Tambone

Texas Events for SADS

A new tune floated above Salado 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.

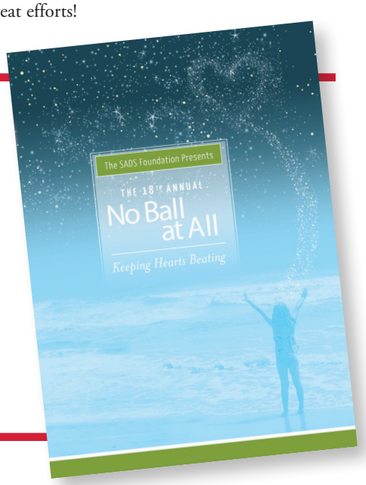
The Brian Price Jumpathon in Dallas, TX was a huge success bringing hundreds of Shelton School kids out on the gym floor to learn the warning signs of SADS while showing off their mad jumping skills! Thanks, as always, to Kathy Martin and Betty Glasheen for your great efforts!

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!

No Ball

The 18th Annual No Ball at All campaign for the SADS Foundation is featuring beautiful Abbey 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.



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.

Community Responds in Lancaster, Ohio

On Friday, February 10th and Saturday, 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 Faint vs. Sudden Death Warning Sign", with approximately 200 healthcare providers in attendance. We then met with the fantastic 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 Birkolz, whose daughter survived a cardiac arrest and Misty 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. We cannot thank Bob and his Fairfield Medical Center committee enough. We'll definitely be working with Fairfield again—stay tuned.

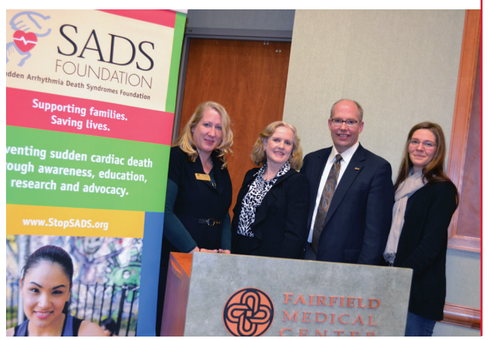
Dr. Michael Ackerman, Misty Morrison, Dr. Douglas Pope, Clint Birkholz


SADS staff, Dr. Ackerman and family members attending

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 8th, 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 "Living and Thriving with the Risk of Sudden Cardiac Death" (FREE!) featuring Dr. Susan Etheridge Michael Ackerman, Dr. Sam Sears and Dr. Kevin Heist.



Laura Wall, Alice Lara, Dr. Ackerman, Misty Morrison

Published Research

MRIs Safe for ICD Patients

New research from Dr. Henry Halperin and a team at John's 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.

Med Ed E-news – December 2011
(complete issue: www.StopSADS.org)

Medical Education Programs — SADS on the Road

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

Cleveland and Lancaster, OH

Thanks to Dr. Aziz (Cleveland Clinic) and Bob Williams, RN (Fairfield Medical Center) for help organizing these events and to Transgenomic, Inc. and Boston Scientific (Fairfield programs) for providing the SADS Foundation with unrestricted grants which made these programs possible.

Orlando, West Palm Beach and Miami, FL

The SADS Foundation participated in the Children's Hospital of Philadelphia (CHOP) annual conference in Orlando, FL. Thanks to Dr. Jorge McCormack, Dr. Grace Wolff, Dr. Patricia Sherron and Dr. Steven Lipshultz help in bringing these educational programs to their facilities and to Boston Scientific and GeneDx for their unrestricted educational grants.

SADS Conditions Highlighted at Philadelphia District School Nurse Meeting

A special thank you to Jackie Henderson, RN and Karen Smoots, 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.

Washington, DC

A special thank you to Dr. Charlie Berul for helping us pull together these important programs. Also thanks to Transgenomic, Inc. and Medtronic for providing the SADS Foundation with unrestricted grants.

Chicago, IL

Thanks to Transgenomic, Inc. for their unrestricted educational grant.

Boston, MA

A special thank you to Dr. Edward Walsh for helping the SADS Foundation bring a medical education seminar to Boston Children's Hospital. Thank you to Transgenomic, Inc. for their unrestricted educational grant.

Advocacy Update: 2012 Focus

- Sustaining federal funding for the Rural and Community Access to Emergency Devices Program
- Chairing the national Sudden Cardiac Arrest Coalition (SCAC)
- Encouraging removal of language from AED cabinets stating the use is intended for trained personnel only.
- Supporting a new registry of sudden cardiac death in young people.
- Sponsoring H.R. 3189: 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!

Insurance Help and New Study

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 actively 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 Anne at Anne@sads.org or 800-STOP-SAD.

Research Update

- **Evaluating Young Women's Experiences with ICDs: study complete** As Erin said, "Without the SADS Foundation, I am certain 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 be publishing results soon! An abstract describing data on the 2-year results have been accepted as a Late Breaking 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-SADFor more information about these studies—and others (CPVT Study, the ICD Sports Registry, etc.).

SADS FOUNDATION
508 East South Temple, Suite 202
Salt Lake City, UT 84102

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

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

Heart and Soul Benefit Concert (Sabrina Keller)
May 19, 2012
San Diego, CA

SADS Family Meeting
May 19, 2012
Washington, DC

Community CPR Day
May 19, 2012
Lancaster, OH

National EMS Week:
May 20-26, 2012
Nationwide

Spring Lake 5 Marathon
May 26, 2012
New Jersey

Celebrate Wayne and Conquer SADS (Wayne Sawyer)
June 1, 2012
Atlanta, GA

HCMA's 15th Annual Meeting!
June 1-3, 2012
Florham Park, NJ

CPR/AED Week:
June 1-7, 2012
Nationwide

Kick-Ball Fundraiser in Memory of Stephanie Mejias:
June 30, 2012
Springfield, NJ

Where's Bob? Rays vs. Orioles:
August 5, 2012
Tampa Bay, FL

Where's Bob? - double header - Nationals vs. Marlins
September 8, 2012
Washington, D.C.

Where's Bob? - double header - Orioles vs. Yankees:
September 8, 2012
Baltimore, MD

SADS FOUNDATION 20 YEARS OF SAVING LIVES

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)"

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.

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