



SADS  
FOUNDATION

# NEWSLETTER



Supporting Families ♥ Saving Lives

Summer Issue 2002

## SADS AT NASPE North American Society of Pacing and Electrophysiology

**Alice Lara, Executive Director**—The SADS Foundation had a wonderful time at the Annual NASPE Conference in San Diego last May. We had a great exhibit which generated lots of interest, questions and support from the thousands of nurses and physicians who attended the meetings. It was a wonderful opportunity to introduce SADS to a number of corporations who will be good partners for us in the future projects.

**Our volunteers**—Deby & Bob Purvis, Diane Holtz, Jeannie Penner, and the Sullivan family: Linda, Ron & Lori—were just fantastic! They worked very hard and represented the Foundation with enthusiasm and competency. Katherine Timothy, a SADS Board member, worked at the booth in between attending the meetings. A special thanks to Katherine for helping me tote all the materials and set up and take down the booth! [\(more photos, pg. 7\)](#)



*The SADS booth at NASPE—before the doors opened! This is catching Alice at a quiet time—most of the time we were mobbed with conference attendees. Special thanks to Rachel (our Development Director) for putting together the new display materials and to Dave (our Program Director) for packing & shipping everything.*

## International Long QT Syndrome Awareness Week 2002

Sept. 9th - 15th

**D**ozens of volunteers around the world are participating in our annual effort to make our communities more aware of the signs and symptoms of cardiac arrhythmias that can lead to sudden death in young people. We're working to prevent these deaths by increasing the diagnosis and treatment of susceptible children.

This year we're focused on gaining local and national media attention, distributing materials to schools, clinics, community centers, etc. and organizing support group meetings to increase knowledge of LQTS.

### How can you help?

#### Working with other volunteers, you can:

- contact the media and tell them your story
- distribute materials your the community—to schools, community centers, physicians, etc.
- organize a local support group for LQTS families
- give a personal gift to help cover the costs of materials
- hold a special event to benefit the SADS Foundation

We have an extensive selection of resources on our website, [www.sads.org](http://www.sads.org), to help you spread the word. You can order materials from the website to be mailed to you or you can print materials directly and copy them yourself (quality will not be as high).

If you are interested in becoming involved in this event, please let us know ([dave@sads.org](mailto:dave@sads.org) or **1-800-STOP SAD**). We can put you in touch with other volunteers in your community or help you start your own effort to reach out to your community.

With your support, we can make a difference and save lives!!

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**Supporting Families © Saving Lives**

**Mission:** To save the lives of children and young adults who are genetically predisposed or otherwise susceptible to sudden death due to cardiac arrhythmias and to provide education and support to families and the medical community who are dealing with these disorders.

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Rachel Day, *Development*  
Dave Wind, *Program Director*

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Raymond L. Woosley, M.D., Ph.D.  
*Phoenix, AZ*

Editor: Alice Lara  
Assistant Editor: Rachel Day

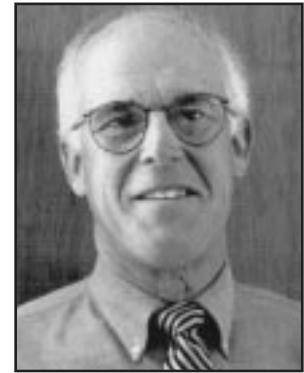


**508 East South Temple #20**  
**Salt Lake City, UT 84102**  
**Phone (801) 531-0937 or**  
**(800) 786-7723**  
**Fax: (801) 531-0945**  
**www.sads.org**

**Pediatric Neurologist Joins SADS' Board**

**W**alter Allan, M.D., a Pediatric Neurologist from Falmouth, Maine, joined our Board this March. Dr. Allan wrote the articles "Long QT Syndrome in Children: the Value of the Rate Corrected QT Interval in Children Who Present with Fainting" and "Long QT Syndrome in Children: the Value of the Rate Corrected QT Interval and DNA Analysis as Screening Tests in the General Population" which were summarized in our Spring Newsletter. He is also the co-author of the book *Kara Mia*, the story of one of his patients who was diagnosed with LQTS co-written with the child's mother Maryann Anglim. You can order a copy from Seahorse Press (<http://home.gwi.net/seahorsepress/>) or online at Amazon.com.

Dr. Allan will work closely with our Medical Committee and is especially interested in diagnostic testing for LQTS.



**What's Up at SADS?**

**Dave Wind in Charge of Programs**

**A**s the new Program Director for the SADS Foundation, I've learned so much over the last few months. My background as a human rights activist exposed me to a variety of experiences, but now I learn something new about people and their needs every day. I enjoy working with Alice and Rachel, but I'm most inspired by SADS' many volunteers, patients and families. I love talking with you and you've helped teach me how important our work is. Thank you for sharing your experience. I look forward to the future, and learning how to better meet your needs.  
—Dave



**Our New Foundation Brochure**

**W**e are very excited about our brochure—including a great picture of two of our volunteers, Karla and Jenna Aaland. We think this brochure represents us, and all of you, well—as a caring and supportive community! Thanks to Lorraine Press for donating the color printing.



# 1ST INTERNATIONAL SADS FOUNDATION FAMILY CONFERENCE

## UNEXPECTED SUDDEN CARDIAC DEATH IN THE YOUNG:

*Diagnosis, Treatment and Living with Arrhythmias Which May Cause Sudden Death*

October 12-13, 2002 at the  
**Royal College of Physicians, Regent's Park**  
 London, UK

*Supported by the PPP Foundation*



The SADS Foundation is committed to improving people's ability to make informed decisions about the diagnosis and treatment of LQTS and other related disorders. Too many people around the world are still unaware of the symptoms and risk factors involved with episodes of sudden death. Young people who are aware of their condition, too often receive inadequate or outdated care.

To better meet this global need for more information, support and resources, SADS is hosting our first international conference for patients and families living with genetic cardiac disorders. We encourage anyone who is living with a congenital arrhythmia, their loved ones, and families who have lost someone to sudden death, to attend this conference and learn more. Our scheduled seminars are as follows:



*Anne and John Jolly, SADS UK leaders, at the WONCA medical conference with a booth about SADS & our International Conference.*

### Sessions:

- Historical Perspective of the Importance of Genetic Research to LQT** - Katherine Timothy
- Brugada & Wolf Parkinson White Syndromes** - Dr Andrew Grace
- Historical Account of People Helping People in LQTS** - Pam Husband
- Long QT Support Group** - Suzanne Brittin
- Importance of Constructing a Family Pedigree** - Katherine Timothy
- Detection and Management of Arrhythmias in Primary Care** - Dr Tom Harris
- Defining and Recording Sudden Deaths from Genetic Arrhythmias** - Dr Mary Sheppard
- Family Pedigree Construction** - Katherine Timothy

- Brugada & Wolf Parkinson White Syndromes & LQT Support Group** - Dr Andrew Grace & Suzanne Brittin
- Bereavement Support** - Anne Jolly & Lin Baldwin
- Long QT Syndrome** - Dr Michael Vincent
- Hypertrophic Cardiomyopathy** - Professor Bill McKenna
- Hypertrophic Cardiomyopathy Association** - Stephanie Cruickshank
- Evaluating Medical Information on the Internet** - Jon Mettler
- Living with the Long QT Syndrome** - Andrea Jones
- Research into LQT** - Dr. Cathy Head
- The Importance of Awareness** - Pam Husband
- Long QT Syndrome** - Dr Michael Vincent
- Cardiomyopathy & the Cardiomyopathy Association** - Stephanie Cruickshank

Our Patient and Family Conference is being held in conjunction with a Certified Medical Education conference, which is focusing on many of the same topics and themes. There will be opportunities to visit with some of the world's leading cardiac specialists, as well as formal question and answer sessions.

### For More Information:

Visit [www.sads.org](http://www.sads.org), Call 1-800STOP-SAD or e-mail: [info@sadsuk.org](mailto:info@sadsuk.org)

### Conference Fee: £20 (about \$31.38) Individual

£36 (about \$56.49) Two family members

£45 (about \$70.61) Three or more immediate family members

# The Differences Between Males & Females with Long QT Syndrome

Katherine Timothy, SADS Foundation Board Member

Studies show that males have a higher risk of syncope, blackout spells, or sudden death) during childhood, (with an average earlier age of 8), through puberty. Where sudden death occurred, males died, on average, at 13 years whereas females died at 20 years. Males had a 32% incidence of sudden death as a first episode in comparison to 9% in women. According to the LQTS Registry, "only a few males had a first cardiac event after 15 years of age whereas about half of the females had a first cardiac event after 15 years of age."

Females have an increased risk of cardiac events after pregnancy— during the 40-week postpartum period. According to a retrospective study, 23.4% of women with LQTS had a cardiac event after their baby was born. This study also noted that treatment with Beta-blockers during and after pregnancy reduced this risk significantly, while not harming the baby.

Women who experience cardiac events during the postpartum period have several things in common:

- over-the-counter medications which prolong the QT interval

- all had their events during severe anxiety, sleep deprivation, "baby blues" or depression.
- loud & unexpected noise—alarm clock, or sudden arousal from sleep
- inattention to proper diet, poor eating habits or extreme weight loss or exercise

## Remember:

1. maintain strict compliance with prescribed Beta-blockers
2. avoid all medications which may further prolong the QT interval
3. maintain a healthy diet & particularly increase intake of potassium-rich foods
4. get plenty of rest
5. remove all alarm clocks or telephones from resting areas
6. reduce, as much as possible, stress & anxiety
7. seek help to relive depression (but be cautious of taking medications for this)
8. consider the addition of omega-3 oils to your diet

## Long QT Genetic Testing

Katherine Timothy, SADS Foundation Board Member

Genetic studies of the long QT syndrome began some 15 years ago when Dr. Michael Vincent wanted to understand the genesis of this little known disorder. Dr. Mark Keating, a cardiologist who additionally specialized in genetic and molecular research, was selected to head the LQT genetic project. By the spring of 1991, he'd isolated the first LQT linkage site on chromosome 11. Over the next 8 years, the Keating laboratory discovered 5 of the 6 genes currently identified, which cause the LQT abnormality.

Even with this explosion of research knowledge regarding LQT and cardiac arrhythmias in general, very little is currently available with respect to genetic testing as a clinical diagnostic tool. There are several reasons for this unfortunate dilemma.

Genetic research and clinical diagnostic genetic testing are very different studies. Genetic researchers are granted ability to research by funding institutions, and are governed by the specific rules. Research findings only become public knowledge as findings are published in professional journals or scientific meetings. The actual research results are highly confidential.

Diagnostic genetic testing is built upon lessons learned from the initial genetic studies. A diagnostic test must have near perfect accuracy before government approval is granted. Years are required

to prove the validity of any given test. Additionally, technology used in research is generally very expensive.

Though we can identify some LQT genetic abnormalities, we still have a long way to go. There are additional genes we don't know about. Developing a clinical diagnostic test without all the answers is simply impossible. Until we know more about the genesis of

LQT, and affordable technology is developed to identify and verify abnormalities within LQT causing genes, clinical testing for the Long QT Syndrome is not feasible.

GeneDx & DNA Sciences offer limited, but expensive, diagnostic testing

for LQTS. Research labs that continue to screen for the known LQT genes are: Dr. Michael Ackerman (Mayo Clinic) and Dr. Silvia Priori (Italy). These may have restrictions due to the research being conducted. The laboratory of Dr. Mark Keating no longer routinely screens for the known LQT genes but continues to actively search for additional LQT causing genes as well as other lethal arrhythmia causing disorders

**“Genetic research and clinical diagnostic genetic testing are very different studies.”**

The complete versions of Katherine's articles, including the scientific articles referenced, are available on our website ([www.sads.org/](http://www.sads.org/)) or by calling us at 1-800-STOP SAD.

## A Good Friend

by Nancy Herdeman

I will never forget the day my dear friend, Ann, called to tell me that her daughter Kaitlin had been diagnosed with LQTS. She had been hospitalized after fainting at a track meet and was diagnosed with the disorder. Ann tried to explain it to me—but I ended up spending a lot of time on the Internet reading about it in order to understand it more completely. When her other children were tested, they discovered her son Ryan also had LQTS. After crying with Ann and for her beautiful children and thanking God that they had been diagnosed before something worse had happened, I began to feel very helpless as a friend.



*LQTS Benefit participants, Cincinnati, Ohio.*

Chicken soup and chocolate chip cookies weren't going to make this "all better". How could I help in a meaningful way? And then it came to me; I wanted to hold a benefit that would raise money for research and promote awareness of this disorder.

Ryan and Kaitlin (and the rest of their family) are very involved in and loved by the competitive swimming community in our area. So, a lot of their friends were devastated by the news that Ryan and Kaitlin would no longer be allowed to compete. They, too, wanted to do something! At first, Ann was nervous about my plan for a walk/run benefit. She didn't want her kids to be earmarked as "different". So, I organized the benefit in the name of LQTS—not specifically for Ryan and Kaitlin. Admittedly, I was nervous too—I never do things like this! I am not usually "the person in charge." But I must tell you, once I got started, all of my plans just fell into place. A neighborhood park graciously donated their facility. My husband and son designed a t-shirt, while my daughters donated their time. A fruit and vegetable market gave us bananas, and a dear friend donated chair massages and bottled water. I sent registration forms to everyone I could think of. Then something very exciting happened.

Registration forms started coming in!

When April 13 finally arrived, it was raining and very gloomy. But my husband and I, along with our three children, headed off to the park anyway. As we started setting up, the rain stopped. Although the day never turned sunny and beautiful we had a wonderful turnout. All our hard work paid off! Afterwards, a friend of mine said the experience was like God putting me on a boat in the middle of a body of water, (He gave me this idea) and not giving me directions (I had no idea how to do this) but, nonetheless, steering me in the right direction. My hope, and challenge, is for those of us who have not been personally affected by this disorder to step out up help.

**“Once I got started, all of my plans fell into place.”**

## No Ball At All 2002

Look for your invitation to our annual No Ball At All. Be ready to stay home with friends and family. Save the cost of a fancy event and use that money to help SADS serve families effected by sudden death. It is through your generous support that we are able to maintain programs for support, awareness, advocacy and education.

**You can help by:**

- ♥ Making a donation
- ♥ Applying for your company's matching funds (they will often match or more than double your contribution)
- ♥ Telling your story and asking a friend(s) to donate to the SADS Foundation

Remember, No Ball At All is the core of our fund raising program. The money we raise pays for our programs through much of next year.

Please let Rachel know if you do not receive an invitation or if you want additional invitations for your family and friends. (rachel@sads.org or 1-800-STOP SADS).

***With your help, No Ball At All 2002 will be the most successful yet!***

## DONATE ONLINE:

Now you can make your donation online—with American Express, Master Card or VISA!



Our secure site is:  
[www.sads.org/donations.html](http://www.sads.org/donations.html)

## Our Heroes: Stories of Survival

### Jo's Story

Let me start by telling you something about Jo. He always loved sports. He started playing baseball when he was 5, picked up softball at 7, and joined the Pee Wee football team at age 9. He's played in USSSA World tournaments and ASA World Tournaments all over the world and holds many first place honors. When he decided to go out for his Jr. High's football team, I was all for it.



A week later my parents came in from Texas to see Jo's first home game. Together we watched Jo's pre-game exercises. We felt the excitement as the team ran through the banner to their places on the bench. The ball snapped, a tackle was made, but a few seconds later it was instant replay. Jo took a

few steps, turned, then hit the ground. I waited for him to get up, but he didn't.

On September 18th I followed the school bus to the first game of the season. I watched as the team warmed up, everyone was excited. Then, on his first play, Jo hit the ground like a ton of bricks. I thought he'd just had the breath knocked out of him. But after a minute he got up. He never complained, or mentioned the incident again. He worked hard at every practice, preparing for his next game.

By the time I got to him he was vomiting, blue in the face and not responding to me. His dad, uncle and off-duty EMT's alternately administered CPR. He was in cardiac arrest. It seemed to take forever for help to come. When the ambulance finally arrived they shocked him 4 times with defibrillator paddles. He was lifeflighted to the Lake Charles hospital where I met the helicopter.

Jo was intubated for 24 hours, and stayed in the ICU for 7 days. The doctors didn't have any answers. He seemed healthy. His heart and tests looked normal. After his release we made many trips back and forth to the doctor. Finally, a cardiologist from Texas Children's Hospital called. He asked if we could meet with him immediately. We left for Houston in an ambulance. Jo was told he had Prolonged QT syndrome. An ICD was implanted two days later.

**“We've made a few changes . . . but we still feel lucky.”**

We've made a few changes because of the diagnosis, but we still feel lucky. The condition is hard for Jo to accept because he still wants to do everything that he loves. I tell him his life is more important. Maybe one day he'll get back to sports – as a coach in charge of the field, instead of a player on it.

### Donna's story

I was normal, an energetic 25 year-old at a job interview when I almost died. On March 18th, 1998 my life suddenly stopped, and then changed. During the interview I had a brief episode of syncope. I regained consciousness but then went into cardiac arrest. Fortunately the two women with me knew CPR and kept oxygen flowing into my body while waiting for help.

Twenty-two minutes later the paramedics arrived-- I was flatlined. EMTs used defibrillator paddles twice, but nothing happened. When I arrived at the emergency room, I was given less than a 1% chance of survival. If by some miracle I did live, doctors predicted I would be brain dead. Family and friends were called in "to say their goodbyes."

To everyone's surprise I defied all the odds. After 4 long days in a coma, I woke

up. My memory was a blur. I was scared, weak, tired and very confused. I'd never even had a broken bone and now I was in the hospital fighting for my life. I'd been celebrating St. Patrick's Day the night before the incident. Why had this happened to me?



The hospital ran a wide variety of tests. I was young and seemed healthy. Finally I was diagnosed with Long QT Syndrome. Doctors wanted to implant an internal defibrillator, to help monitor my heart rhythms and keep them stable. All I could do was cry. I was still heavily medicated and very confused. But once I understood the seriousness of the condition, I knew I needed the surgery.

The operation was a success, but my recovery was painful. Months past before I tried to get back to my "normal" life. At first it was hard and scary to live with the large device in my chest. But with time I realized how lucky I was to be alive. I began to better understand how to live with my condition and that I was

okay. Now I call the ICD "my trophy."

Five years later I am more alive than ever. Thanks to wonderful doctors and advances in technology, I am living a normal life doing all the things I love. Since receiving the ICD, I haven't had any complications or episodes. I realize the importance of living life to the fullest each and every day. There isn't time to feel sorry for yourself. Every second counts.

## Tom's story

Tom was diagnosed with LQTS when he was 9 years old. With no family history of sudden death, the news was quite a shock.

Tom's medical history has been very eventful. The day after returning home from a church youth ski trip, he had a full cardiac arrest. Our minister brought pictures from the trip to the hospital. There was Tom with his friends in a victory stance on a high peak. It was hard to believe that our son, in the hos-

pital bed on a ventilator, had been celebrating life on a mountain top just a few days earlier.

Tom made a full recovery and is still celebrating his life. A gifted athlete, it was very difficult for Tom to give up sports. At age 9, when the doctors suggested golf, he reluctantly agreed. Through the years his enthusiasm has increased. Of course there will always be a



longing in his heart for the team sports he wasn't able to participate in. But now at twenty-one, he's a great golfer and loves the game.

One of Tom's greatest strengths is his positive effect on people. His sense of humor and lightheartedness put people at ease. He's great with kids. His balance of encouragement and teasing spurs them on to try their hardest. Of course some of his gifts are innate, but we know his compassion and warmth are also the result of overcoming and living with the challenges of Long QT syndrome.

**“Tom made a full recovery and is still celebrating his life.”**

Since October of 2001 I have been trying to get a portable defibrillator donated to my son's school. He has Long QT, along with my two nieces who also go to the same Catholic elementary school. It was a long battle since they were only being donated to public schools. With the help of our local congressman's office we were able to have one donated through the Sunoco Oil Company. I just want to let people know that it can be done—even in a Catholic school—with a little work.

*Joan Scirrotto, Philadelphia, PA*

Just want you all to know that the Cardiology Conference held at Christus St. Patrick Hospital by Dr. Jim McKinnie (Cardiology and Electrophysiology) on LQTS was a great hit! We had super attendance and a large number of requests for information on LQTS—in the form of brochures, medications and various methods of obtaining more information—from many of the professional members of the audience. I was just amazed at the level of interest...especially from the neurologists and several of the Family Practice physicians in attendance.

*Colleen C. Fontenot, RN*

## Notes From SADS Volunteers Making A Difference

I had read the article about Colleen trying to get defibrillators in her school district in Illinois. I have already done it here in Miami-Dade County. My company raised enough money to donate 9 defibrillators and we had to get school board approval to donate them because of the expense. Then they voted to buy one for every High School in the district. I think it is a total of 34 High Schools that now house the Defibrillator. She can use this to help possibly get their approval.

*Ellen Mitchell, Miami, Florida*

The NIKE event went great! I was hoping for more people, but we had a good number of employees there and they learned some valuable information. We had about 40 people sign up for CPR AED training and around 300 people now know what an AED is, how it works, what it does, and most important where the AEDs are located on the NIKE campus.

*Blair Jones, Beaverton, Oregon*

## More Photos from NASPE



*Volunteer's Deby & Bob Purvis discuss SADS programs with Dr. Michael Ackerman (Mayo Clinic) at the NASPE conference.*



*Diane Holtz staffing the booth during one of her 2 days volunteering at the NASPE conference.*

# Raising Public Awareness About LQTS

**E**ducating the public about the LQTS is one of the primary goals of the SADS Foundation because making the public aware of the symptoms **saves lives**.

The SADS Foundation strongly encourages each individual associated with LQTS to embark upon a public awareness campaign in his/her community. Even if you use no organized media, by informing and educating people who work with children and young people (coaches, teachers, recreation centers, church youth leaders, etc.) and parents of the symptoms of the LQTS, children can be protected. **Saturate your community with information about the Long QT Syndrome.** Anyone who comes into contact with young people should know how to recognize symptoms.

When calling these various organizations, make it clear to them that **circulating this information will save the lives of young people**.

**Remember, in all your presentations, to make these points:**

1. Children and young people who die from long QT syndrome usually appear healthy, vital and normal.
2. The symptoms of LQTS include: fainting episodes or blackouts during or following physical exertion, fainting episodes or blackouts as a result of emotional excitement / distress / startle, and any family history of unexplained death in an otherwise healthy young person.
3. LQTS is not rare: 1 in 4,000 people may have LQTS.
4. Acquired and inherited LQTS are absolutely treatable and treatment saves lives!
5. Please visit [www.sads.org/lqts\\_homepage.html](http://www.sads.org/lqts_homepage.html) for more of this document, as well as other ideas just for SADS volunteers.

***Watch for your No Ball invitation in the mail and request more for all your friends!***



*Original Watercolor donated by Susan Diston.*

**Now on  
[www.sads.org](http://www.sads.org)**

**National Contact Volunteers:** If you need to talk with someone in your state, please give us a call or look at our website for information.

**The Drugs to Avoid List:** You can find the list on our website or.

*If you would like a copy of either of these lists mailed or faxed to you, contact us at [sads@sads.org](mailto:sads@sads.org), by mail or at 1-800-STOPSAD.*

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