



Genetic Testing For Everyone

Genetic testing for LQTS is now the “standard of care” and for other SADS conditions (like CPVT, Brugada, etc.) it is increasingly being used to diagnose and treat people. For people with high QT numbers, the genetic test will help your physician recommend treatment—including an ICD. It will also help your family members to get diagnosed and treated. For people with a “borderline” diagnosis because your QTc number may be low (more

normal) and you have no symptoms, genetic testing can help “rule out” or “confirm” your diagnosis of LQTS.

There are two commercial, CLIA certified labs from which your physician can order your genetic test: PGx Health and GeneDx. As with other services, it is important to be a wise consumer so research each company to see which is the best choice for you.

COMPANIES THAT TEST FOR LQTS

PGxHealth

www.pgxhealth.com/familion

Customer Service Department at
877-2-PGxHealth (877-274-9432)

GeneDx

www.genedx.com/site/cardiology_genetic_testing_services

301-519-2100

Strategies for Navigating Genetic Testing?

1. Test the most symptomatic person in your family (or the one with the highest QTc number) first OR the family member who has a “good” diagnosis and has good insurance.
Rationale: this is the most expensive test for the family—all other family tests are much less expensive when you know the family mutation
2. Appeal your insurance company’s decision if it doesn’t pay enough of the cost. Sometimes multiple appeals are necessary. For help: talk with the lab that is doing your test, look on SADS’ website for information, or contact Joanne Robinson at 800-786-7723 (Joanne@sads.org). Remember it is especially helpful to have your employer advocate for you.
3. Research what, if any, financial assistance programs are available at each company

Was your genetic test negative?

If your Familion or GeneDx genetic test was negative you should:

- Talk with your physician to see if she/he thinks you really don’t have the condition (LQTS, etc.)
- Discuss the need for a second opinion (SADS can help you or your physician with this) to see if your other tests would still be enough to diagnose your condition. Remember, in none of these SADS conditions do we know all the genes responsible
- If you and your physician think you do have the condition but have an unknown gene, contact SADS, or have your physician contact SADS, for a list of research labs that have an interest in further analysis of “negative” samples



If your research genetic test was negative you should:

- Contact all the labs where your sample was sent and make sure they have your current contact information
- Ask the lab if they compare your sample against newly identified mutations, and if so, how often and when the last comparing was done
 - Ask them if they need any new samples from you
 - Consider getting the “index” or full test again through Familion or GeneDx—a lot has been discovered since early research tests

Laura Wall, Vice President of Development and Marketing

I am delighted to have joined the SADS team. I have many years of non-profit fundraising experience including work with the American Heart Association, the David Eccles School of Business and the Swaner EcoCenter. I am a native Utahan, and graduated with a BS in Communication from the University of Utah with an emphasis on marketing. I bring enthusiasm, passion and

excitement for this amazing cause, as well as extensive experience in capital campaigns, raising and managing annual and operating funds, event planning, soliciting donations and volunteer management.

I live in Salt Lake with my three lovely children and enjoy spending time gardening, writing, and being with my family.



Congratulations to SADS Scientific Advisor, Dr. Charles Antzelevitch

Masonic lab celebrates 50 years of service

"What we're celebrating is 50 years of service to humanity," said Charles Antzelevitch, executive director and director of research at the laboratory. "We're celebrating 50 years of accomplishment in which we have made a very impressive mark on the medical community." Today, the lab is known around the world for research in experimental cardiology.

Our new Program Coordinator

Adrienne Butterwick graduated from the University of Utah in 2007 with a B.S. in Behavioral Science and Health with a minor in Biology. During her undergraduate experience, she was involved in many student health and anti-sexual violence groups. Since she received her degree, she has been working as a research scientist in the pharmaceutical sector. She enjoys spending her time cycling, kayaking, reading, and playing with her cat Eleanor. She is extremely excited to be a part of the SADS Foundation and hopes to help make this year's awareness activities the best yet!



Heidi Wachter

I am so thrilled to be the SADS Foundation's new office manager/program associate. I am a native of St. Paul, Minnesota, but have lived in several states and have traveled worldwide. I earned a Master's Degree in Feminist Studies from San Francisco State University and a Bachelor's from Mills College in Women Studies and Literature.



I've been looking to break into the non-profit world for years and set a goal to start my own organization before I'm 40. My past jobs were in the legal, marketing/advertising, printing and consulting fields. I've volunteered and interned at many non-profits and am excited to be part of the SADS team and put all my past educational, technical and professional experience to good use raising money, raising awareness and saving lives!

SADS
FOUNDATION

**Sudden Arrhythmia Death Syndromes
(SADS) Foundation**

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SADS Safe Schools Month A Success

Volunteers in every state worked to make their school a SADS Safe School during the 2nd Annual SADS Safe Schools Month this September. Distributing materials, initiating AED programs and Medical Emergency Plans and making sure their kids had a Care Plan in case of an emergency—SADS volunteers are great!



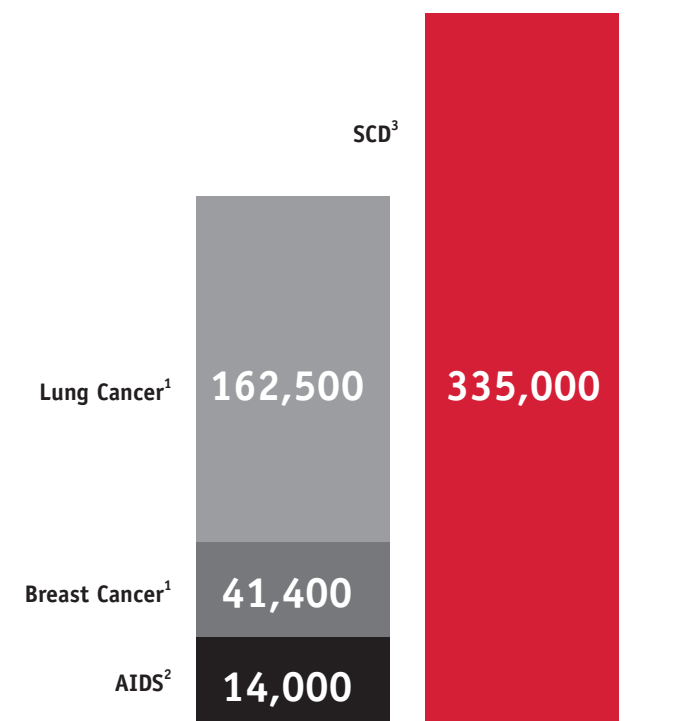
SCA Awareness Month Coalition

SADS has organized a Coalition of Advocacy Groups for Sudden Cardiac Arrest (SCA) Awareness Month comprised of advocacy organizations that have an interest in promoting awareness of SCA and in prevention of SCD. In May, Alice Lara invited groups to meet in Boston and develop plans. The SCA Coalition is focused on national issues that have the opportunity to influence the media, policy makers and health care providers. We are passionate about preventing sudden cardiac arrest deaths through initiatives that lead to greater public awareness, research and access to life-saving therapies.

For October, 2009 we will have a coalition website with messages about SCA (stopcardiacarrest.org), media “events” with survivors and material for volunteers from all organizations to get to the public.

If you would like to help us “get the word out”, contact Adrienne at Adrienne@sads.org or 1-800-Stop SAD.

Sudden Cardiac Death claims more lives each year than these other diseases combined:



1 American Cancer Society. Cancer Facts and Figures 2006.

2 CIA. The World Factbook – Rank order – HIV/AIDs – deaths. Available at <http://www.cia.gov>.

3 American Heart Association. 2005 Heart and Stroke Statistics Update.

Announcing SADS New 2010 Awareness Campaign!

We have developed an exciting new Awareness Campaign to help us “get the word out” about SADS conditions in a big way in 2010. Watch our website for more information and be sure we have your email address for early announcements of the exciting campaign activities. Or email Adrienne (adrienne@sads.org) or call 1-800-STOP-SAD (786-7723) to get involved. Be a part of this new campaign to save a life!

Sudden Cardiac Death is significantly under-reported. Even medical experts say that fatality rates may be much higher because SCD deaths are often mislabeled as “heart attack” or “SIDS” or “drowning.” Frequently, no autopsy is performed.

To have a chance of surviving, victims of Sudden Cardiac Arrest must receive a life-saving defibrillation within the first 4 – 6 minutes of an attack, when brain and permanent death start to occur.

Automatic External Defibrillators (AEDs) can increase the survival rate for SCA up to 90 percent.

My Daughter Was Amazing

Stephanie Mejias, an elementary education and psychology major at The College of New Jersey, passed away suddenly in her sleep on July 27, 2009. With no signs of fatigue or symptoms of any illness, Stephanie was unexpectedly taken away from the ones she loved. She was 19 and would have been a junior this year. Her death quickly ended an opportunity for a dedicated student to help the ones she really cared for: her family, friends and the students she hoped to teach one day.

She was also very active in her school and community. She swam for Union High School and also competed for the Cranford Gators swim team in Cranford, N.J. Not only did she turn out to be an accomplished swimmer, she also studied and practiced karate, eventually earning a black belt.

Her sudden death came as a shock to everyone. However, many were quick to show their love and support. The family received a massive response from close friends and sorority sisters during the viewing and funeral, which took place on July 30 and

31, respectively. Even people who were not available to attend the services sent their regards in any way they could. "My daughter was amazing. The viewing was unbelievable. My family and I were humbled by how many people she touched," Stephanie's father said.



Stephanie truly impacted the people she was around. "What I learned from this whole situation was that you never know how long you have with someone," Stephanie's best friend said. "What is even more amazing is how someone as special as Stephanie can truly touch and move you in any way possible."

One of Stephanie's favorite quotes helps people remember what kind of person she really was: "Do not look back and grieve over the past, for it is gone; and do not be troubled about the future, for it has not yet come. Live in the present, and make it so beautiful that it will be worth remembering."

Gifts in Memory

Establishing a memorial fund is a meaningful way to honor and remember your loved one while making a difference. It is also a way for friends and family to remember their loved one every year.



If you would like to establish or contribute to a memorial fund, please contact Laura at laura@sads.org or call 1-800-STOP SAD.

Heart Beaters:

Libby Jaekel

Special thanks to Libby Jaekel who was the pioneer of the SADS Facebook page. She wrote: 'I'm pretty excited to see that it really has helped people. I created the first group to help support others and push for awareness of the disease to help save lives. I hope that its growing success continues!' Little did any of us know it would grow so fast and touch so many people. Way to go, Libby! As of mid-September, there are more than 5,000 members of SADS Facebook Cause.



Greg Totero

Greg Totero, a junior at the State University of New York at Geneseo, spoke at the SADS Family Seminar at NYU this May. Greg had a cardiac arrest at the age of 7, and was implanted with an ICD. He spoke about the challenges of growing up with Long QT, and how those challenges helped shape him into the successful college student he is now – enjoying a 'great life and good friends'.



BJ Ellis

BJ Ellis, a high school senior, presented a visual overview of his life with Long QT at the SADS Family Seminar in New York City on May 16th, 2009. Diagnosed at 2 years old after several fainting episodes, BJ has been on beta blockers ever since. BJ's presentation covered his journey from childhood to the present time. BJ was captain of the drum section in the school band his senior year. To view a copy of BJ's Power Point, please visit our website at www.StopSADS.org.

3rd Annual Climb to Conquer SADS

We are delighted to announce that our 3rd Annual Climb to Conquer SADS was the most successful yet. Our team of 9 climbers reached the summit of Mt. Rainier and honored families affected by SADS conditions. The summit was snowy and wind-swept, but that didn't stop our climbers from sharing their inspiration to complete the Climb. Brian Hoots, climbing in honor of Nancy Adams' son Jesse,



said that upon reading Jesse's story to the team, the clouds parted and the mountain greeted them with clear blue skies and the sun shone brightly on them. As tears welled in their eyes, each acknowledged the higher purpose of why they were doing the Climb. As they descended, they moved into a world where everything was a fresh white, painted in sunshine. Sign up now to support Climb 2010!



Thanks to Suzie Diston, our Climb to Conquer SADS Coordinator this year! She volunteered many hours to make sure Climb with was a success. (Suzie, Nancy Adams and Laura Wall)

Family Fundraising Events

It's been a busy year for friends and families of the SADS Foundation as they plan and execute amazing events around the country. If you and your family are ready to start a fundraising and awareness-raising event in your area – you're in great company! We have all the tools you'll need to make a successful event. Below is a small sampling of some of our events:



In February, the Badger Family put together a beautiful gala event – the 4th annual Brianna Badger Memorial Starry Night Gala, in Denver, CO. Guests mingled as they shopped in the silent auction, and listed raptly to former Miss Massachusetts as she spoke of overcoming the challenges presented by her Long QT diagnosis.

In Green River, Wyoming, the family of Keith L. Young organized the First Annual Keith L. Young Memorial 5-K run/walk in honor of Keith who passed away due to a heart arrhythmia while training for a marathon. More than 400 community members

rallied together on the cool, breezy day, to raise funds and learn more about SADS conditions.

The family and friends of Ryan Weidler held the most successful golf tournament to date this year in Norristown, PA. The 4th Annual Ryan Weidler Memorial Golf Outing raised an outstanding \$10,000 which will go to support the families and save the lives of those affected by SADS conditions.



Folks in Carol Stream, IL have a special way to celebrate the holidays. In honor of Brittany Valene who died in February 2005 from complications of Long QT, the neighbors keep her memory alive with "Brittany's Trees". Thanks to the Guthrie family, trees

are set up on lawns throughout town the Saturday after Thanksgiving. For a small donation of \$35, neighbors get a tree stand and pole, three sets of white lights and a real 6 foot Scotch pine tree.

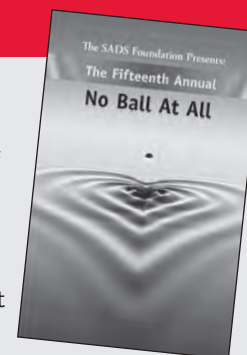
Our newest fundraiser was organized by a young man in Scotts Township, PA. Alex Rojak lives (and thrives) with Long QT. He orchestrated the first annual Sing It! For SADS event. This was an American Idol type competition. Alex is doing a phenomenal job!



Of course, this is a small sampling of the family fund-raisers that are going on all the time. For an up-to-date calendar of events, be sure to visit our website at www.StopSADS.org.

No Ball At All

It's not too late to participate in the No Ball at All campaign for 2009. This year's art work was provided by Bill Badger (Brianna Badger Starry Night Gala), and features the story of Mary Hardies' daughter, Heidi. It's a very impactful way to get your friends and family to understand the importance of raising awareness of SADS conditions. It's also a convenient way to make a donation to the SADS Foundation. Call and get your No Ball invitations today.



SADS Family Seminars

So far in 2009, SADS has sponsored or co-sponsored three SADS Family Seminars.

January 10th Dr. Sylvia Priori, a SADS board member and international expert on LQTS, spoke to 40 family members at the "Is it in the Genes?" seminar. Dr. Priori has established a practice at NYU Medical Center which includes a state of the art research laboratory.

On May 16th at NYU, the SADS Foundation organized a family seminar and more than 40 people attended. Julia Wynn, a Genetic Counselor at Columbia University Presbyterian Hospital spoke on the Genetic Information Non Discrimination Act (GINA), and BJ Ellis and Greg Totero, two youth speakers, shared their experiences about growing up

with LQTS. Jill Miller, an attorney in New York, shared her experience dealing with her insurance denial for genetic testing. Thanks NYU for donating the space and lunch!

On August 22nd SADS co-sponsored a seminar with Arizona Pediatric Cardiology Associates and Phoenix Children's Hospital.



There were 98 family members and 21 school nurses who registered. Dr. Mitch Cohen, a SADS Scientific Advisor and Pediatric Electrophysiologist at Arizona Pediatric Cardiology gave an overview of channelopathies. Dr. Susan Etheridge, SADS board Vice President and Professor of Pediatrics at Primary Children's Hospital in Utah, spoke about genetic testing. Dr. Klaus Romero, from ArizonaCERT, spoke about drugs that affect the QT interval. Thanks Arizona Cardiology Associates for lunch and Phoenix Children's Hospital for the room!

Watch our website (www.StopSADS.org) for more seminars this year. Contact Joanne (Joanne@sads.org or 1-800-Stop SAD) if you want to help organize a seminar in your area.

SADS Participates in National Conferences in 2009

(HRS) Heart Rhythm Society Scientific Sessions, May 13-16, Boston, MA

SADS educated health professionals with our booth and materials about SADS conditions and the resources we offer to their patients. HRS is primarily made up of pediatric and adult electrophysiologists (cardiologists who specialize in the electrical system of the heart). This is the key medical group that deals with SADS conditions. The HRS conference and their scientific journal are sources for your physician to find the latest research for SADS conditions. More than 13,000 physicians attend from



countries around the world. We also held the annual meeting of our Scientific Advisors during HRS. We focused on universal screening for SADS conditions this year—where we are and where we need to go to make this a reality.

Genetic Alliance Annual Conference, July 17-19, Washington, DC

Alice Lara, SADS' President & CEO, spoke at this conference. Joanne Robinson, SADS Director of Family Support Services, and Alice also participated in the conference's "Day on the Hill" visiting various legislator's offices to discuss advocacy points that affect individuals and families with genetic diseases.

National Association of Medical Examiners (NAME), September 11-16, San Francisco, CA

After meeting with the Utah State Chief Medical Examiner and discussing ways to increase education and collaboration between disease advocates and medical examiners, Alice Lara attended the NAME annual conference to advance that collaboration. We shared our booth with the National Society of Genetic Counselors Cardiac Special Interest Group.

Program Hopes to Identify New Genes

UCSF Comprehensive Genetic Arrhythmia Program hopes to identify new genes that are associated with arrhythmias and SCD and determine how mutations in these genes cause cardiac arrhythmias. In particular they are looking for subjects who:

- Have a history of palpitations, fainting, or near-fatal cardiac arrhythmias that are not the result of physical damage to the heart; or
- Have been diagnosed with one of the six types of arrhythmias they are studying; or
- Are a family member of a person with one of the arrhythmias under study.

Contact Heidi (heidi@sads.org or 1-800 Stop SAD) if you're interested in participating in this research.

Physicians Receive the Latest Information at SADS Seminars

This year we have greatly expanded the number of SADS physician seminars around the country. So far we have held meetings in cities ranging from Philadelphia and New York to Minneapolis, San Francisco, Salt Lake, Stanford, Alpena and Houston. Presented by Dr. Michael Ackerman, Dr. Susan Etheridge, Dr. Marty Tristani-Firouzi, and Dr. David Bradley, these sessions allow physicians to update their knowledge of the very latest research regarding SADS conditions.

For information about upcoming seminars: www.StopSADS.org. To request a seminar, email Alice (alice@sads.org) or call 1-800-Stop SAD.

Long QT Syndrome and H1N1 What do you need to know?

Things To Do When You Have The Flu

1. Avoid low blood potassium (caused by diuretic drug use, vomiting or diarrhea)
2. Be especially careful about not taking drugs which prolong the QT interval
3. If your child has a fever (over 100°), contact your doctor as she/he may need an EKG

Tamiflu and Relenza are drugs often used when a person has H1N1 (or is highly suspected of having it) and is at high-risk. As far as we can determine today, these drugs can be safely taken by LQTS patients

if needed. We know about a couple of children who have safely taken Tamiflu this summer with no problem. If you have had experience taking either of these drugs, please let me know (alice@sads.org or 1-800 STOP SAD).

Previous experience with the seasonal flu vaccine hasn't shown reasons for concern for Long QT patients. Since the H1N1 vaccine is still not available, there is no data at this time but our experts are recommending the flu and swine flu vaccines to their Long QT patients.

Insurance...

Insurance is wonderful, especially when it covers medically necessary diagnostic and treatment options! But when it doesn't, it can complicate your life at a time when you are adjusting to a SADS diagnosis in your family. Our website (www.StopSADS.org) has some great information to help—including two very thorough information sheets titled "Health Insurance Tips and Resources" and "Resources for Genetic Testing Insurance Questions". These are found under "Family Support".

Some insurance companies are good at covering SADS-related testing and treatment, but many are not. If yours is not, it is time to **APPEAL, APPEAL, APPEAL!** SADS can help make the appeal process easier. We can provide samples of successful appeals, with the identifying information removed. Some commonly appealed issues are:

- Paying out of network co-pays when there are no "in network" providers of that service (e.g. LQT specialists, or genetic testing).
- High co-pays
- Denied coverage for AEDs, ICDs, Genetic Testing, or a LQT Specialist

Many people don't realize that 2 or 3 appeals are just part of the approval process for some carriers. Most carriers also have the option to request an outside review company for your appeal. It is only when enough appeals are filed—and won—that policy is impacted, and carriers stop "automatically" denying coverage. For that reason we always encourage every family to begin the approval process with their company and appeal high co-pays or denials. Contact Joanne Robinson at 800-786-7723 or Joanne@sads.org, if you have any recommendations or questions.

What do you Need to Know About GINA?

The Genetic Information Nondiscrimination Act was signed into law by President Bush on May 21, 2008. GINA will prohibit discrimination on the basis of genetic information with respect to health insurance and employment. It prevents health insurers from denying coverage or adjusting premiums based on an individual's predisposition to a genetic condition. It also prohibits employers from discriminating on the basis of predictive genetic information.

The health insurance provisions took effect on May 21, 2009, and the employment provisions will take effect November 21, 2009.

For more information about how this will effect you, visit our website: www.StopSADS.org. If you have questions or wish to report discrimination based on your genetic information, or contact Joanne at Joanne@sads.org or 1-800-STOP SAD.



SADS Foundation Young Investigator Award in Cardiac Channelopathies

The Second Annual SADS Foundation Young Investigator Award in Cardiac Channelopathies was given to Stacy Killen, MD (Dr. George). This award is given to encourage

the next generation of researchers in SADS conditions and recognizes an outstanding, original, new academic work in the field of cardiac channelopathies.



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Local Volunteer Networks

Last month, SADS put the first volunteer contacts on our website—the Local Telephone/Email Volunteer and the Local Network Contact. Go to our website and check out your local area! Email your state contacts and let them know of your interest in any activities in your area.

Contact Joanne Robinson at 800-786-7723 or joanne@sads.org if you are interested in being a local contact or telephone/email support volunteer. You only need to: (1) have experience with LQTS in your family and (2) share your personal experience with newly or previously diagnosed families.

Advocacy Corner

Get the Latest



facebook

For Facebook – type in Sudden Arrhythmia Death Syndromes (SADS) Foundation. To follow us on Twitter, type in SADSFoundation. Happy Tweeting!

Do you have an AED?

Take this short, 3 minute survey and tell us about your AED experience. This survey will provide valuable information for us to better serve you and your family! And, we hope to use it to improve insurance reimbursement. StopSADS.org

Coming Events

2009 Events

National Society of Genetic Counselors (NSCG)

Atlanta, GA –
November 12-15

American Heart Association and Physician Seminar

Orlando, FL –
November 14-18

Brittany's Trees – Volunteer Event

Chicago, IL –
November 28

2010 Events

Parent Heart Watch Annual Conference

Arlington, Texas –
January 15-18

Brian Price Jump-a-thon-Volunteer Event

Dallas, TX
February 12

Brianna Badger's Starry Night Gala – Volunteer Event

Denver, CO –
February 27