



20 Years of SADS

Katherine Timothy

In 1989 Dr. Vincent made a formal collaboration with the Human Genetic Department at the University of Utah to discover the genesis of the Long QT syndrome. He then generously loaned Katherine Timothy to cardiologist and researcher, Mark Keating, to help in this quest. Katherine's logs, dated Friday, November 16th 1990, said "Had meeting with the Marks (meaning Mark Keating and his

mentor Mark Leppert), informing them of Dr. Vincent's success in arranging for pedigrees to be sent from Jerusalem and Italy, also that the Baylor group is very active in their own genetic research. Mark reported on finding linkage to chromosome 11 with an unbelievably positive lod score of plus 16. WONDERFUL FIND!" This was LQTS type 1.

April 19th 1991, Dr. Vincent presented his foundation ideas to the research group. He was most interested in furthering the education of physicians and research and to help people and families affected with the Long QT syndrome. At that time, he had been working with some branches of this very large LQT family for almost 20 years. He contacted an attorney friend to draw up the papers for a 501(c)(3) charitable organization. This friend, David Salisbury, was a man of extensive legal expertise and non-profit experience. He became the Vice President, Katherine Timothy was Secretary, and Dr. Michael Vincent was the President, Chair of the Board, and Chief Medical Officer. They were the founding members. This was the simple beginning of the SADS Foundation.

In 1992, Long QT syndrome and the SADS Foundation were featured on NBC's Today Show. This morning TV spot brought thousands of phone calls to LDS Hospital—so many, that every voice mail was jammed to the limit.

The SADS Foundation's mission and goals have remained the same for the past 20 years: to save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities. The goals/programs: patient family support, medical education, public awareness, and research/advocacy.

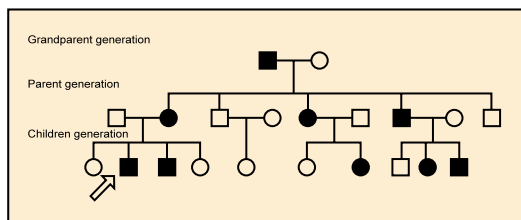
In the twenty years since its inception, more than 50,000 individuals have received educational materials and support. Chapters of SADS were established in Canada (1998), Great Britain (1999) and Australia (2000). SADS held its first international conference in London in October 2002.

To see the complete timeline of long QT syndrome (actually first seen on an ECG in 1957) and the SADS Foundation—as well as many pictures of the early years—visit www.StopSADS.org. To tell your story of a SADS condition (we especially want to hear from those early SADS families), visit the 20th Anniversary page on our website or call us at 1-800-Stop SAD.



Holidays – Time to Talk

The Holiday Season is a time for your family to gather and share stories, gifts, and meals. This year we hope you take a few minutes during this special time to reach out to family members who might not know there is a potentially dangerous genetic condition in the family. If you have not told all the branches of your family tree, now is the time. Please contact them before a life is lost to these treatable conditions. If you need assistance talking to your family, order a pedigree kit by contacting Anne Maurer, anne@sads.org. This informative kit will cover all the information and steps need to make sure your entire family is safe.



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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*Thanks for Making the
Last 20 Years possible!*

Heart.org Program

Log onto <http://radio.theheart.org/mayo-talks/2012/4/19/4-genetic-heart-rhythm-diseases-with-dr-michael-ackerman> to listen to "Genetic Heart-rhythm Diseases with Dr. Michael Ackerman," a heart.org radio program in collaboration with the Mayo Clinic.



CPR: Simple—and Effective!

By now you've heard the news about hands-only CPR, but have you told anyone else? Did you know that CPR is rarely used by the average person during the event of an emergency? Studies have shown that even watching a simple YouTube video can allow someone adequate skills to actually perform hands-only CPR and yes—save lives! You have an important opportunity to inform your friends and family of one of the most simple and effective ways to keep your community safe: CPR! Visit www.StopSADS.org/CPR for a variety of videos demonstrating hands-only CPR and the use of Automated External Defibrillators (AEDs) as well as materials and other helpful tools for helping others become informed. Even furry friends need a safe environment, so while you're there brush up on CPR for cats and dogs too!

Heartwarming Project in Honor of Casey Shockley

Casey Shockley was a 17 year old lacrosse player who passed away in 1996 due to an undetected SADS condition. Having left a lasting impact in the community of Chapel Hill, NC, a statue was erected in her memory at the high school she attended. Several years later when it came time for Cole Shoup, a boy scout from Casey's home town to determine his Eagle Scout project, he chose to spruce up the memorial statue and in the process, raise awareness of the warning signs of SADS conditions. Cole got many areas of his community involved including his soccer team and even hosted a press event with a physician from University of North Carolina! Visit the www.StopSADS.org/News to read the full story about Cole and his amazing project. We're so thankful to have young advocates such as Cole, working to make a difference in their community. Way to go, Cole!

If your child has or is working on a project that relates to SADS in any way, we'd love to hear about it! Contact Adrienne Butterwick, at Adrienne@sads.org or call 800-STOP-SAD.

SADS Ambassador Training

The SADS Foundation's 6th International Conference kicked off with the first ever SADS Ambassador Training in which patients, families and professionals were trained in various areas of volunteering including advocacy, awareness, fundraising, and family support.

We're very excited to announce that the Ambassador training will be offered virtually beginning in 2013! For all those who did not have the chance to attend the live Ambassador training, you can now take the online Ambassador training and receive your ambassador ribbon. Stay tuned for details on how you can access the virtual training.

A special thanks to everyone who participated and made the SADS Ambassador training a success. We look forward to building a stronger volunteer and support network and thus raising awareness to greater heights in 2013!

SADS Safe Schools Campaign

The annual SADS Safe Schools campaign was another huge success with volunteers in all fifty states and even several countries participating! This year, the campaign focused specifically on the following issues:

- * Every child should have a risk assessment history at regular intervals: preschool, before/during middle school, before/during high school and before participation in organized sports.
- * Every school should have a medical emergency response plan in place, which includes a plan for cardiopulmonary resuscitation (CPR) and an automated external defibrillator (AED) in schools.
- * Every school child with a SADS condition should have an individualized care plan in place.
- * Every school with a child who has a diagnosed SADS condition should have an AED program.
- * All high school students should be trained in CPR and AED protocol as a requirement for graduation.
- * Everyone should be aware of the warning signs that may indicate a child at risk of a sudden cardiac arrest.



As we prepare for the 2013 SADS Safe Schools campaign, it is important to consider other models of how schools and communities are working together to ensure a safe environment for all. Check out the SADS website www.StopSADS.org/Awareness/SADSSafeSchools for examples from other schools including tips to use in your community.

Kristen Hether's Story

When I was 26 years old, living in Alaska in 1996, I eagerly awaited my Reader's Digest every month. I remember being fascinated by an article highlighting Dr. Michael Vincent and his research on a condition called Long QT Syndrome. Coincidentally, a month later, while working at a doctor's office, my co-worker needed a test subject to try out the new ECG machine. The results showed a prolonged QT. Something triggered a recollection of the term "long QT" and the fact that this wasn't a good thing. By this time in my life, I had had five seizures and been diagnosed with an unexplained familial seizure disorder, which my sister also had. The next day I approached one of the doctors in the office and shared my concerns. I showed him the ECG results and told him about the article I had read. He must have given me a convincing argument as to why I should not worry because I let it go. Over the next few years, I experienced more seizure episodes and just attributed it to my unexplained seizure disorder. Then for 12 years I had no seizures and believed all of that was behind me.

In the spring of 2011, I went to a local hospital for a heart screening. The nurse went over the results with me and explained how great my blood work was and that I only had a 3% risk of developing heart disease in the next 10 years and oh, my ECG showed a prolonged QT so just be careful when standing, I might get dizzy. I left a little perplexed and felt some faint tug in my memory when I heard "prolonged QT."



The next morning I collapsed and seized. I had blood tests and another ECG and was to return on Monday. On Monday, I followed his nurse back to her office and barely made it to a chair before having another seizure. My cardiologist called later with news of great concern. She believed I was at risk for sudden death and asked if I had a history of passing out or seizures, or of any family members dying suddenly. I was fitted with an external defibrillator to wear 24/7 until they could confirm what was causing my condition. Two days later at home, I collapsed again and woke up to the sound of the defibrillator commanding someone to call 911. I had experienced a life-saving shock. This last episode led to my diagnosis of Long QT Syndrome. I now have an ICD which has defibrillated me one time since I received it a year ago. I pursued genetic testing for me and my children, siblings and parents.

One sister now has an ICD as a result of the genetic tests. All my children have a confirmed diagnosis as well as my other sister and one of her three children. The most amazing discovery was finding out BOTH my parents

have type 2 Long QT Syndrome! The SADS Foundation was instrumental in guiding me through this journey. They were an amazing source of knowledge and support as I tried to learn all I could about this life-altering condition. I have had the privilege of meeting with Dr. Ackerman at the Mayo Clinic where my children and I felt we had gotten our lives back and have a future to look forward to. I was also able to meet Dr. Vincent, whose Reader's Digest article 16 years ago is what led to our diagnosis. I know that God has spared me for a purpose. It is hard to read the stories of families that discovered their diagnosis through the death of a family member. Of course I now have a passion to inform people of this condition that can so suddenly destroy lives.

The SADS Foundation wants to thank several new corporate partners. Welcome to Merit Medical, AED.com, the Sorenson Foundation, Primary Children's Medical Center, Intermountain Health Care, and more. With the support of these excellent companies and foundations, we can save more lives! To become a corporate partner of the SADS Foundation, call Laura today! 1-801-531-0937.

NYU Family Meeting

The SADS Foundation paired up with NYU Langone Medical Center's Cardiovascular Genetics Program to host another successful Family Seminar on October 20th in the Big Apple. This year's seminar featured talks from Dr. Silvia Priori and her team which covered future treatment options and advances in the field of channelopathies. Families came away with an in-depth understanding of what the future holds for their treatment, and also got to meet other families with SADS conditions in their area.



Give the Gift of Life

As the holidays near, you're likely planning your shopping list. This year, make it easy on yourself and meaningful to others by giving a gift in someone's name to the SADS Foundation. We will send them a beautiful card letting them know of your thoughtful gesture, and you can check another thing off your busy holiday list. It's simple – just visit www.StopSADS.org and go to 'donate now' or e-mail laura@sads.org and we'll make it happen!

Oktoberfest and Heartoberfest!

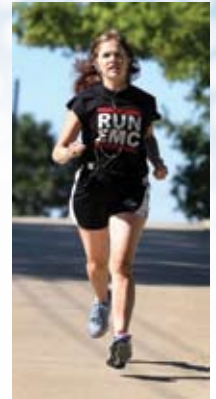
Bridging the country from Colorado Springs, CO to Saratoga Springs, NY, the Layton and Tolosky families hosted their own fantastic versions of Oktoberfest – raising funds and awareness nation-wide. The Layton Oktoberfest exceeded all expectations bringing more than 450 people to Bill and Sally Layton's home in Colorado Springs and raising the most money in their history – topping out at \$10,300! Special thanks to these incredible people for their ongoing support.

The Tolosky's Christie's Heartoberfest drew people from all over upstate New York to this special gathering in memory of Christie Tolosky. Crowds oohed and aaahed over the amazing auction items and donated generously. Prost! (German for cheers), and well done!



Erin McGuire Clark is our Global Hero!

Erin, a 44-year-old with LQT was one of 25 long-distance runners from across the globe who was honored as a 2012 Medtronic Global Hero as part of the Medtronic Twin Cities Marathon on Oct. 7. The program honors runners with implanted medical devices who continue to pursue their passion and serve as inspiration to others. Erin wrote: "...much of my story is thanks to the SADS Foundation! I have designated the \$1000 donation from Medtronic to go to the SADS Foundation in honor of Dr. Michael Ackerman for his passionate dedication to helping patients to "live full."



Where's Bob? Ask Phil and Manny!

New developments are in store for the "Where's Bob?" campaign for 2013. Meet Phil and Manny – two exceptional young men who are picking up the baton and are visiting 6 western states representing "Where's Bob?" and the SADS Foundation. You can order your "Flat Bob" and your "Flat Bob" t-shirt today at the SADS Foundation's store. Stay tuned for news.

Got Heart?

Lyn Gizzi and her family held a SADS Awareness and fundraising day called "Got Heart?" at their home football game September 22. This event, in honor of Hunter Gizzi who was recently cleared to

play his favorite sport – football - spread the word about SADS conditions and the SADS Foundation. They have raised \$7,500 for the SADS Foundation so far! Photo: Irvington Football Team.

Announcement of Courts K. Cleveland, Jr. Endowment

We are absolutely thrilled to announce the first endowment gift to the SADS Foundation, provided by the widow of the late Texas philanthropist, Courts K. Cleveland, Jr. The endowment will fund the SADS Foundation's



Young Investigator Awards which are given to outstanding young researchers in the field of cardiac channelopathies. To learn more about Courts K. Cleveland, Jr., or how to establish an endowment, please visit our website.



Long QT Syndrome and Sports Participation

In this brief, but important research letter entitled Competitive Sports Participation in Athletes with Congenital Long QT Syndrome, published online July 21, 2012 in JAMA, authors Dr. Jonathan Johnson and Dr. Michael Ackerman discuss results from a study of 353 long QT syndrome (LQTS) patients evaluated at the Mayo Clinic. Records were reviewed for athletic participation after their LQTS diagnosis and LQTS-related events during a mean follow up of 5.1 years.

The authors describe that their approach at the Mayo Clinic is to provide athletes and their families with sufficient information to enable an informed decision about sports participation after their diagnosis of LQTS. Their letter provides specific information about the care and counseling that each family receives as

well as the tailored therapy administered. Each sports participant also received an external defibrillator as a mandatory practice.

Results found that the majority (223, 63%) of patients either were not involved in sports or chose to discontinue sports after evaluation.



130 patients (37%) chose to remain competitive athletes, including 20 with ICD's. Of these, 60 athletes were competing contrary to Bethesda guidelines. The first group described had no sports related events, and only 1 athlete received 2 appropriate VF terminating shocks. This athlete admitted to not taking beta blocker medication regularly.

The authors close with the following comment: Although many individuals with LQTS will choose to remain in competitive sports, athletes and their families are capable of self disqualification. With more than 650 athlete-years of follow-up, we report a low rate of LQTS triggered cardiac events during sports. Limitations include the small sample size and limited length of follow-up.

Expert Panel Discussions

The SADS Foundation's Scientific Advisors are an impressive list of the world's leading experts in cardiac channelopathies and other SADS conditions. Recently, we have had an increasing number of physicians submitting difficult case studies and specific questions for discussion amongst our knowledgeable group of experts.

Through this process, physicians receive cutting edge information and thoughts on the management of their difficult cases.

If you are a physician and have a specific question or a difficult case study that you would like to share with our panel, please contact Christine at Christine@sads.org.

Medical Education Seminar

A medical education seminar was held for local physicians and healthcare providers at the New Yorker in Salt Lake City, UT on July 17th. A special thanks to Dr. Susan Etheridge, Dr. Jared Bunch and Dr. Melanie Everitt for their talks on channelopathies and cardiomyopathies and to Transgenomic for their unrestricted educational grant.



SADS Physician Referral Network - Online (Coming Soon!)

The SADS Foundation is working to publish our physician referral list online, providing our families with the names of qualified specialists in their area. The practice of referring families to local healthcare providers is nothing new for the SADS Foundation, however, an online format will be a great new tool for our community. If you have any questions, feel free to contact Christine at Christine@sads.org or 203.640.8683.

Wondering About the Safety of Your Supplements?

The National Institute of Health's Office of Dietary Supplements has developed a new website to strengthen knowledge and understanding of dietary supplements by evaluating scientific information, stimulating and supporting research, disseminating research results, and educating the public to foster an enhanced quality of life and health for the U.S. population. They even have a free mobile app for keeping track of your supplements!

Visit the SADS website to see the recent scientific info is on your over-the-counter supplements.



And, as always--check with your physician before taking any new medications or supplements.

Advocacy Update:

In celebration of National Sudden Cardiac Arrest (SCA) Awareness Month, the SCA Coalition (SCAC) circulated a petition to gather signatures in support of CPR education for all high school students and AEDs in schools. The SCAC was successful in gathering over 5,000 signatures! This petition is an important piece of a larger initiative to gain support from both the United States Department of Education and Department of

Health and Human Services on national issues relating to SCA. A special thanks to all our wonderful advocates who took to the streets to raise awareness and gather signatures for SCA Awareness month!

Action Alert! If you're already a subscriber to the SADS Foundation's e-newsletters, you've seen the information regarding a recent action alert, asking lawmakers to support funding for vital public health programs as well as encourage CPR education for high school students at the state level. We'll keep you posted on the progress of both of these issues, as more information is available.

To get involved in SADS advocacy efforts or find out more about a specific issue, contact Adrienne Butterwick at Adrienne@sads.org or call 800-STOP-SAD.



Another Beautiful Quilt Needs a Home!



At the 6th International Conference in Atlanta, Linda Dellinger donated a beautiful hand-made quilt for a raffle at the conference. This year, we have been given another beautiful, hand-made quilt made by Patti Toter of Cornwall, NY. Patti's son, Greg, survived a cardiac arrest at the young age of 7 and was diagnosed with Long QT Syndrome shortly afterwards. Since then, the Toter family have become amazing advocates in their community and dedicated SADS Foundation volunteers. Visit <https://www.sads.org/Donate/Quilt-Opportunity-Drawing> to see more photos and give a donation of just \$10 for your chance to win this lovely quilt! The winner will be announced on December 7, 2012 and the quilt will arrive in the mail by December 21st! Good luck!

Pregnancy & LQTS

The topic of pregnancy and Long QT Syndrome has become increasingly important as individuals who are diagnosed begin to plan to have families of their own. Dr. Bettina Cuneo, a pediatric cardiologist who specializes in fetal echocardiography, has spent many years devoted to researching pregnancy and LQTS. Dr. Cuneo is utilizing a new form of technology to look beyond the fetal echocardiogram: a fetal magnetocardiogram (fMCG). An fMCG is a non-invasive test assessing fetal heart rhythms and electrical conduction. An fMCG utilizes a biomagnetometer that resides in a magnetically shielded room the size of a large closet. The test causes no distress to the

mother or the fetus and also involves an ultrasound machine to locate the position of the fetus and an electrocardiogram (ECG) attached to the mother's abdomen and thighs. The biomagnetometer is positioned over the mother's abdomen. The entire process takes about two hours. Results from the fMCG are critical in detecting prolonged QT intervals but also episodes of Torsades de pointes (TdP) that are not visible through a simple echocardiogram. At that time, medications can be administered to the mother that cross the placenta and keep the fetus safe all the way through delivery.

To read about one patient's experience with the fMCG, visit: www.StopSADS.org/Pregnancy.



Insurance Coverage for SADS Patients and Families

This important study hopes to make health, life and travel insurance coverage more accessible for everyone.

www.stopSADS.org

Do your part today and take this survey!

Missed the Conference? Looking for more CMEs or CEUs?

The SADS Foundation is delighted to offer a video recording of the medical lectures presented at the 6th International Conference held October 12-14 in Salt Lake City. This comprehensive video captures in HD the vast knowledge presented this year by experts such as Dr. Michael Ackerman, Dr. Susan Etheridge, and Dr. Robert Campbell. The video is offered at the SADS online store. Preorder yours today! Also CMEs and CEUs are available for viewing this video.

Check www.StopSADS.org for the newsletter
to find links to the full articles and other
information from this newsletter.

Upcoming Events

American Heart Association Scientific Sessions

Los Angeles, CA
November 3-7

Medical Education Seminar

Phoenix, AZ
November 10 & 11

Thanksgiving-SADS

November 22-25
SADS office closed

Brittany's Trees

Carol Stream, IL
November 24

Christmas

December 24 and 25
SADS office closed

Sudden Cardiac Arrest in Children

Anaheim, CA
January 25-26

7th International SADS Conference

Columbus, OH
Fall 2013

Are you unsure what to get that special someone for Christmas?

SADS has two new t shirts available. Photographer Mike Flaherty has captured the beauty of Park City Utah in these beautiful images that SADS has made into a boxed card set. We have tree ornaments available in brass and pewter. None of these ideas strike your fancy? Please visit our store on our website at www.StopSADS.org for more gift ideas.

