



Atlanta Conference a Success

"The conference...so greatly exceeded my expectations that it gives me goose bumps. I can't thank you enough, and everyone else involved for providing it for us... It means a lot to both Ken and me to have gained so much information and understanding and that helps fill those sad holes in our hearts. The people we met will always be an encouragement that we couldn't possibly get any other way."

- Wendy Mitchell



Panel of physicians take questions during lunch meeting in Atlanta.



Marsha Elixson, R.N. (Children's Healthcare of Atlanta), Alica Lara (SADS), Dr. Michael Vincent (SADS), Dr. Peggy Strieper (Children's).

The Atlanta conference was an incredible success. More than 100 family members, young and old, attended. Medical presenters distilled LQTS and SADS-specific information using non-technical terminology to provide in-depth information about these conditions. Attendees enjoyed

interacting and exchanging stories and advice among themselves as well.

Friday's sessions generated feedback for Foundation staff about ways to involve volunteers more effectively; projects volunteers were interested in implementing; and program

needs of families. Staff presented the Foundation's new SADS warning signs, which are fainting or seizure; family history of young sudden death; or unusual chest pain or shortness of breath during exercise. Volunteers talked about projects to expand school athletic physicals to include screening for Long QT or other forms of SADS and to increase AED awareness and use.

Presentations on Saturday began with an in depth look at the heart's systems, and continued on to provide family members with a clearer understanding of the challenges of diagnosis and the individuality of treatment. Presenters underscored that a longer than average QT interval is often not Long QT Syndrome. An ECG alone cannot provide an adequate diagnosis, and may indeed provide a false sense of comfort. To adequately diagnose Long QT Syndrome, a good family medical history is absolutely critical. Faints, drownings, and accidents that might have resulted from a loss of consciousness in the family are all important clues.

Automatic external defibrillators (AED's) were much in discussion, and several were on display at two tables staffed by Phillip's distributor, Education for Life and by Doug Kalmbach, a volunteer firefighter. Physicians pointed out that while AED's located in schools and other public places are life-saving devices, it is critical that people know where AED's are located and how to use them. There were several sad stories of people having a cardiac arrest near an AED, but nobody knowing where it was or how to use it.

SADS Foundation staff has begun planning next year's conference, probably somewhere in the western United States. Stay tuned for details.

See related story pg. 5.

3rd International SADS Foundation Conference

August 27- 28, 2004
Salt Lake City, UT
www.sads.org

More kids programming, CPR with AED training an option and other exciting topics.

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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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Gwen Davis Joins Us as Program Director

My first introduction to the SADS Foundation was last year at Dr. Vincent's office when my two children and I were identified as having Long QT. It explained many unanswered questions. My background is in the arts. I ran my own business for many years, allowing me opportunities to work in a variety of capacities. I joined the dedicated staff of SADS in October and I have been amazed at the stories, the statistics, the unselfish dedication and the resilience of the families who have been touched by this syndrome. I am excited to be a part of the SADS lifesaving mission and look forward to getting to know you. Thank you. Gwen



Tori and Mark Goudy with Gwen Davis, SADS Program Director, at our booth at the 27th Annual Emergency Medical Services Association Conference in Salt Lake City.

STUDY OF EMOTIONAL TRIGGERS OF CARDIAC EVENTS

Dr. Richard Lane, of the University of Arizona, is currently enrolling subjects in an NIH-sponsored study of factors that precede (and possibly "trigger") cardiac events in people with LQTS. This study is being conducted in collaboration with Drs. Arthur Moss and Wojciech Zareba of the University of Rochester Long QT Registry. Members of the research team are conducting telephone interviews of individuals who have experienced syncope or cardiac arrest, within days or weeks of such an event.

If you, or someone close to you, experiences syncope or cardiac arrest, please let us know as soon as possible. We would like to obtain your permission to send you more information about this study. You may contact the Project Coordinator, Sabrina Geoffron, by phone at (520)626-5342, or by email at sgeoff@email.arizona.edu.

NEW RESEARCH

AED Community Programs can save lives

Use of portable defibrillators by non-emergency responders on victims of cardiac arrest doubled during a four-year period in Seattle and King County, Washington. Survival rates were similar to or better than those of people treated by emergency medical service workers, researchers reported at the American Heart Association's Scientific Sessions 2003.

New Guidelines for Automatic External Defibrillators and Children

AEDs may be used for children 1 to 8 years of age who have no signs of circulation. The device should deliver a pediatric dose and the arrhythmia detection

algorithm used in the device should not recommend delivery of a shock for nonshockable rhythms.

Fish oils can prevent dangerous heart rhythms

Eating oily fish (salmon, tuna, etc.) at least twice per week can prevent cardiac arrhythmias that can lead to sudden death. The study by Jing X. Kang, M.D., Ph.D.; Yong-Fu Xiao, M.D., Ph.D.; and George E. Billman, Ph.D. was published in *Circulation: Journal of the American Heart Association*, May 2003.

Diet Pills, Herbs and other Over-the-Counter substances may be dangerous in LQTS
As you all know, some medications, including "cold pills", which you can get without a prescription, should not be

taken by people with Long QT Syndrome. Heart arrhythmias have been linked with many over-the-counter pills, supplements and herbal remedies.

In a recent study by Dr. Brian McBride, 60 percent of the patients who took Metabolife356, a popular weight loss supplement, had their QT prolonged by 30 milliseconds. As a comparison, he pointed out that the FDA either banned or refused to approve several drugs that prolonged QT by just 13 milliseconds—among them the popular allergy drug Seldane.

Many of these products are not tested enough to know what their effects will be. Therefore, you should always ask your doctor before taking any product.

The SADS Foundation Position on AEDs

Tragically, several thousand young people between the ages of 1 and 22 die of sudden cardiac arrest (SCA) each year in the United States. Another 350,000 middle-aged and elderly people lose their lives to SCA annually. Most of these deaths occur in the home or in the community and not in the hospital.

In sudden cardiac arrest, the heart no longer pumps blood to the brain. Without the oxygen and nutrients supplied by the blood, brain cells begin to die within minutes, and death soon follows. Cardiopulmonary resuscitation (CPR) can help keep blood circulating, but unless Emergency Medical Services (EMS) arrive quickly, survival is unlikely. SCA is the most prevalent medical emergency today.

Sudden cardiac arrest does not have to be fatal. Just as many of us have witnessed on television's "ER", it is often possible to shock the heart back into a normal rhythm with a device called a defibrillator. If an SCA occurs outside a hospital environment and if an Automated External Defibrillator (AED) is available in this same location, then an AED can be used to shock the heart of the victim and hopefully restore normal rhythm. Early defibrillation of cardiac arrest victims is essential. The earlier the victim is defibrillated, the greater the chance of survival. In cities where CPR training is widespread and EMS response is rapid, the survival rate increased from nine percent to 30 percent when AEDs were available to first responders (American Heart Association, 1998). When an AED is used, SCA survival rates can rise from under 5% to over 60%. This increase in the rate of survival occurs because the window of opportunity for restoring life after a SCA is very short—only about 5 minutes.

Advances in technology have made AEDs small, portable, and easy-to-use. This means that AEDs can be used by members of the public, including security guards, teachers, coaches, students, recreational facility staff, and family members or caregivers of people at high risk for cardiac arrest. The training required to use an AED is relatively brief and can be delivered in conjunction with a CPR course.

Therefore, the SADS Foundation recommends:

New Keating Research

The Keating Laboratory is seeking to enroll any willing participants from all racial and ethnically diverse groups in their continuing genetic studies looking for markers of risk or susceptibility for cardiac arrhythmias. This study is not exclusive for LQT, but seeks to include anyone who has experienced an unexplained cardiac arrest or has had a child, parent or sibling taken with unexplained sudden cardiac death under the age of 35 years.

Participation would include a signed consent, permission for personal patient contact, release for copies of ECGs/clinical records and a blood draw or buccal swab sample for DNA extraction. For interested individuals, large or small family groups, please contact project's clinical coordinator, Katherine Timothy by phone at 801-444-9874 or email at Katherine.timothy@genetics.utah.edu.

- All EMS personnel, including first responders (firefighters, police, security personnel etc.) should be trained to operate AEDs and have easy access to AEDs. All emergency medical vehicles should be equipped with defibrillators (manual or AEDs).
- Early access defibrillation must be combined with other elements of the American Heart Association's "Chain of Survival"—early access, early CPR, and early access to Advanced Cardiac Life Support (ACLS).
- Laypeople should have access to AEDs at home when combined with CPR and AED training.
- Bystander-initiated automatic external defibrillation should be available in rural communities and congested urban areas where resuscitation strategies have had little success.
- Legislation to ensure AED access for emergency medical services and at public sites such as office buildings, stadiums, arenas, and other sites where large numbers of the public gather.
- Legislation to ensure immunity from liability for any person using an AED to save a life.

MEDIA AWARENESS CAMPAIGN: LONG QT STORIES NEEDED

The SADS Foundation volunteers and staff are working hard collecting stories and pictures of people who have been affected by LQTS. We will use this information to contact national media including Oprah, Larry King, etc. for the 2004 Awareness Campaign. Tell us how LQT has affected your life, your family and your friends.

When writing your story, please include information such as: what steps led up to finding out about it, what has happened since then, were the medical professionals aware of LQT, what lengths you had to go to for help, etc.

The more stories—and photos—the better!

Please send your story, any photos and contact information by the end of February to: SADS Foundation, 508 East South Temple, Ste. 20, Salt Lake City, UT, 84102 or e-mail: stories@sads.org or submit online at www.sads.org.

If you have any questions please contact Cyndi, the volunteer in charge of this project, at CYNDICHA@msn.com or Gwen at SADS (1-800-STOP SAD).

Please be aware that the stories and pictures cannot be returned and will be property of the SADS Foundation. Therefore, we will need a signed release statement included with your story.



Alarm Clock Tip

Monica Weaver sent us a tip for an alarm clock that her daughter, Katie, uses. "The light and sound start very subtly and increase over a 30 minute period—much safer than a loud buzzer", said Monica. "We've had very good success with it and thought others might be interested. Besides, you can choose a number of natural sounds for the alarm...rain, tropical forest, etc. and it includes scented pellets for a gradual release of aroma." www.hammacher.com

SADS Awareness Month

A major part of “supporting families, saving lives” is educating our families, friends and community about the reality of arrhythmias, which can cause sudden death. And that’s what the Annual SADS Awareness Month is all about. Although awareness should be promoted all year long, the month of October provides the opportunity for an intense, concerted effort to join forces and focus our energy on saving lives through spreading our knowledge and experience. Once again, we have been very impressed by YOU—your passion, creativity, sacrifice and work. You touched the lives of thousands of people in a very short amount of time. During October 2003, you distributed over 2,500 brochures, 250 posters and 500 ‘teacher packets’. You covered areas from New York to Texas to California—20 states in all. You were involved in a myriad of activities such as sharing literature with physicians, teachers, and community centers, giving presentations to health professionals, and civic centers, orchestrating both large and small fund raisers, and sharing your story with radio, television and newspaper. A big THANK YOU goes out to all who participated in this year’s Awareness Month!

If you were not able to participate in this year’s Awareness Month, IT’S NOT TOO LATE to get the word out. We provide great educational literature all year long. Take a look at YOUR family, YOUR neighborhood, YOUR community, and YOUR schools. You supply the passion, we can help with the rest—ideas for general awareness, fund raising, working with the media and offering support to other families. Contact us at sads@sads.org or www.sads.org/LQTS.html and click on LQTS Materials Request Form.



Utah Schools Project

As part of a Utah school awareness project, the SADS Foundation had a booth at the Utah Education Association conference last month. More than 350 informational flyers were passed out, and more than 200 people stopped to ask questions, most prompted by personal experiences with SADS deaths or symptoms.

When this project is done, more than 1,600 posters will be on school walls, and over 23,000 teacher information sheets, 800 athletic information sheets, and 120 nurse packets will have been distributed. Parents home schooling children will find this information at health departments, libraries, and children’s centers.

Telling Your Story

Radio stations, television stations, newspapers and magazines across the nation WANT to hear your story! And many of you have publicized your stories—quite successfully. Media allows us to reach thousands of people with just a few words or sound bytes—perhaps a picture or two.

Don’t be shy or intimidated about working with your local media. Feeling green? We have lots of “how to” media help. Just email Gwen at gwen@sads.org. And remember—please let us know if you are planning to talk to the media (& especially if you are successful!).

MEDIA COVERAGE During SADS Awareness Month

Idaho State Journal

Pocatello, ID
“Answers too late to save kids; grandkid can still be helped” and

The Southside Times

“Southsider fights to save others from long QT syndrome”
Both featuring the family of Jackie Leslie

Janesville Gazette

Janesville, WI
“A Faint Irregularity” and
Channel 13 News
Rockford, IL
Featuring the family of Victoria Brown

Westwood Pine Press

Westwood, CA
“Satterfield speaks out on deadly syndrome” and

Make A Wish Foundation News and Notes

“Christina’s Selfless Wish”
Both featuring the family of Chrissy Satterfield
She was also featured on KRCR, KRAC, and UPN of California

Our Kids Atlanta

Atlanta, GA
“Conference Spotlights Sudden Death In Kids”
Featuring the family of Blake Morris

Tooele Transcript Bulletin

Tooele, UT
“SADS foundation works to save lives”
Featuring the SADS Foundation

Southern Utah News

Kanab, UT
“SADS—Saving lives in Utah”
Featuring the SADS Foundation

Moab Times-Independent

Moab, UT
“October is SADS Awareness Month”
Featuring the SADS Foundation

The Tremonton Leader

Tremonton, UT
“October is SADS Month”
Featuring the SADS Foundation

Marietta Daily Journal

Marietta, GA
“Family fights deadly heart condition”
Featuring Renee Skillman, Reginald Walden and family

KABC-TV News

Los Angeles, CA
“Long QT Syndrome, A Heart Disease that Could Go Undetected”
Featuring the Weaver family

The N’West Iowa Review

Sheldon, IA
“The long and short of it: Family promotes awareness of Long QT Syndrome and SADS”
Featuring the Bakker family

Continued on next page



Pam Carlock, R.N. and Patti Androsko, R.N. co-presented at our conference.

Healing Wall

During our recent conference in Atlanta, people were able to share and read stories from the Healing Wall. Conceived and brought to life by Patti Androsko (with a little help from SADS), the Healing Wall greatly enhanced the spirit of the SADS Conference. The coupling of pictures and written letters were neatly framed

and displayed for all participants to see. It was both humbling and inspiring to learn of families' grief, courage and bravery living lives affected by cardiac arrhythmias. It is not too late to contribute to our ever-growing Healing Wall. Please contact us for details.

Thanks Patti!



Melissa Sue (Brown)Titus

September 5, 1979 -
September 1, 2002

Melissa was born September 5, 1979 weighing 8 pounds 7 ounces. I was a single parent at the age of 17. My parents watched my daughter so I could graduate.

When I was about 24, I was diagnosed with Epilepsy, and then when my daughter turned 17 she had her 1st seizure. She was taken to the hospital but was diagnosed with depression. Then my daughter passed out again and I realized it was the same symptoms as what I had had at her age. We would pass out in our sleep when awakened by a phone ringing or from being startled.



I took her to my neurologist for an EEG but he said he did not think she needed this done. I asked him "why couldn't she have what I have?" His reply was "you're different." I thought maybe he was right since he had the PHD. But deep down I thought different. As we left I

said to my daughter "when you do this again maybe they will listen and see you have what I have" But my daughter never got that chance. five years later my daughter died in her sleep.

After Melissa's death I wanted to find out everything about why she died. So I got both of our records, and I discovered that both of us had abnormal EKG's with the prolonged QT. So I did research on Long QT Syndrome and we fit all the symptoms. She told the doctors the symptoms she was having but they did not do anything. Melissa was on a drug that was making her very dizzy and she called the doctor but they just told her to take it 2 more weeks. She died 4 days

later. This drug is a drug that people with QT cannot take. If only they would have told her to stop taking it, especially when she was having these side affects.

Our family is not only faced with my daughter's death but we are faced with a very serious disease—one that doctors have over looked with my daughter and I. Having long QT, I have to make a choice about having a Defibrillator. Right now I have refused, because the most important person is no longer in my life. My mom has LQTS and possibly my nephew. You can just die if not treated. If they would have only listened to us and looked into her symptoms, my history, and records, my daughter would still be here.

-Victoria Brown

Continued from previous page

CBS 46 News Channel
Atlanta, GA
"Many Teenagers May Be Susceptible to Heart-Stopping Disease"
Featuring the family of Wendy Mitchell

Long Beach Press Telegram
Long Beach, CA
"Daughters Alerted to Rare Condition"
Featuring the O'Brien family
Good Housekeeping Magazine
Seattle, WA

"Saved in Seattle"
Featuring the family of Kayla Burt
The Australian
Queensland, Australia
"Missing a beat with LQTS"
Featuring the family of Samantha Deveson

ABC 27 News WHTM
Harrisburg, PA
"Long QT Syndrome"
Featuring the family of Rhonda Becker
Talk Radio Show
Chicago

The Heart and Hands Award

Each year our nation recognizes the vital role of philanthropy in our communities and in our lives with National Philanthropy Day. On this day we honor organizations and individuals who contribute time, talent and money in an effort to improve the circumstance of others.

As part of Philanthropy Day, the Utah Nonprofits Association and the Utah Society of Fund Raisers present a special award acknowledging the impact individuals have made to their respective causes.

We are pleased to announce that in 2003, Sandra Stayer, received The Heart and Hands Award at an honorary luncheon in Salt Lake City.

“It was an honor to receive this year’s Heart and Hands Award”, said Sandra. “It is a pleasure to work with the SADS Foundation. My main goal in working with SADS is awareness. My husband died in 1995 from Long QT and my daughter, now 13, has it too, along with her uncle and aunt and several cousins. I know first hand that people can live normal lives and not even realize that they need to be diagnosed. Tiffany is a tall, strong teenager that no one would realize has to take a beta blocker or is on a potassium study or even that she is part of a genetic research study with Dr. Vincent. It is my desire to educate people to become more aware of their hearts.”

National Philanthropy Day



Celebrating Utah's Philanthropists

Because of Sandra Stayer’s desire to educate people to become more aware of their hearts, she has supported and volunteered many hours to SADS Awareness programs and events. “She is always willing to help and is so positive and caring”, said Gwen Davis, SADS Program Director. “I always call Sandra when we need someone to make a difference in our community.”



Dr. Michael Vincent, Dr. Lei Zhang, Sandra Stayer and her daughter, Tiffany at the SADS Picnic this fall.

TIPS For Good Health

Screening for LQTS

Did you know that in approximately 10% of LQTS patients the initial ECG is normal, and in about 40% the QT interval is not prolonged enough to clearly diagnose LQTS? In these cases, an exercise ECG or a “Holter” monitor (worn for 24 hours or more) will usually clarify the diagnosis. The exercise test should be a low level, longer interval test (exercise for 10 minutes or more without your heart rate going over 150-160 beats/minute). If you have been told that members of your family do not have LQTS based only on a resting ECG, you may want these people to be tested with an exercise test.

Medication

Is your child taking enough medication for his/her weight? Children should be checked at least yearly to see if their medication is still working. If your child is going through a ‘growth spurt,’ she/he should be checked more frequently (maybe even every 3 months). ‘Checking’ is usually the same exercise test as described above.

Medic Alert Jewelry

SADS suggests that everyone with LQTS wear jewelry that will indicate their condition and will lead health professionals to more information about your care and treatment in the case of an emergency. www.medicalert.org

Local Emergency Room

Does the emergency room that you would use know about LQTS? Stop by and ask the ER staff to do an in-service training on LQTS. We will give you materials to use and to leave for the ER reference files. (1-800-STOP SAD or sads@sads.org)



SADS UK &
OXFORD GENETICS
KNOWLEDGE PARK

Present a conference:
Cardiac Arrhythmias, Research and Therapy;
A holistic approach

June 26th – 27th, 2004

Hanover International Hotel, Daventry, England

www.sadsuk.org

RUNNING LONG FOR LONG QT

Talk about spreading the word! I was a walking (or running in this case) billboard for Long QT Syndrome during my run in the New York City Marathon, November 2.

As I ran over the 5 bridges that took me into the 5 incredible boroughs filled with cheering, appreciative New York City fans (the best in the world as far as I'm concerned!), my t-shirt had my name and the letters "LQT" on it. As I would pass by the people, they would see my name and yell out, "Go Cyndi!" ...and then become a little perplexed because they weren't quite sure what "LQT" was supposed to mean. And if they asked as I was running by, I would yell back to them..."It stands for Long QT--it's a heart condition!"

Now, of course, all those people I told that to thought I was the one running the marathon with

this Long QT heart condition! In actuality I was using the marathon as a fundraiser to



raise awareness of Long QT and to raise money for the Sudden Arrhythmia Death Syndrome (SADS) Foundation.

Since we found out last spring that my husband and two children had LQTS, the SADS

Foundation has helped us immensely in our struggle to understand this heart condition that affects my family. I wanted to do something to give back to them and help others know about this relatively unknown condition, but what could I do? Then I found out I made it

through the lottery to get into the New York City Marathon (my lucky number was picked!) and I thought, well, if "Team in Training" can raise money for Leukemia and "Race for the Cure" can raise money for Breast Cancer Awareness, then maybe I can be a one-man (or woman in this case!) fundraiser for LQT! After getting in touch with Sarah Marsden at SADS, the project was underway. Shortly before the marathon I sent out a personal letter to family and friends explaining what I was doing and why, along with printed forms from SADS to explain how people could sponsor me per mile or for the whole marathon. I wasn't really sure what kind of reply to expect,

but certainly not the kind of response I got! Donations started pouring in from family, friends and people in the community who heard about what I was doing. My husband's business (thank you Merrill Lynch!) matched employee donations, which really put the total over the top. So far to date, it looks like my Running Long for Long QT campaign in the NYC Marathon, has raised over \$6,000! Much more than I ever expected!

I always tell my children the quote, "To whom much is given, much is expected." Well, I feel like our family is so blessed, even with the medical condition we are trying to get through, that it was important for me to be able to give back something in return, as well as maybe help others out there who aren't aware of LQTS.

(Cyndi Chambers lives in Ocala, Florida with her family. She is a free-lance writer, and coaches middle school volleyball, basketball and track. She competes in race distances from 5k's to marathons, and sprint triathlons, but most of all enjoys hanging out with her family.)

Thank You

Special thanks to the individuals and organizations whose major financial support for the SADS Foundation made possible our 2nd International Conference: *Preventing Unexpected Sudden Cardiac Death in the Young*:

Guidant Foundation

Medtronic, Inc.

The Church of Jesus Christ of Latter Day Saints Foundation

The Deseret Foundation

The George S. and Dolores Doré Eccles Foundation



Several hundred SADS Foundation supporters descended on the Layton family home in Colorado Springs, Colorado for the 6th annual Octoberfest SADS benefit. A roaring success, more than \$2,000 was raised for life-saving programs. It was a lot of fun too!

SADS E-Newsletter

SADS will soon have an E-Newsletter (NOT to replace our mailed one). Here are a few extra advantages to receiving our new E-mail newsletter:

- More frequent, up-to-date news regarding SADS, Long QT and other cardiac arrhythmias.
- More 'earth friendly'—for those who wish to replace paper with electronic copy.
- Late-breaking news quickly shared with all E-news recipients. (Such as the television coverage of LQT on the Discovery Health Channel last month.)
- The E-news will include links to various websites/information etc.

If you do not receive occasional E-mail from SADS, we may not have your E-mail address. If you want to be included, send your E-mail address to Dave at dave@sads.org.



On October eleventh, 75 guests at Chris and Denise Falzon's annual Brian Falzon Memorial Charity Road Rally benefit raced around southeastern Michigan, searching for clues hidden in pumpkins, balloons and popcorn that led to a fabulous dinner party at Leo's Coney Island. This year's winning team included Jim and Jolie Warpool and Dan and Leslie Shingleton, shown celebrating above.

Children's Expression Contest 2004 Call for entries

This year's theme is: My Heart

Categories: Art, Poetry or Short Story

The SADS Foundation is sponsoring a Children's Expression contest. For more information go to www.sads.org or contact Gwen at 1.800.786.7723 (gwen@sads.org).

Submission Deadline will be February 27, 2004.

Support the SADS Foundation and purchase this roomy tote for volunteer materials or other items. The bag is 12" tall x 14 1/2" wide with one front pocket. Heavy canvas with comfortable, wide shoulder handle. Cost is \$18 (includes postage). www.sads.org or 800-786-7723.

