



New Awareness/Prevention Program Introduction Coincides with Pennsylvania's First Long QT Awareness Week and Elicits Parent and Grandparent Response

Byron L. Goldstein, Community Relations Specialist and Independent Consultant

Abington School District is a high-achieving public school district just outside of Philadelphia. I brought the idea of promoting Long QT awareness to the attention of our school district superintendent and school physician and they said, "go for it." In conjunction with our partners at Abington Memorial Hospital and using materials from the SADS Foundation and those we developed, we introduced a program to generate awareness with parents and guardians, nurses, athletic coaches, teachers, and the medical community in our area. SADS Foundation Executive Director Alice Lara participated in the community awareness presentations, a press conference, taping of a segment for our local cable TV program, meeting with school nurses, and other activities.

Our pilot program, which we will continue to develop as a model for other school districts, targeted three areas:

- School nurses, teachers, athletic coaches, and other staff
- Parents and guardians
- Physicians and pediatricians and other health care professionals in conjunction with Abington Memorial Hospital

- The general community

The program included specific items such as:

1. **Informational letters to all Abington parents and guardians** that provided information about Long QT Syndrome and other SADS conditions and risk assessment questions we developed in conjunction with the SADS Foundation that parents should consider about their child's health and then discuss with their family physician.

2. **Increasing our school nurses' and teachers' awareness about Long QT Syndrome and other SADS conditions.** We made our staff more aware about Long QT to sensitize the staff to anything they might observe that might affect student health and learning.

The SADS Foundation is committed to supporting families and saving lives through awareness, prevention, family support, medical education, advocacy and research.

3. **Working with Abington Memorial Hospital** – to increase awareness of members of the medical community about SADS conditions so that they may better respond to questions parents may have.
4. **Communication with the PIAA (Pennsylvania Interscholastic Athletic Association)** – to recommend that they include specific screening questions on their questionnaire regarding Long QT and heart arrhythmias.
5. **Working with the local media** to increase awareness in the community about Long QT Syndrome and to publicize the steps Abington School District is taking on this issue. Several TV stations, the Philadelphia news radio station, and several newspapers attended and covered our press conference.

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RESULTS. The Long QT Awareness project is a pilot program and we anticipate that it will evolve further. As a result of the media coverage and parent materials, we have received a number of telephone calls asking for more information. We have heard from parents and grandparents whose family members may be affected with Long QT. We refer callers to their family physicians and to the SADS Foundation for more information. Several parents whose children have been identified with Long QT have initiated meetings with our school nurses and staff to develop incident emergency action steps. We have provided information to a neighboring school district that is considering the program for its families. We are planning a community information program with Abington

Memorial Hospital for next fall, and will hopefully be working with the SADS Foundation to develop a model and materials for other school districts in the country.

Our program has involved considerable coordination and work by many people. But we all agree that if we save but even one life, it will be well worth it.

Staff Changes at SADS

Stephanie

I joined the SADS Foundation in April as an intern. I was diagnosed with WPW Syndrome in 2003 and am thrilled to have the opportunity to promote awareness of LQT and other cardiac syndromes. I am a senior at the University of Utah and have background working in physical therapy, emergency medical services, youth corrections and public relations. It is wonderful to be part of a group with a noble and worthwhile cause.

Krissi Newton—The New Jenny

We are so excited to have Krissi join us as the new Program Associate. She has lots of experience working with kids and also nonprofit experience. She comes to us from Atlanta, GA and has just moved to Salt Lake to be closer to her mother and brother. We know you will love her Southern accent when you call the Foundation. (P.S. Jenny is still going to be with us—she will be taking over Sarah's job as SADS' Development Director.)

Good Bye Sarah

We are all going to greatly miss our Development Director, Sarah, as she leaves us to tend to her garden, take long walks with her dog and road-trips with her husband. Thanks for all the good times we've had with you and the good work you've done for SADS!



Nancy Adams Joins the SADS Foundation Board

Nancy's son Jesse died on May 21, 2003, of Sudden Cardiac Arrhythmia at the age of 21. Jesse was diagnosed with PVC's four years before his death during a routine sports physical while trying out for the High School Track team. We were told that Jesse's condition was in no way life threatening and he was permitted to participate in sports. Jesse died peacefully at home in his sleep.



She attended the 3rd International SADS Foundation Conference in Salt Lake City in 2004 and there met Katherine Timothy who enlisted her family in a Harvard Research Study. Nancy also attended and helped at the 4th International SADS Foundation Conference in Chicago in 2005.

Nancy Adams provides finance operations, business planning & analysis and accounting services to The Hope Heart Institute, a non-profit organization located in Seattle. The mission of The Hope Heart Institute is "to serve humanity through cardiovascular research and education.

We are very excited to have Nancy on our Board with her expertise in the areas of: Business Planning, Finance, Budgeting, Strategic Plan, etc. She will be a super advocate for SADS families by promoting cardiac arrhythmia research, funding, and education.

Volunteer organized events

Who knew SADS Foundation volunteers were such creative, organized, and committed people? Actually, staff had suspected it for years. But here's proof! Volunteer organized events are taking off. Contact Jennifer@sads.org for the scoop on upcoming events near you:

- Ryan Weidler Memorial Golf Invitational – July, eastern Pennsylvania
- PT Cruiser Drawing — August 21, national

Events you may have missed include:

- 2/14 – The Shelton School Jump-A-Thon (Dallas, TX)
- 5/21 – Cyndie Baker's Scrapbooking (N. Branford, CT)
- 5/26 – Tommy Marren Memorial Beef and Beer (Aston, PA)
- 5/14 — Brian Anderson Memorial Run (Sewell, NJ)



A great turnout for the Brian Anderson Memorial 5K run.

No Ball At All

In the SADS Foundation's tradition of (almost) painless fundraising, a capital crew of No Ball Dinner Committee members have joined staff to stamp and label invitations, cajoling their family and friends into buying tickets to No Ball XII – the most not-happening event of the summer. Results are starting to add up: more than \$15,500 has arrived thus far, all to fund family support, nurse and physician education, and community awareness programs. Please join us in a standing ovation for Committee members:



Scott & Kathi Blum
Janet M. Clarke
Jodi Engel
Denise & Christopher Falzon
The Gallinaro Family
Tom & Jennie Geisler
Monique Gribbins
Molly & Alex deGroh
Jodi Wilinsky Hill & Frank Hill
Chris & Sue Jensen Family

Denise Louise Larivee
Shirley McMillin
Darrell & Connie Ogden
Amanda Sandlin
Dr. Rebecca Schaffer
Mark, Nettie, & Bobby Simpson
Dick Stafford
Bernadette Thompson
The Traynor Family
Jon, Sheilah, Kimi & Jenny Woods

Matchmaking! Watch your donation double...

Please speak with your manager or human resources department about matching your donations with a corporate contribution. The list of companies that have recently matched employees' donations to SADS keeps on growing.

Bank of America
BP Foundation
CNA Surety
The Economist Group
GlaxoSmithKline
Leo Burnett Company
Merrill Lynch
MicroSoft

Oracle Corporation
PG&E Corporation
Prudential Financial
SBC/Sprint
Starbucks
TAP Pharmaceutical
Tenet Healthcare
Wachovia Bank

Adam Matthew Duarte

August 25, 1996-July 12, 2003

Adam was the best part of our lives. He was an amazing little boy and was loved by many. In the summer of 2002, he had his first episode. He had gone to a water park and we were told that he was climbing steps to get on a water slide when he fell, bumped his head, had a seizure and fainted. He was taken to the ER where a CT scan was performed. They said it could be a simple bruise from the fall, which could've triggered the seizure. Adam spent the night in the hospital in the Pediatric ICU. The following day an MRI was performed and we were told that it was a bruise and that with time it would go away. We took Adam home and took great care of him however it wasn't long before Adam had another episode. Once again Adam ended up in the ER, this time in a different hospital. Once again we were told that the bruise was still present and that he might experience more seizures until the bruise was completely gone. He was put on the anti-seizure medication, Depakote. However, he still suffered from seizures. He was in and out of the hospital. He always kept

his appointments, including those to the cardiologist for a heart murmur.

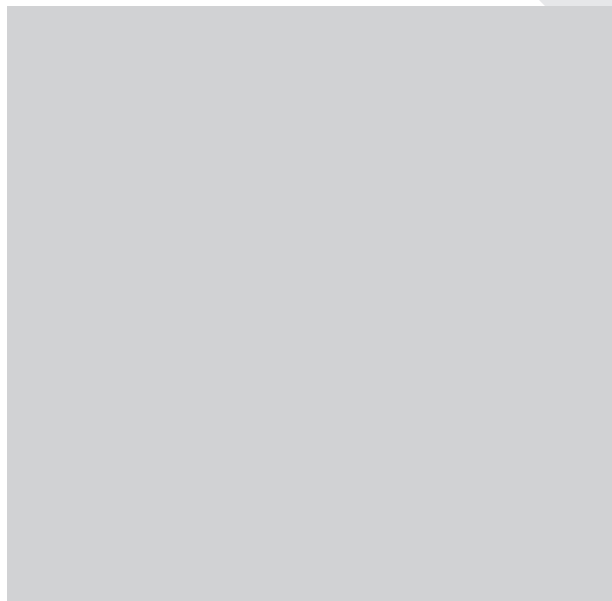
On Sunday June 29th Adam woke up and requested that we go out for breakfast. Adam loved to eat out. That morning we were happy. The family was together and everything felt perfect. After breakfast we decided to join some friends for a day at the beach. Adam

was running around wetting his feet when he told his mother he was going to come over to me, his aunt. I

remember he was running with open arms, happy, when he collapsed.

The lifeguard administered CPR, which was soon taken over by the Fire Department as they transported Adam to the hospital. Adam had fallen into a coma and was being kept alive through life support. Almost one year and four hospitals after his first episode, we were we told that Adam had prolonged QT syndrome.

He had suffered severe brain damage and could be kept alive however he would be in a vegetative state. We made the decision to take him off life support. On July 11th at 10:30pm Adam's oxygen was removed. The



morning of July 12th we were allowed to sit on a rocking chair and take turns rocking Adam as he slowly died. That night at 10:30pm Adam took his last breath.

Adam died at six years ten months and thirteen days. When Adam died a part of us died. Our lives will never be the same without him.

Adam loved all types of sports and animals. Adam was a smart boy and would say he would grow up to be a professional athlete or a fireman. It hurts that we will never see him grow into a fine young man. Adam is survived by his mother, his grandparents, and his aunt.

Stories

We want your stories! We can put any length story online at <http://sads.org/stories/index.htm>. We can also publish some of them in print (200-300 words). Please include photos of your child &/or your family.

Katy's Story

When I was 19 years old my younger brother Andrew died suddenly on his way home from summer school, and my life changed forever. I was seen by the cardiologists at Texas Children's Hospital soon after his death, and my diagnosis of LQTS was made.

The next few years of my life were spent trying to do all the things I wanted to do while fighting the constant side effects of the beta blockers. That has always been my biggest challenge. And in a major effort to stay in control of this frustrating situation, I became a nurse. While I don't work in cardiology, I have now been at Texas Children's Hospital as an operating room nurse for 10 years.

My husband and I decided not to have biological children in an effort to stop LQTS in our family. While this is not a decision that I advocate for everyone, it has been a blessing for us. We brought our adopted daughter home from the hospital when she was two days old, and we haven't looked back since!

Losing my brother made me keenly aware of how precious life is. With the encouragement of my family and the strength of my faith, I am trying to find joy in this journey, and make every day count.



Congratulations to Katy Moore who starred in the leading role of Anna Leonowens in the King and I. The show ran in April at the Miller Outdoor Theatre in Houston.

Jaime Spreads Awareness

Jaime Miller was on a mission: inform the community about the disease that nearly took her life at age 15. Many thought this mission would die when Jaime passed away suddenly on January 3, 2006, but thanks to the organization of the Donner Jaime Miller Invitational; Jaime's dreams are still alive.

Jaime's Long QT was discovered in a most unfortunate situation. While competing in the 50 yard freestyle at the high school sectional meet, Jaime was in leading the race when she suddenly slowed down. Jaime sunk to the bottom of the pool. When she was pulled from the water, it was thought that her heart was not beating since doctors could not find a pulse. After she was revived, it was determined Jaime's heart was beating so fast—up to 400 beats per minute—that her pulse was undetectable. This is when she was diagnosed with Long QT. Doctors told her she could not compete in competitive sports.

Even though Jaime could not compete, she still remained

physically active. Jaime got involved in coaching swimming and teaching fitness classes. And that is when her mission to inform started.

Jaime lived for 12 years with Long QT. She died suddenly on January 3rd this year.

The swim meet took place June 2-4, 2006, and was a truly magical event. Words cannot describe the comfort and peace the Miller family and Jaime's friends felt through this event. We truly came through on Jaime's wish of informing the public about Long QT. From our donation boxes alone, we raised \$500! We reached over 600 swimmers and their families. Countless

people came up to us and shared their Long QT stories, asked if their child should get checked for Long QT, and thanked us for bringing this disease to their attention. We passed out information to parents, teachers, school nurses, doctors, and caring friends and family.

Jaime was definitely smiling down on the Donner pool this weekend. We look forward to an even better meet next year!

Sarah E. Sullivan



Jaime's sister Melissa Dondlinger, Brittany Miller, Sarah Sullivan enjoy the Donner Jaime Miller Swim Meet

Media, Media, Media for SADS Awareness Month in September

The response from Primetime was fantastic and we thank all of you that contacted your local media. Because of this success, media exposure is the primary goal of this year's awareness month this September.

We are preparing media kits to be delivered by you directly to your media of choice and have instructions on how to best reach the media. Look for more information on our website www.sads.org.

Our second awareness month goal is to have September named as official SADS Awareness Month in each state. A few states, counties and cities have already accomplished this and we are thrilled. Information on proclamations to name September as SADS Awareness Month is also available from the Foundation.

In addition, we are pursuing a federal initiative to name September as National SADS Awareness Month. We are also try-

ing to get an article in a national woman's magazine that will utilize a version of the SADS Risk Assessment as a self-test to make parents more aware of their children's risk for sudden death. If anyone has any contacts at one of the national magazines like Good Housekeeping, Woman's Day, Real Simple, etc.—please let Stephanie know (Stephanie@sads.org).

Of course the school nurse program will continue in September. We hope to recruit more volunteers to work with schools in their community and to encourage the addition of the questions from the Risk Assessment Form to all physical examination forms.

If you would like to participate in SADS Awareness Month this September, please let us know by filling out the form at www.sads.org/awareness/ideas.htm or by calling 800-786-7723.

Update on the School Nurse Campaign

Big thanks to everyone who has volunteered to participate in the school nurse campaign! David Yancey, the Intern working on this project, has spent the past 3 months getting us up and running. 120 people have contacted us—and more are being added every week. So far 2,621 school nurse, teacher, and coaches packets, 3,340 posters, 1,274 Long QT brochures, and 4,470 SADS brochures have been requested. We are working hard to get the material mailed to everyone. It's not too late to add your school or school district to our list! Over the summer we will be evaluating the program and making any necessary changes in order to begin again in the fall. Please sign up at www.sads.org/School/schmatlsrequest.html or contact us at sads@sads.org if you are interested in participating.

SADS Airs on Primetime

On Thursday, April 6, ABC's Primetime Live aired a show on health stories including one on the Long QT syndrome. We were very pleased with the piece and the increased awareness as a result of the media exposure.

Over 35 volunteers contacted local media to request a follow-up story. ABC 4 in Utah featuring Dr. Michael Vincent, Karen Doust and her son, Peter Doust. ABC-40 in Springfield, MA interviewed members of the Tolosky family. A feature ran in Fort Wayne, IN on D. Renfro. KOMO TV News in Seattle, WA interviewed Nancy Adams and Kayla Burt. Sally and Bill Layton were featured on KRDO in Colorado Springs. Articles also ran in the Orange County Register and the Hawkeye in Burlington, Iowa.

Recently, the Chicago Tribune featured a story and KOMO TV News in Seattle, WA featured a second, longer interview. Following the Primetime broadcast we received hundreds of emails and phone calls. We are very pleased with the response and hope the inquiries continue.



QT Drug List Updates

QT Drug Lists - Added:

List 2

- Clozapine (June 30, 2005)
- Ranolazine (Feb 23, 2006)

List 3

- Tolterodine (Detrol and Detrol LA) (March 1, 2006)



SADS office volunteer, Annalee Diston, making packets that people requested for the school nurse campaign.

Volunteer Opportunities at SADS

A big thanks to everyone that has volunteered with us over the last few months. Your help has been invaluable. We have several big projects planned for the second half of the year and will continue to need your help.

We have received a tremendous response to our school nurse awareness campaign. Please see page 6 for details. We need assistance putting together packets to be distributed. If you are available to stop by our office for a few hours, please contact us at sads@sads.org or 531-0937.

Awareness Month is coming up in September. Please see page 6 for more details. We will need everyone's help to make it a success. Please contact Jenny at Jennifer@sads.org for information on how to get involved.

We have two seminars planned for the end of the year. The first will be held in Boston and the second in Chicago. We need volunteers in those areas to help coordinate these seminars and fundraise. Please contact krissi@sads.org for details on how to join these committees.

www.sads.org

SADS has some new scientific articles on our website relating to genetic testing.

“The Role of Genetic Testing in the Diagnosis and Treatment of Long QT Syndrome.”

This is the newest article, by Dr. Susan Etheridge, that discusses some of the things we have learned since the clinical genetic test was released in 2004.

<http://sads.org/Genetics/genetictesting.htm>

“Genetic Testing for the Congenital Long QT Syndrome” outlines who should be tested and how to get tested. It also includes information about compiling your family health history.

<http://sads.org/Genetics/Clinical%20Testing.htm>

“Testing—How to Navigate the Maze” discusses the differences between clinical genetic testing and research genetic testing.

<http://sads.org/Genetics/genetics.html>

Scientific Articles Resource Page includes several other articles about genetic testing.

<http://sads.org/Genetics/resources.htm>

Heart Rhythm Society 2006

Jenny and I had a very productive and busy time in Boston this year:

- meeting with volunteers to begin planning for the Boston SADS Seminar (in Sept)
- working with the Task Force on Sudden Death in the Young to plan a consensus conference for 2007
- meeting with SADS Scientific Advisors and learning about the new research that will affect SADS' families
- discussing a possible new SADS national event for 2007
- talking with attendees who stopped by our booth.

Watch for more about what we learned and what we are planning in the SADS E.Newsletter (To sign up for our e.newsletter, click on the “Take our SADS Survey” box at www.sads.org).

Thank you to Peggy Kempton, Becky Valentine, Bob Magner, Erica Perry and her sons, SueBeth Brown, and Rebecca and Frank Schaffer for their help at the booth. It was great to see everyone!

Results of the ICD Survey

In the last issue of the newsletter, as part of our expanding role in covering ICD news and in advocating for ICD patients, we asked members with ICDs to complete a survey on their experiences. We received more than 60 surveys—that included more than 58 adults, more than 17 children and more than 28 other family members with ICDs. The average age of the children was 12 years. Of the

surveys we received, more than half have had their ICD fire. Approximately 20% have experienced problems with their ICD ranging from recalls to fractured leads to multiple problems. We are continuing to collect information from our members. If you are interested in completing a survey, please go www.sads.org and click on the survey box or call us at 1-800-786-7723.

SADS Seminars in 2006

We are trying something new this year with SADS seminars—we're expanding our traditional 2-hour seminar to be more like a mini-conference. The seminar in Atlanta in March included about 10 school nurses and lasted more than five hours—including lunch. The seminars in Boston and Chicago will also include sessions just for kids (like at our International Conference). The Boston seminar will also include paramedics and EMTs as well as vendor tables with AEDs. The Chicago seminar—still in the planning stage—will have sessions about specific conditions that can cause sudden death in the young and may last a full day. Watch for more information on our website and in our E.Newsletter. (To sign up for our e.newsletter, click on the "Take our SADS Survey" box at www.sads.org).

Saturday, September 17th, 2006 SADS Seminar in Boston, MA

November, 2006 SADS Seminar in Chicago, IL

SADS Foundation Needs You

Participate in SADS Awareness Month.

Fill out a form at www.sads.org/School/schmatlsrequest.html or call 800-786-7723

School campaign in your schools.

Fill out a form at www.sads.org/awareness/ideas.htm or call 800-786-7723

Kids age 11 to 19 help plan special website and seminars.

Contact Krissi (krissi@sads.org) or call (800-786-7723)

Work on SADS Seminars in Boston, Chicago and Denver

Contact Krissi (krissi@sads.org) or call (800-786-7723)

Fund Raising Event for SADS.

Find forms and information at <http://www.sads.org/Development/main.html> or contact Jenny (jennifer@sads.org; 800-786-7723)

National women's magazine contact(s)

Contact Stephanie (stephanie@sads.org)

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