



Screening—Who, When and How Should We Screen

With the SADS Foundation's mission to save the lives of children and young adults who have genetic heart conditions, the Board of Directors and Scientific Advisors met several times in 2009 to discuss screening and how we might make it more effective.

1. Experts estimate that 50% of the sudden death victims had preceding "warning signs." Therefore, proper recognition of these warning signs could significantly reduce the number of these deaths--overnight.

Recommendation: Screening **all** kids using the SADS Risk Assessment Form every few years (preschool, before/during middle school, before/during high school and before participating in organized sports). *Note: despite the emphasis on sports-*

related deaths, the majority (90% to 95%) of SCDs in young people are not related to participation in competitive sports.

2. When the sudden cardiac arrest was truly the individual's and their family's first event, there are only two ways to prevent their tragedy— rapid access to automatic external defibrillators (AEDs) and universal electrocardiographic (ECG) screening
3. We know that a single ECG done in your doctor's office is not diagnostic for many people.

Recommendation: Increase research funding for scientific and "real world" studies to determine the most effective and efficient methods of ECG screening.

The SADS Foundation strongly believes that our young people **deserve** screening to prevent these tragic deaths. We need to continue to screen for the warning signs, advocate for CPR and AED programs and support research for ECG screening.

AHA's New Guidelines for Sudden Death in the Young

The American Heart Association's newly published guidelines focus on two things the SADS Foundation has been recommending for many years: 1) guidelines for the autopsy of young SCD victims (our guidelines are in the process of being officially approved) and 2) comprehensive cardiological and genetic examination for the first degree relatives.

Keeping Hearts Beating Q2: Sports and Athletics

We're cruising right along with the Keeping Hearts Beating campaign! If you haven't joined in, you're missing out! Here's what we're focusing on in the second quarter.

We need volunteers to take posters to locations such as:

- Community recreation centers such as YMCA, etc
- Local gyms/fitness centers
- Sporting event/practice venues
- Community parks

Visit the volunteer resources page on our website to find a list of locations in your area.

In addition to this, SADS has issued an official AED letter of importance. This letter will be used to approach various athletic and recreational facilities in order to advocate for an AED policy. Visit the awareness page on our website to read the letter and find out how to contact facilities in your area.

To find out more or sign up to volunteer, e-mail Adrienne at adrienne@sads.org or call 1-800-STOP-SAD (1-800-786-7723). Awareness alerts will be sent out via e-mail with different events and volunteer activities that you don't want to miss!

Have you ever fainted while exercising?

Each year 350,000 Americans die suddenly and unexpectedly because their heart abruptly stops beating.

If you or your child has any of the following, contact your physician:

- Family history of unexpected, unexplained sudden death in a person under 50.
- Fainting (syncopal) or seizure during exercise, excitement or startle.
- Concomitant or unusual chest pain and/or shortness of breath during exercise.

Fainting is the most common symptom of a very deadly heart condition.

For more information on how you can protect yourself and your family, contact the SADS Foundation.

1-800-STOP-SAD
www.StopSADS.org

SADS FOUNDATION

Find the AED at your gym—they save lives!

Online Pedigree Program Is Ready!

Go online and "register" your family at <http://sads.innolyst.com>. The Online Pedigree Program is able to:

- Send information directly to family members to help with any problems they may have/had with screening and remind them of the importance of completing the screening process
- View other participant's answers (without any identifying information) about quality of life, exercise, and their experience with a SADS diagnosis

Call or email Joanne Robinson at Joanne@SADS.org or 800-786-7723 if you have any questions.

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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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Keeping Hearts Beating Q1

The first quarter was a great success —thanks to our wonderful volunteers! We had more than 100 volunteers distribute materials to libraries and other public places in almost every single state. We're excited about this success as we carry the momentum into the second quarter.

Here is a brief update on the happenings from Q1:

- Regina Pickett of League City, Texas, coordinated a SADS presentation to over 100 school nurses.
- SADS exhibited at the Utah State School Nurse Association's annual spring conference.
- Kelsey Houbeshel of Millersville, Pennsylvania distributed SADS material and information campus wide and even at the university board meeting.

- Volunteers took posters to ALL libraries in the state of Utah.
- Materials were distributed in Australia, England, Germany, the Netherlands, and Greece!

Now we're bringing the excitement right to you on our new awareness highlights page on the SADS website. Take a picture of you and your friends or family hanging posters, distributing materials, or sporting your Keeping Hearts Beating wristbands and we'll put it on the webpage. Who knows, your photo might even be in the next newsletter!

SADS International Conference in 2011

Watch for the return of our International Conference on the Prevention of SCA/SCD in the Young. Seminars and activities for physicians (and other healthcare professionals), families, young people, SADS volunteers, and more are being planned. We will announce the date, place and more details on our website soon!

Recognizing the Jaime Miller Invitational

Among the many outstanding community awareness events organized by SADS volunteers, we'd like to recognize the Jaime Miller Invitational held each June in Indiana. Thousands of swimmers, teachers, school nurses, coaches and families have learned about Long QT and the warning signs at this fabulous weekend full of sun, swimming and education.

Jaime Miller, for whom the event was named, died suddenly on January 3, 2006 due to Long QT.



SADS Quick Polls: Getting Results!

Have you noticed the SADS quick polls on our website and e-newsletters? We're asking questions and we hear your answers! Here are a few of the recent results.

Vote for a Wristband! The majority of people voted for a solid red wristband, so that's what we got! Check out the SADS store to see the wristband and make your order today.



Tech Savvy? 73% of respondents said they would prefer to see a video of SADS family and medical seminars if unable to attend. With this in mind, we'd like to announce that the New York family seminar in June will be filmed and featured on our website!

In The News

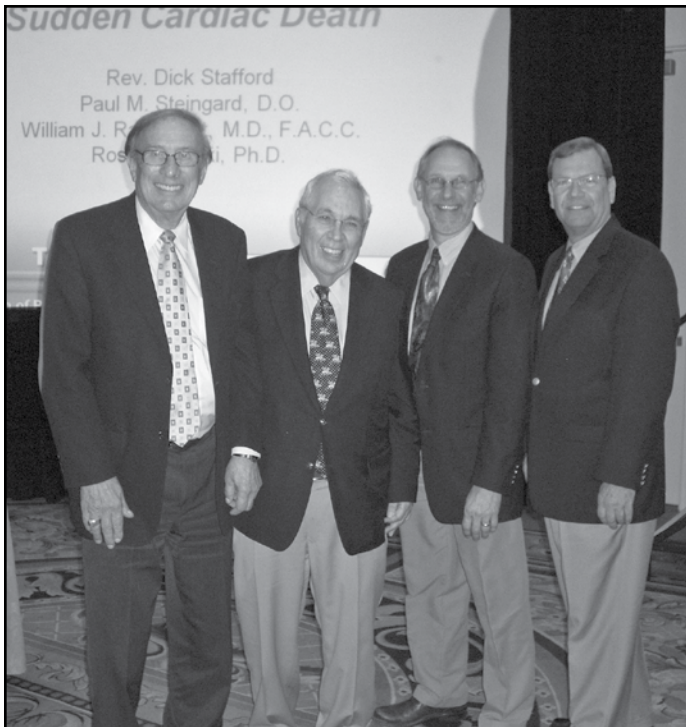
LQT patient, Emily Bioty, and her family were featured in an article in their local newspaper for their awareness-raising efforts. Jackson, MI.

Kathy Martin's annual fundraising event, The Brian Price Jump-A-Thon, was featured in a story in the *Dallas Morning News*.

An article on the ICD Sports Registry was in the February issue of *Sports Illustrated*.

SADS Foundation volunteer, Cindy Dollen, had an awareness article that she wrote published in the *Laurel Gazette*. Laurel, MD.

Local Network Contact volunteer, Dick Stafford, was a co-presenter on "Sudden Cardiac Death in Young Athletes" at the American College of Osteopathic Family Physicians annual meeting in Las Vegas.



In this picture L - R :

Dr. Bill Rappaport, Senior Cardiologist, Arizona Heart Institute

Dr. Paul Steingard, Sports Medicine (former team doc for the Phoenix Suns)

Dr. Ross Kosinski, Dean of Students Midwestern University (Medical School)

Dick Stafford, Long Q-T Family

Congratulations

Congratulations to Executive Producer Molly Smith, of "The Blind Side". "The Blind Side" was nominated for an Oscar and Sandra Bullock was awarded best actress! Molly's sister, Windland Smith Rice, passed away from LQT in 2005, and ever since, Molly and her family have been enthusiastic supporters of the SADS Foundation and strong advocates for SADS awareness. We're excited to see what's next in Molly's meteoric rise.



New & Improved! SADSConnect for Youth

Thanks to our Youth Advisory Panel for their help in revitalizing this project! Get to know them a bit here: www.StopSADS.org/. The program includes:

- A letter to youth from youth in the family packet
- Young Adult/Youth Contacts online
- Teen/Children Networking
- Website living and thriving stories by young people
- Youth focus at seminars & conferences
- Monthly youth day on SADS website discussion board

For more information on this exciting program, contact Joanne at Joanne@sads.org or call 1-800-STOP-SAD.

SCA Coalition Planning Events in Oct.

The Sudden Cardiac Arrest Coalition is planning two events this October in Washington, D.C. To kick off SCA Awareness Month, on October 5th, we will have a breakfast meeting at the National Press Club intended to boost awareness nationally and then a "Briefing on the Hill" at lunch to increase awareness among Congress people and their staff. Watch for more details!

Remembering Abbey

Abbey was a 10-year-old girl
Abbey was a beautiful, happy child
Abbey was an honor roll student
Abbey was a putt-putt player
Abbey was a joy
Abbey was Boo-Boo bear's mommy
Abbey was a moviemaker & a picture taker
Abbey was a game lover
Abbey was our daughter, sister,
granddaughter and friend
Abbey was a hula dancer
Abbey was the macaroni and cheese maker
Abbey was a Monopoly shark
Abbey was silly, sweet and funny
Abbey was a ballerina cosmetologist
Abbey was misdiagnosed with Epilepsy
Abbey was an aspiring hobo
Abbey was scared by a bee
Abbey was riding in an ambulance again
Abbey was sent to Levin Children's
Hospital in Charlotte, NC
Abbey was in Pediatric Intensive Care for
a week
Abbey was suffering complications from
Long QT Syndrome
Abbey was pronounced brain dead on
November 22, 2009
Abbey was...

Abbey is loved
Abbey is missed

www.rememberingabbey.com



Abbey's memorial page can be viewed at
<http://www.sads.org/memorial-pages/Wambach.html>

Establishing a memorial fund is a meaningful way to honor and remember your loved one while making a difference. If you would like to establish or contribute to a memorial fund, please contact Laura at laura@sads.org or call 1-800-STOP SAD.

Heart Beaters

Yasi Emamian

Yasi Emamian is a 14 year old 9th grader in California. After a three fainting episodes in PE when she was 7 years old, she was diagnosed with LQT.

Even though there were some initial adjustments, Yasi decided early on that her diagnosis wasn't going to define her, but instead contribute to who she was. She has received her varsity letter for golf, has a room full of medals and trophies for speech and debate, and is just starting the season for girl's softball at her school.

Yasi recently represented the "young teen" perspective on a panel for the SADS

Family Seminar in LA and has spoken to other audiences advocating for heart safety.

When Yasi was three and all of her friends wanted to be fairy princesses—she wanted to be a doctor. After being diagnosed that desire has increased, she is currently applying at the LA Children's Hospital summer program for students to gain exposure to the medical field. Wouldn't you love Yasi to be your doctor someday?!



Jordan Nichols

**Jordan S. Nichols Survives
Brush With Death From
Brugada Syndrome**

Jordan Nichols, a young, aspiring actor living between Memphis and NYC, survived a sudden cardiac arrest brought on by Brugada Syndrome (a SADS condition) in January.

Jordan, along with his family and friends, turned his near-tragic experience into an amazing benefit concert "From the Heart" for the SADS Foundation in Memphis, March 29. A sold-out crowd



attended the event at the beautiful new **Playhouse on the Square** where guests were treated to musical selections, dance and more in this first class production. More than \$9,000 dollars was raised. Jordan's incredible talent, wonderful voice and inspiring story made everyone grateful for the chance to attend and celebrate his full recovery.

Jordan's life was saved by a quick-thinking nursing student who immediately started CPR after Jordan's cardiac arrest. An AED was also used and, after being diagnosed, Jordan was implanted with an ICD. He is continuing to follow his dreams of performing on Broadway, and will serve as a spokesperson for the SADS Foundation, raising awareness of SADS conditions and saving lives!

Get to know our Youth Advisors

Here is a summary of some of our youth advisors' stories. To read their full story in their own words visit: www.StopSADS.org.

Jillian: I had a Left Cardiac Sympathetic Denervation surgery now I am running Division 1 cross country and track at LMU in California.

Chris - My life has changed some since the diagnosis. This condition has pushed my body and mind to places I never thought possible, and I feel stronger than I ever did before.

Sarah - I've been lucky in that I've been able to lead a very normal life since my diagnosis as long as I remember to take my medication!

Eliana - I discovered my love for horses—which has become a passion and a career for me. Although times have been tough, you learn how to see the beauty in life and other ways to enjoy it.

Continued on next page: YOUTH

Shawn Marie

On September 10, 2008 at 3:07 pm my wife Shawn Marie passed away at 35, from a previously undetected heart condition (ARVD).

Shawn Marie was full of life. She had a love for kids and animals. Shawn and I did everything together – every weekend was an adventure for us. One of the things we both loved was going to baseball games.

After Shawn passed the everyday routine of getting up and going to work was easy, the not so easy times were my free times. I found I was having a hard time finding stuff to look forward to – my life was just a routine. Then Shawn's cousin Jack gave me the idea to go to all the MLB ballparks in one season. This would give me stuff to look forward to while learning how to live life again. So I did it!

As the quest to get to all 30 ballparks was winding down I was asked over and over about what's next? I really didn't have an answer. Then on August 21st – my



official Fenway game which was ballpark #28, my story was picked up by a few local news stations in Boston and aired that night. Of

the many nice emails I received after the broadcast the one that stuck out to me was from Laura who works for the Sudden Arrhythmia Death Syndrome Foundation. Laura told me all about SADS and even though ARVD is not technically a SADS disease – its symptoms and dire consequences mirror one another.

So this upcoming summer I am on a Mission to help raise awareness about SADS as I travel the country again attending a game at all 30 MLB ballparks. I, with the assistance of the fine folks at stopSADS.org, have set up a memorial for Shawn Marie. My goal this summer is to raise \$10,000.

-Bob DeVries

Badgers Break \$100K!

This February 27th, Bill and Cheryl Badger have reached an incredible milestone – raising more than \$100,000 in honor of their little girl, Brianna, who passed away from SADS. The Badgers have hosted the Starry Night Gala every year since Brianna passed away. Now, with two boys and a new baby girl, they are hanging up the ball gown and tuxedo and have agreed to be the “No Ball at All” family in 2011. How perfect is that?!

YOUTH: Continued from previous page

Matt - I have taken up music, received an ICD, raced in the US national championships in 2002 for road bicycle racing, became a biomedical engineer, and work for Medtronic. Despite challenges along the way, I am still living a very enjoyable and happy life.

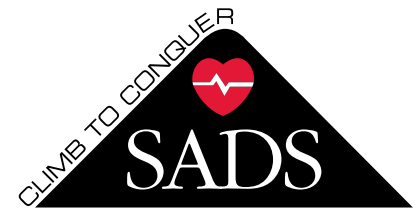
Greg - Being diagnosed with LQT has directed my interests towards medicine. It has also given me a perspective that puts many of the trivial problems of day to day life in a light that makes them seem much more insignificant and a lot easier to handle.

Anna, Diagnosed at 11: I have found plenty of ways to keep in shape and have fun! In high school I was the Assistant Coach of my cross country team. My diagnosis has also encouraged me to find ways to help others.

Elizabeth: Here's the short list of things I've done because my life changed course: pottery, rowing, horsebackriding, kayaking, hiking, drawing, painting, photography, theatre, a capella choral ensemble, travel, golf, running, rock climbing, guitar, piano, cooking, yoga, volunteering. I feel great and I am safe, so I have peace of mind. Mostly I think about all the fun stuff of life.

Climb to Conquer SADS

It's time to Climb to Conquer SADS again! Anthony and Kathy and the Lucatuorto family have agreed to be the National Chairs of this year's event. They will provide support, inspiration and all-around good information for any family or community who would like to sponsor a climber. Sign up today to be paired with your climber and start raising awareness and funds together. You can e-mail the Lucatuortos at lucatuor@optonline.net.



No Ball at All 2010

Have you gotten your invitation to attend “No Ball at All? Chairs Denise Falzon and Jackie Kaas-Vines would love for you to participate. To request your invitation, please e-mail laura@sads.org.



Best in America

SADS Foundation has been awarded the prestigious “Best in America” seal of approval by the Independent Charities of America. If you participate in the CFC (combined federal campaigns), be sure to look for us.



What is Your SADS Risk Profile?

In the same way that a diabetic knows their blood glucose number, SADS individuals should know the key factors that form their personal “risk profile” for the different SADS conditions. For Long QT Syndrome, for instance, those key factors are:

1. QTc number
2. type of LQTS – through genetic testing (LQTS 1, etc.)
3. where your mutation is on the gene (location, location, location)
4. symptom history, with particular emphasis on the length of time since the last symptom
5. age
6. gender

Knowing more about your personal risk profile--and your children's--can help you

make informed decisions about treatment options (i.e. ICD) and exercise and activity choices.

It is common to have individuals who are higher risk and lower risk in the same family. This is especially important when considering the family screening process. Adults who are older may not have a great deal of risk. However, they can pass LQTS on to one of their children who may have a higher risk profile. If that should happen, it is important to have that child identified as early in their life as possible. This is best done by genetic testing for your family mutation.

Help educate family members about the importance of genetic testing. If a family mutation is known, it could save the life of someone in a future generation.

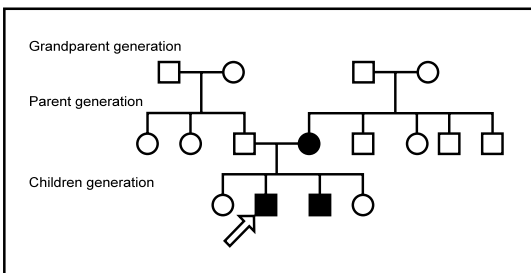


SADS educated over 100 physicians in the LA area in January and held a family seminar with Dr. Ackerman and Dr. Shannon and a fantastic Youth Panel. Thanks Joanne for organizing such a successful event!

Genetic Counselors – A Helpful Resource for SADS Families

By: Heather MacLeod, MS CGC and Amy Sturm, MS CGC

Did you know there are medical professionals who are specifically trained to talk about genetics and genetic testing? These medical professionals are called genetic counselors. Genetic counselors are trained in medical genetics and psychosocial counseling. They



are experts in assessing your family history, facilitating genetic testing and providing this information to you and your physician. Genetic counselors also help you understand how your SADS condition is inherited, and identify other family members who could benefit from screening.

Genetic testing for many of the SADS conditions became available in 2004. Since that time additional genes have been added to

the tests available and the number of labs offering testing has increased. Insurance coverage for genetic testing has improved and most families have good coverage for genetic testing. Be sure to check out both companies (www.StopSADS.org for links) to see what you might have to pay. Genetic counselors are helpful in working with insurance companies in this process.

Clinical genetic testing, if positive, is helpful in confirming a diagnosis. The results of genetic testing can also influence treatment. Further, if a mutation is identified in a family it can be used to screen other at-risk family members to know for sure whether they have a risk for a SADS condition or not—and whether their children need to be tested (their children are not at risk if the parents test negative).

In addition, genetic counselors can help you consider genetic issues before pregnancy, such as the risk of passing the condition on to your children.

In the past 10 years a new specialty in genetic counseling has emerged: cardiac genetic counselors. These are genetic

counselors who have specialized in cardiovascular genetics. Most genetic counselors are members of the National Society of Genetic Counselors (NSGC). The NSGC website has up-to-date member contact information. You can search for a genetic counselor in your area at www.nsgc.org under the Find a Counselor link. To search specifically for a cardiac genetic counselor select “cardiac” under area of practice.

Patient Assistance Programs for Genetic Testing

The two companies offering clinical genetic testing are now offering a \$500 limit on out-of-pocket expenses for people who have commercial insurance (with some limitations). They also will still assist you and your physician in dealing with your insurance company. Check out our website for contact information for GeneDx and PGx Health and make sure you know what the cost to you will be for your test. (www.StopSADS.org).

Participating in Research Studies

By Stuart Berger, MD

It is SADS' goal to prevent sudden cardiac arrest (SCA) and sudden cardiac death (SCD). In general, prevention strategies can be divided into primary prevention strategies and secondary prevention strategies. Primary prevention strategies imply that identification of those at risk (screening) will allow for an intervention that will prevent SCA. Secondary prevention strategies imply optimization of rapid and efficient intervention such that when an episode of SCA occurs, the intervention(s) will insure survival.

The most common and universally accepted primary prevention strategy is the "pre-participation evaluation" (PPE)—in not just athletes but the general popula-



tion of children and young adults. The PPE requires a careful and comprehensive targeted personal history, family history and physical examination as recommended by the American Heart Association (AHA). Additional screening with the use of ECGs is not recommended by the AHA. Several logistic issues must be solved including costs, manpower for evaluation of the studies, recommendation of appropriate normal values, as well as the variable incidence of false positives (and their implications and handling) before this recommendation can be adopted universally in the United States.

Secondary prevention is an additional important strategy in the prevention of SCD. Education of communities in the

rapid deployment of cardiopulmonary resuscitation (CPR) and the use of automated external defibrillators (AEDs) can save lives. Results of the adult public access defibrillation (PAD) trial, as well as multiple reports from casinos, the airline industry and schools suggest a survival advantage to CPR-AED programs compared to standard CPR alone. Such successes suggest that we should continue to advocate for this form of community education and that we should include our schools. The latter strategy has saved the lives of children and young adults as well as older adults.

SCA and SCD can indeed be prevented by a multiplicity of strategies, none of which are mutually exclusive. We look forward to much more work in the areas of advocacy and education as we go forward on our mission of life saving work. The future is very bright in the area of prevention.

Advocacy Update

In recent months, the SADS Foundation joined an alliance with the National Athletic Trainer's Association to address the youth sports safety crisis in America.

We signed a letter of support requesting Congress close the loophole to medical underwriting in the Senate Health Care Reform bill. These provisions allowed insurance companies to charge individuals with pre-existing conditions more.

We also added our name to a letter calling for increased funding for *HRSA's Rural and Community Access to Emergency Devices Program (AED)*. Thanks to the SADS Foundation e-news subscribers that joined our efforts by contacting their Congress members.

The SADS Foundation signed a letter to Congress requesting continued support for NIH funding, which is essential to sustain advances in science and the economic impacts of the research it funds. Special thanks to the many e-news subscribers that informed us that they contacted their representatives in support of continued funding.

In March, 2010, in a step forward for the integration of genetics into medicine, Francis Collins, M.D., Ph.D., Director of the National Institutes of Health (NIH), announced a voluntary registry for genetic tests offered by labs nationwide. The registry will be hosted at NIH, which will complete a broad consultation with prospective users and submitters before the registry is established.

Health Reform Bill—Benefits For SADS Families This Year

On March 29th, the "Patient Protection and Affordable Care Act" (PPACA) was signed into law. There are some immediate benefits that might affect SADS families this year:

- Young adults will be able to stay on their parent's insurance until age 26.
- Children (up to age 19) with a pre-existing condition will not be denied coverage.
- Insurers will no longer be able to cancel your insurance if you get sick.
- High-risk pools will be established for people with pre-existing conditions who have been uninsured for at least six months.
- There will be no more lifetime benefits caps.
- New insurance plans will be required to implement an appeals process.

Starting in 2014, the legislation requires guarantee issue and renewability of coverage and allows rating variation based only on age, rating area, family composition, and tobacco use. It also eliminates pre-existing coverage exclusions for adults and prohibits annual benefit caps.

Some other things that will affect research and the development of new medications are that the law requires insurance coverage during clinical trials, expands support for comparative Effectiveness Research and establishes an approval pathway at the Food and Drug Administration for generic biologics (with 12 years of exclusivity for the innovator product).



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Camps for SADS Kids

Camp Del Corazon in California (www.campdelcorazon.org/)

Camp Odayin in Minnesota (www.campodayin.org)

Camp Taylor in California/Hawaii (www.kidsheartcamp.org)

Pacer Camp in Massachusetts (www.childrenshospital.org/pacercamp)

Wired Together in Alabama (<http://www.childrensharbor.com/pdf/2010IllnessCamps.pdf>)

Camp Boggy Creek in Florida (boggycreek.org)

Other camps listed on our website: www.StopSADS.org (Living with SADS section).

What's New on the Web

You can always find updated information about our programs, events and purchase merchandise as well as make a donation on our website at www.StopSADS.org. Here are some of the things you can find:

- A new list of drugs to avoid for Brugada Syndrome;
- The 2009 4th quarter literature review
- New and updated Brugada and Long QT brochures;
- Information on the season and H1N1 flu and SADS conditions;
- A Spanish version of the Long QT brochure;
- FDA alerts about drug or medical device recalls
- A new SADS Foundation brochure;
- Awareness program spotlight

Upcoming Events

Brian Anderson 5k Run

May 9, 2010
Sewell, NJ

Heart Rhythm Society Annual Conference

May 12 - 15, 2010
Denver, CO

Keith L. Young Memorial 5k Run

May 22, 2010
Green River, WY

SADS Family and Medical Seminar

June 5, 2010
NYC, NY

Climb to Conquer SADS

July 8 -11, 2010
Seattle, WA

Run for Rosanna

July 24, 2010
Van Nuys, CA



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