



## SADS Conference In Salt Lake

Friday - August 27th - Saturday August 28th  
Salt Lake City Marriott City Center

The 3rd International SADS Foundation Conference will be an event that you will not want to miss. As one participant put it last year, "the conference...so greatly exceeded my expectations that it gives me goose bumps." And for those of you who were with us in Atlanta, we have added many new discussions, including new research, genetic testing, early detection strategies, as well as an opportunity to get certified in CPR with an AED (Friday morning), learn how to research your family history (Friday or Saturday) and programming for your kids.

We will again have a reception on Friday evening and, this year, we have a family trip to the 'red rock country' of Utah after the conference. Join Dr. Vincent, the SADS staff and many volunteers for a relaxing trip—make new friends and have a great time together! The Registration Fee is \$120 for Physicians (Saturday), \$75 for Nurses and Allied Professionals (Saturday), \$75 for Patients, Families, and others (includes Friday and Saturday), \$20 each for additional adult family members, and \$55 for teens (age 10 and over).



*Salt Lake City Skyline,  
Photographer:  
Frank Jensen,  
Courtesy of Utah  
Travel Council*

Surrounded by the majestic beauty of the Wasatch Mountains, this year's conference will be held at the Salt Lake City Marriott City Center. It is located in the 'heart' of Salt Lake City within walking distance to cultural

events, dining and entertainment including the Temple Square Genealogy Library.

For more information on the Conference, visit our website at [www.sads.org](http://www.sads.org) or call 1-800-STOP-SAD (786-7723).

## Kids and Teens Summer Camp Adventure

Friday, August 27th 1:00 p.m. – 4:00 p.m.  
Ages 10 – 16 years old

With nature at its best, the kids will make new friends and renew old friendships at Camp Kostopulos Residential Summer Camp. It is set in a wilderness environment where the kids and teens will socialize and engage in a variety of activities including horseback riding, games, low ropes course, art and nature activities (perhaps fishing if the creek is running). It is situated in the Wasatch Mountains on 25 acres ten minutes from Salt Lake City. There will be a staff ratio of 1:4.

This opportunity is limited to 20 participants (age 10 and over). The cost is included in teen registration (\$55). Pre-registration is required. For information please contact Gwen at 1-800-STOP-SAD or [gwen@sads.org](mailto:gwen@sads.org)

The Kostopulos Dream Foundation is an agency dedicated to improving the lives of people with/without disabilities. For over thirty years they have offered recreational opportunities for individuals of all ages and abilities. Camp K has received accreditation from the American Camping Association, an agency that set standards for camp operations across the U.S. [www.campk.org](http://www.campk.org)

## TEEN's Agenda (age 10-16)

### FRIDAY

1:00–4:00 p.m. ....Kamp Kostopulos—low ropes course, ride horses, art and nature activities etc.

### SATURDAY

8:30.....Hospitality Room—hang out with volunteers

9:30.....Take Charge of Your Body—it's your life and your health

10:30.....How the Heart Works, About LQTS & Questions—ask the Doctor anything

11:30.....Lunch with everyone in the hospitality room

1:30.....CPR/AED Training—fun & games and play with the machines

3:30.....Hospitality Room—hang out with savvy kids

## More Conference Inside:

Post-Conference Trip to "Red-Rock Country"

Family History Search pre-conference

Healing Wall

CPR/AED Workshops

More info at [www.sads.org/conf04/index.htm](http://www.sads.org/conf04/index.htm)



## Medtronic Foundation Sponsors Conference

Dr. David Satcher, 16th Surgeon General of the United States under Presidents Bill Clinton and George W. Bush, recently addressed representatives of more than 40 national patient associations and called for increased investment in health promotion and disease prevention to stem the tide of rising disparities in health care for African-Americans.

The SADS Foundation participated in Making Links to the African-American Community: Strategies for Outreach, a day-long conference in early February 2004, which was co-sponsored by the Medtronic Foundation and Black Women's Health Imperative.



*Penny Hunt, Medtronic Foundation; Alice Lara, SADS Foundation & Lorraine Cole, Black Women's Health Imperative.*

### The Hypertrophic Cardiomyopathy Association

#### 7th Annual Meeting & NJ-ACC Annual Meeting

Expert Cardiology Summit on HCM  
Medical Professional Meeting  
June 5, 2004  
Patients, Families and Friends  
June 4-6, 2004

Headquarters Plaza Hotel, Morristown, New Jersey  
<http://www.4hcm.org/meetinginfo/> or 973-983-7429

**Ashley Jolly**  
**sad** SADS UK &  
Sudden Adult Death Trust OXFORD GENETICS  
KNOWLEDGE PARK

#### Present a conference:

Cardiac Arrhythmias, Research and Therapy; A holistic approach  
June 26th – 27th, 2004

Hanover International Hotel, Daventry, England

At the 1st International SADS Conference held in London last year it became clear that the regular opportunity to gain up to date information and knowledge and to share experiences was crucial to people living with heart conditions that cause cardiac arrhythmias and those whose loved ones have sadly died through a suspected fatal cardiac arrhythmia. To follow up on the success of the conference last year we are running another event this year. In addition to providing opportunities to share experiences, the conference this year will include presentations on the latest clinical and research developments. We hope that you will be able to come along. [http://www.sadsuk.org/booking\\_form.htm](http://www.sadsuk.org/booking_form.htm)

### From Alice's Desk:

Last summer I wrote a little article about genetic discrimination and the Congressional Bill that was just out of committee. The bill has now passed the Senate. We are urging the House of Representatives to consider and pass the Genetic Information Nondiscrimination Act now.

Unless we begin to address medical privacy issues, many of us may not be able to obtain insurance in the future. Please write your Congress Person now or look online for more information: <http://www.geneticalliance.org/just-sayno.html>

What's in your genes  
is YOUR BUSINESS



Contact your Congressman. Get Senate Bill 1053  
OFF THE DESK and ON THE FLOOR!

### Possibilities: Young ICD Connection

October 15 & 16, 2004  
Michigan



Special overnight camp for young people with IDCs and their parents and special friends. For information: Sarah LeRoy (734) 763-5970 or [sleroy@umic.edu](mailto:sleroy@umic.edu)

# Testing—How to Navigate the Maze

Genetic studies became a part of researching Long QT Syndrome (LQTS) about 15 years ago. The first genes that cause LQTS were published on March 10, 1995. Research projects required volunteers with suspected LQTS to give a blood or a tissue sample to the researcher, who would then attempt to find “abnormal” parts of a gene that caused the symptoms. These long and expensive projects were not designed to give each individual the results of testing their sample, but to provide researchers and physicians with more knowledge of LQTS that would benefit everyone.

Clinical genetic testing, however, is designed to aid in an individual’s diagnosis of a disorder. In accordance with federal legislation passed to ensure accuracy and reliability, the results of clinical genetic tests must be obtained or verified in a laboratory that complies with the Clinical Laboratory Improvement Amendment (CLIA) before being released to patients and their doctors. A clinical LQTS genetic test will be available through Genaissance Pharmaceuticals (New Haven, Connecticut) beginning in summer 2004. This diagnostic test will analyze for mutations in the 5 LQTS channel genes that account for 65-75% of LQTS: LQT1 (KCNQ1 or KVLQT1), LQT2 (KCNH2 or HERG), LQT3 (SCN5A), LQT5 (KCNE1 or minK), and LQT6 (KCNE2 or MiRP1).

As with all genetic tests, there are some important limitations to LQTS genetic testing. It is important for families and referring physicians to realize that the genetic test will not be 100% accurate. This means that not every family with LQTS will have a mutation in one of the five LQTS genes tested. Approximately, one-third of families with LQTS diagnosis will receive negative genetic test results. Thus, if the suspicion for LQTS is high, a negative genetic test cannot and should not be used to “rule out” the diagnosis. In other words, if test results are negative, a patient may still have LQTS—we just do not know the genetic cause.

Another challenge is to know when a DNA change is a LQTS-causing mutation and when is it a polymorphism, or non-disease causing change. Technically, a “mutation” in a gene is simply a variation in the accepted sequence of DNA code. With the com-

pletion of the Human Genome Project, we have learned that the word “normal” no longer has meaning when it comes to a person’s genetic makeup. Genetic variations occur in great numbers in the human genome (our total genetic makeup) and not all the genetic variations produce physical traits (symptoms or disease). This improved understanding of genetic variation means that on those genes that are associated with LQTS, variations will occur that do not produce LQTS. Many gene variations occur without causing LQTS. Distinguishing the variations that cause LQTS from innocuous ones can be difficult—people can have the genetic mutation but be asymptomatic. Some percentage of tests will return a positive result, i.e. a mutation on one of the known LQTS genes was found, but in fact the mutation is not LQTS-producing. Much research has already taken place to distinguish important DNA changes in the LQTS genes from unimportant ones. For example, Ackerman and colleagues have published a compendium of normal genetic variation, or non-LQTS producing polymorphisms, helpful in the proper interpretation of the LQTS genetic test. More polymorphisms on the LQTS related genes remain to be identified.

Finally, information about other potential issues, such as pricing and health insurance coverage of such tests is not yet known. It seems likely that LQTS genetic testing will be covered given the important clinical role it can play in the evaluation of LQTS. Already, the past decade of research has shown why the patient’s underlying genotype is informative. A person’s genotype can help guide treatment strategies in some cases. In addition, if a LQTS-producing genetic variant is discovered in one family member, a less-expensive test for only that mutation becomes the diagnostic gold standard for near relatives and is far superior than the current standard of care, the screening electrocardiogram. Once a diagnosis of LQTS is established in the family, the screening ECG will misclassify many family members. Here, the genetic test identifies who in the family possesses the LQTS-causing mutation and who does not regardless of the electrocardiogram. With this information, the physician can conduct additional tests on family members with the mutation to discern their diagnosis, the appropriate type of treatment, and other preventative measures to recommend.

## Taken from GeneTests Laboratory website

### What is Genetic Testing?

A genetic test is the analysis of human DNA, RNA, chromosomes, proteins or certain metabolites in order to detect alterations related to a heritable disorder. This can be accomplished by directly examining the DNA or RNA that makes up a gene (direct testing), looking at markers co-inherited with a disease-causing gene (linkage testing), assaying certain metabolites (biochemical testing), or examining the chromosomes (cytogenetic testing).

### What is a Research Study?

Research studies are those in which specimens are examined for the purpose of understanding a condition better, or developing a clinical test.

#### Points to consider:

Laboratories performing research testing are not subject to CLIA regulation.

The cost of research testing is generally covered by the researcher.

Test results are generally not given to patients or their providers. If test results are shared with the provider or patient, the laboratory

must be CLIA approved. FYI, this is not always true. First, test results if disseminated are always given to the study participant, not to the provider. This is a key difference between a research test result and a clinical test. Second, Institutional Review Boards have granted permission for investigators to inform a study participant of his or her test result even if the laboratory is not CLIA-approved.

Rarely, a research laboratory will, at the patient’s request, share potentially useful findings with a clinical laboratory so the patient’s test results can be confirmed and a formal report issued.

Continued on page 5: Tests



# Pre Conference Family History Library Workshop Discovering Your Roots

The Family History Workshop will be held:

Thursday August 26th 2004 6:00 p.m.– 8:00 p.m.

Friday, August 27th 2004 9:00 a.m. – 11:00 a.m.

Knowing your medical history is very important in today's genetic environment—especially for people with LQTS & other genetic disorders. Come work with the experts (Katherine Timothy, geneticists and Loni Gardner, a certified genealogist) in the world's largest storehouse of genealogical records to find out more about your family which could help save a life.



For information please contact Gwen (gwen@sads.org or 800-786-7723) ASAP so we can send you a packet of information.

“I found several distant cousins I never knew about and who hadn't heard about LQTS. What a rewarding experience!”-Dick Stafford

The Family History Library is free of charge and open Tuesday thru Saturday 7:30 a.m. – 10:00 p.m.

## Healing Wall

Thanks to Patti Androsko, one of our devoted volunteers, the inception and first exhibition of the 'Healing Wall' in Atlanta was met with much approval and enthusiasm. So, we have decided to continue the tradition another year. The display will include photos and stories of people touched by Long QT. The format will be very similar to that in Atlanta.

Before August 10th, 2004, please send in a photo no larger than 4x6 inches and a written story no larger than 4x6 inches (about 200 words). An email containing your photo and story would be very beneficial but hard copy is ok too. If you have previously sent us a story for any other reason than the healing wall, we would be happy to include it with your permission. Just let us know.

It is so very humbling and inspiring to learn about the grief, courage and bravery of families living lives affected by cardiac arrhythmias. Thank you for sharing experiences to benefit the lives of others.

For more information, please email Dave at [dave@sads.org](mailto:dave@sads.org)

## New this year! Pre-conference CPR—AED Certification Training

Friday, August 27<sup>th</sup> — 8:00 a.m. — 12:00 p.m.  
\$25.00 per person (limit 12 people)  
Must be 16 years or older

**Teen CPR/AED Training** Saturday afternoon is part of Teen program  
No certification but will have hands-on practice  
No extra charge—included in Teen registration.



*Arches National Monument, Photographer: Frank Jensen,  
Courtesy of Utah Travel Council*

## Post Conference Retreat

**Arches National Park and Colorado River  
August 29th – August 31st**

Join us for a delightful, fascinating and relaxing tour of Utah's most unusual and beautiful scenery. We have arranged for a 3 day, two night vacation package that includes a Monday night buffet overlooking the Colorado River and one activity such as: the excitement of rafting the Colorado River, and/or horseback riding in famous castle valley, golfing or down-hill mountain biking plus hiking through Arches National Park. All this combined with the all-inclusive comfort and amenities of Red Cliffs Ranch on the banks of the Colorado River

**Limited space available—sign up early to reserve your spot (before July 30 for the best rate of \$199/person total for the first two people in room. Additional persons up to 6 in Queen Suite \$119.00 per person if available.)**

**More information: [www.sads.org/conf04/Moab.htm](http://www.sads.org/conf04/Moab.htm)**

# A Life Saved, A Life Given

The day was beautiful and sunny and special; it was the day of my baptism. The water felt wonderful and I stepped in to the creek. That's the last thing I remember. I passed out and fell down face-first as I left the water. 911 was called and CPR was started. I woke up and was taken to the hospital by ambulance. Doctors thought that epilepsy was possible and recommended an EEG. My parents had them do a cardiac workup also, which was negative.

During the next 2 years I experienced three more "fainting spells" that no one could diagnose. In 1991, at age twelve, I experienced my third faint while playing on a merry-go-round. My parents took me to Children's Hospital in Seattle. The next day, while playing in a piano recital, I had a cardiac arrest. I was taken to the hospital in Walla Walla unconscious and in cardiac distress, and then transported to Seattle.

For four days I remained in a coma. My parents were told I might never awaken and that I had suffered brain damage from the length of time my heart was stopped. Then, I woke up—a miracle.

Dr. Bardy diagnosed Long QT Syndrome and bradycardia and suggested an implanted cardiac defibrillator (ICD). In April of 1991 my first ICD was implanted and I was started on Inderal (a beta-blocker).

Over the next few months I experienced numerous 'firings' of my ICD. After each episode, I traveled to Seattle to have the ICD checked. A surgery re-attached a broken lead, dislodged while I was playing with a rowing machine. After 2 1/2 years I received a new ICD (usually they last 4-6 years). At least this new device was smaller and much improved. In 1996, while carpooling to school with a friend, the device suddenly shocked me without warning. A lead had broken and I needed my third ICD.



Taliba Tomezek

Sarah Tomezek

In 1997, while vacationing in Idaho, on the St. Joe River, my family suffered its greatest loss to LQTS. It was a beautiful summer day and we had all jumped in to "ride" the waves of a passing boat. As my youngest sister Sarah and I were climbing onto the dock, Sarah turned around to see Talitha, our middle sister, floating face down in the water. Sarah pulled Talitha's head out of the water and my mom and I pulled her onto the dock and started CPR. An ambulance arrived and took Talitha to the local hospital. She was defibrillated two more times without effect. Talitha was airlifted to Spokane and, during the next three days, our family and friends hoped for another miracle.

On August 3, 1997, my beautiful sister was pronounced brain dead. She was 16 years old. Talitha had wanted to be an organ donor so we made the difficult decision to pass on the gift of life.

Due to the genetic likelihood that LQTS affected Sarah, my parents were encouraged to have an ICD implanted as a precaution. Sarah has dealt with the frightening events of my diagnosis, survived the death of a sibling, and adjusted to life with an ICD of her own. She has grown into a beautiful young woman and will graduate high school this year.

Long QT impacted my life in a profound way. Several of my close friends found my diagnosis too frightening to deal with and distanced themselves from me. Despite restrictions on activities, I remained involved in 4-H, rode horses, became a junior volunteer at Walla Walla General Hospital and earned my Certified Nursing Assistant (CAN) license my senior year of high school. I married my high school sweetheart, Nicholas and work as a registered nurse at Children's Hospital and Regional Medical Center of Seattle.

- Rachael Tomczek

## VOLUNTEERS NEEDED TO MAKE CONFERENCE SUCCESSFUL

"The SADS Foundation's success is based on thousands of individuals and families who share their stories, strength and financial resources. Physicians and researchers contribute their knowledge, clinical care and time. I thank you all, and invite your participation and support of the SADS Foundation and its life-saving programs."

G. Michael Vincent, 2002

We would like to thank all of the volunteers who have gener-

ously been helping with the planning of the 3rd International SADS Conference. We welcome volunteers who would like to help in any of the following areas: Media, Hospitality, and/or Logistics.

For more information on volunteering to help with the conference please contact Gwen Davis, Program Director or at [gwen@sads.org](mailto:gwen@sads.org) or 1-800-STOP-SAD (786-7723)

Tests: Continued from page 3

Requests for participation in research may be denied, at the laboratory's discretion, if the laboratory has sufficient samples or the family does not fit the research project goals.

### What is a Clinical Test?

Clinical tests are those in which specimens are examined and results reported to the medical care provider or patient for the purpose of diagnosis or treatment of an individual patient.

### Points to consider:

United States laboratories

performing clinical tests must be CLIA approved.

There is a charge for clinical tests; cost varies by complexity of the test.

Test results are reported in writing to the referring physician ordering the test.

The time between specimen submission and reporting of results varies between laboratories and may be based in part on the complexity of the testing.

# FREQUENTLY ASKED QUESTIONS

1. **My son only fainted once, a year ago, and it hasn't happened again since. Do I still need to be concerned?**

Yes. A single fainting spell or blackout can be the first sign of Long QT Syndrome (LQTS). If the faint happened with exercise or while swimming, or if other family members have also experienced fainting spells or a sudden unexplained death, you should have your son seen by a cardiologist or electrophysiologist.

2. **Neither my daughter's father nor I have ever fainted and we have had no sudden deaths in our family. Our daughter can't have Long QT Syndrome then, can she?**

Yes, she still could. The absence of fainting in a family does not mean that your daughter doesn't have LQTS. About 1/3 of people who inherit this condition have no known family history of fainting spells or unexplained sudden deaths. Therefore, the parents could be LQTS genetic carriers and could have passed that gene on to their children.

3. **My son died three years ago and his death was attributed to arrhythmia. I've read up on Long QT Syndrome and it sounds like my son may have had this. What should I do?**

First, SADS can send you a medical packet with the most current findings about LQTS. Next, if you have other children, they need to go to a pediatric cardiologist or electrophysiologist and be screened for LQTS. Both birth parents need to be

screened by an adult cardiologist or electrophysiologist as well.

The screening is performed by having an electrocardiogram or EKG Stress Test. This is a simple, non-invasive, and relatively inexpensive test. It is the best method, next to genetic testing, to identify inherited LQTS. The key issue is that the screening of other immediate family members is critical to identifying LQTS as the possible cause of death of a deceased loved one and, if it is found, diagnosing and treating the affected relatives to prevent additional tragic deaths.

4. **Following my daughter's unexplained sudden death our two other children had EKG stress tests and neither of them showed a prolonged QT interval. Does that rule out long QT syndrome as the cause of her death?**

No, each child has a 50-50 chance of inheriting LQTS from the affected parent. Therefore, it is quite possible that your daughter inherited it while your other two kids did not. Both of her biological parents need to be screened to rule out inherited LQTS. If both tests come back normal, then it is very unlikely that your daughter died from LQTS.

5. **What QT interval is considered prolonged enough for a diagnosis of LQTS?**

The best discriminator between an LQTS heart and a normal heart is a QTc (rate-corrected QT interval) of 0.46 seconds or longer. Approximately 30% of LQTS patients have a QTc interval shorter than this, and a small percentage of healthy individuals have a QTc of 0.45 or 0.46. Therefore, this discriminating point is neither completely sensitive nor specific\*. A QTc interval of 0.48 seconds or greater in women and 0.47 seconds or greater in men appears to be nearly diagnostic of LQTS in the absence of drugs or other forms of heart disease which might independently lengthen the QT interval.

\*other symptoms and family history become critical clues.

6. **I was diagnosed as "borderline" LQTS. What does that mean?**

Borderline means that the QT interval on the electrocardiogram is not diagnostic of long QT syndrome but overlaps with the QT interval of normal heart rhythms. Thus it is not diagnostic and further tests, such as a Holter monitor (you wear this for a period of time) or a stress test (ECG when walking on a treadmill), are necessary to clarify the diagnosis.

7. **My son's doctor is restricting him from all competitive sports, is that really necessary?**

Many LQTS symptoms/events, such as blackout spells and sudden death, occur during or immediately following physical activity, especially when associated with intense emotions. Physical activity coupled with high emotions is a key component of competitive sports. However, many LQTS patients can participate in modest recreational sports depending on their individual circumstances, including the presence of previous symptoms, QT interval during exercise and their treatment.

8. **What, if any, are the long-term side effects of beta blockers?**

Beta blockers have almost no long-term side effects. In the absence of asthma or underlying diabetes there are no known long-term side effects. It has been demonstrated that children taking beta blockers throughout their growth and development years seem to have no adverse consequences. In young women, it appears that beta blockers, particularly Propranolol, can be safely taken during conception, pregnancy, and breast feeding. Some uncommon short-term side effects of beta blockers are lethargy, weight gain, and depression. If you are noticing any of these side effects, talk to your doctor about temporarily reducing the dose, which usually allows the body to adjust and the symptoms to disappear, or switching to another brand of beta blocker. There are several on the market which are very effective for LQTS.

## Long QT Story Media Awareness Campaign

Thank you for the many stories and pictures documenting how LQTS has affected your life, your family and your friends.

Matt Lambert, a media volunteer, is writing a press release and cover letter to introduce the stories in a package to send to the media for the 2004 Awareness Campaign.

If you have any media connections—know any people in the media we should contact, please contact us.

We are continuing to collect stories—if you would like your story included in this effort, please send it to me by the end of May: [gwen@sads.org](mailto:gwen@sads.org) fax: 801-531-0945 SADS Foundation 508 East South Temple Salt Lake City, UT 84102 phone: 800-786-7723.





# DOUBLE YOUR DOLLAR!

Individual donors contributed more than \$100,000 to SADS Foundation programs in 2003. We hear that most newsletter readers work in corporate America. Most employers will match employee's donations to organizations like SADS dollar for dollar—sometimes more! The fastest way to fund conferences, awareness campaigns, physician education and other SADS programs is for generous donors like yourselves to complete your employer's matching gift form, usually available from your manager or human services department, and send it along to the Foundation when you make your gift.

**Thanks to these companies for matching employee support.**

<b>Abbott Laboratories</b>	<b>McKesson*</b>
<b>AT&amp;T</b>	<b>Moody's Investors Service*</b>
<b>Chevron</b>	<b>Oracle</b>
<b>Cisco Systems</b>	<b>PNC Bank Corp</b>
<b>Citigo</b>	<b>Speer Leeds &amp; Kellogg</b>
<b>Legacy Marketing Group</b>	<b>State Farm Insurance</b>
<b>Lockheed Martin</b>	<b>TAP Pharmaceuticals</b>
<b>JP Morgan Chase</b>	<b>Tenet healthcare</b>
<b>Lucent*</b>	<b>FleetBoston Financial</b>
<b>Mellon Bank</b>	
<b>Merrill Lynch</b>	

\*These companies will make financial grants to SADS based on employee volunteer hours, not monetary donations.

## No Ball At All—the BEST party to miss

Many thanks to this year's No Ball Dinner Committee. They've been slaving away, organizing their rolodexes, buying band-aids for paper cuts, and mixing antidotes to envelope glue goo, all in preparation for SADS' most unforgettable non-event! Each year's No Ball "guests" cover the costs of the SADS' telephone, webpage, and much of the newsletter, for the entire year.

### 2004 No Ball Dinner Committee

Mary and Charles Berg	John and Kathleen O'Hare
Suzi, Paul, Hank and Kyle Dollman	Terry & Vicki O'Neill
Denise and Christopher Falzon, <i>in memory of our son, Brian</i>	Valerie and Gary Pemberton - <i>Tom is doing great with assistance of organizations like SADS! Please join us in our "No Ball At All."</i>
Caroline Kelly Figenshu <i>in memory of my daughter, Donna Marie Kelly, 1962-1984, loved and remembered daily</i>	Pamela L. Reich
Shirley Gaster	Dorothy and Jim Renner
Larry and Rona Greenstein	Mark, Nettie, & Bobby Simpson, in honor of James Simpson
Jodi Wilinsky Hill and Frank Hill	Alice Smith, <i>in Loving Memory of Stephen A. Smith. Stephen Smith left this world abruptly with words unsaid, dreams unachieved and life unfinished. Please help mend other broken hearts</i>
Kathy and John Ibbetson, <i>in Chickie's memory</i>	Katherine Timothy
Barbara LaBarr	Jon and Martha Zaborowski
The Larivee Family, <i>in memory of our beloved daughter Kellie Louise Larivee</i>	
Sharon and Jim Lentino	
Robert P. Magner, Jr.	
<i>Thank you from Mariah, Rachael, Ahlea, Terra and our future children with Long QT</i>	

This year the event will be held any evening this summer, in the privacy of your own home, with the family members you care most about. If you haven't received and

invitation, and have dinner dress you're just dying to wear around the house, please call Sarah at 800-786-7723 to purchase your ticket to the best non-event of the year!

## Join the Legacy Circle

For more than ten years the Sudden Arrhythmia Death Syndromes Foundation has been saving the lives of young people afflicted with Long QT Syndrome and other hereditary arrhythmias. Over this time, hundreds if not thousand of lives have been saved through SADS work. None of this would have been possible without the financial support of thousand of people and institutions believing sincerely in the importance of this work and difference that is being made.

In order to better fulfill the mission of the SADS Foundation, and to appropriately acknowledge the financial generosity of those who make SADS' efforts possible, the Foundation has established the SADS Legacy Circle. *See the enclosed Annual Report for the Circle's current membership.*

### Benefits of Circle Membership

- Semi-annual updates from the Executive Director and Board President.
- Exclusive invitations to annual Circles of Support receptions.
- Advanced invitation to SADS events occurring around the country and internationally.



## SADS E-Newsletter

On May 1st, 2004, the very first SADS electronic newsletter was launched into cyberspace and should have arrived safely in your "inbox." If you did not receive our e-newsletter, perhaps...

*We do not have your current email address? Or we do have your email address but we're not getting through?*

We may have been inadvertently blocked by your 'anti-spam' program. Please check with your ISP (internet service provider) or email service provider. Make sure sads@sads.org is on your "good" list. The word SPAM next to FROM SADS is a good indication we are on your "bad" list.

If you want to receive our e-newsletter and did not, please let us know.

dave@sads.org or 800-STOP-SAD

(All personal information provided to SADS is for internal use only —unless permission is granted otherwise.)

## Networking Program

After a temporary hiatus, the SADS Networking program is up and running. Our objective is to simply provide contact information and limited medical histories of people living with LQT who desire to communicate with others in similar circumstances.

The program is not, however, a vehicle to obtain medical advice. Always seek medical advice from qualified health professionals.

*The quick and easy protocol is:*  
Fill out a short online form at [www.sads.org/networking.htm](http://www.sads.org/networking.htm)

Checkmark the 'permission' box which allows SADS to share very limited personal information such as first name, state of residence, email address, medical diagnosis and treatment, etc.

Access the password-protected portion of the website to contact and communicate with other people in close proximity or similar circumstances.

(Respect for participants' privacy and sensitivity is of the utmost importance. Involvement in the Networking program is strictly voluntary. You may have your information removed from the site at any time. Thank you.)

## What's New on the SADS Site?

Recent stories and pictures you have shared with us over the past few months  
[www.sads.org/stories/index.htm](http://www.sads.org/stories/index.htm)

Atlanta Conference Attendee list for those of you who want to stay in touch  
[www.sads.org/Atlanta/atlanta\\_networking.htm](http://www.sads.org/Atlanta/atlanta_networking.htm)

New information on genetic testing  
[www.sads.org/genetics.htm](http://www.sads.org/genetics.htm)

Networking Program enrollment form  
[www.sads.org/networking.htm](http://www.sads.org/networking.htm)

### We welcome your feedback!

Please let us know changes/additions you would like to see on the site.

It's here for YOU.  
([dave@sads.org](mailto:dave@sads.org))

