



9th Annual International SADS Foundation Conference

September 30 – October 2, 2016, San Diego, CA

Family Program Highlights 2016

We are excited about our Family Program for the 2016 Conference in beautiful San Diego – plan to bring the whole family! Our conference will be located at the Marriott in Mission Valley, close to popular attractions.

Registration will open at noon on Friday, September 30th, with favorites like SADS 101 and Heart Safe School Accreditation training. You won't want to miss the "Take Steps to Stop SADS" 25th Anniversary Kick Off Event, with buses to transport attendees to Mission Bay Park for our sunset fundraising walk along Mission Bay.

On Saturday, we will hear updates on the Latest Treatment Strategies and Cutting-Edge Research, as well as with the popular "Fireside Chat" with Dr. Ackerman. Afternoon

sessions will feature disease-specific breakouts for Brugada Syndrome and CPVT, as well as special sessions on Women, Hormones, and Life Changes, and a session for Non-Affected family members (e.g., connect with others who have performed CPR on a spouse!). The Healing Wall Ceremony will follow, with plenty of time to network at our evening social hour.



Sunday morning will wrap up at noon, featuring panel discussions on Pregnancy and Starting a Family, and Dealing with your school. Be sure to join us in San Diego! StopSADS.org/Conference2016

Youth and Teens Track

We will feature a separate track just for youth (8-12) and teens (13-19).

- How the Heart Works
- Treatment and Beta Blockers
- Can I Still Play Sports?
- No Parents Allowed

Take Steps to Stop SADS at our conference or in your community

The SADS Foundation is establishing our signature event Take Steps to Stop SADS as we prepare to celebrate our 25th Anniversary. It's been 25 successful years since Dr. G. Michael Vincent believed there must be "a better way" and founded our organization to save the lives and support the families of children and adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Our kickoff for this event will be Friday, September 30, at the end of the first day of the 9th Annual International SADS Foundation Conference to be held in San Diego, California. Our walking trail will be at Mission Bay Park and all participants will receive a new SADS T-Shirt. After we return from the walk, we will enjoy a poolside reception at the Marriott Mission Valley hotel where prizes will be awarded for walkers who collected the most pledges to benefit the SADS Foundation.

Also, the SADS Foundation will be here to help you should you want to set up this event in your local community at a time and place of your choice. For further information about Take Steps to Stop SADS at the conference or in your community, please contact Jan at 801-272-3023 or jan@sads.org.



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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Director of Medical Education/ Chief Operating Officer

I discovered the SADS Foundation after working in public service and higher education for almost 25 years. Instantly recognizing the impact and importance of the SADS Foundation I was eager to join the team. Fortunately, I have been afforded an opportunity of a lifetime and now serve as our Director of Medical Education/Chief Operating Officer.

Prior to joining the SADS Foundation I worked for the University of Utah School of Medicine; a place where I obtained a stronger appreciation for heart health awareness after a family member was diagnosed with heart failure. From that experience I became a heart health evangelist and now preach the importance of heart health to all who will listen.



I am an avid supporter of the University of Utah (Go Utes!) which is where I earned my undergraduate degrees, history and political science, and my Master of Public Administration degree. My wife and I live in a small suburb within the Salt Lake Metropolitan area. We have three sons, whom we're honored to be known as their parents, and a small dog named Teddy. I greatly enjoy architecture, urban design, tinkering on cars, politics, and researching historical subjects.

Farewell Matt

After working as both Director of Family Support and then Director of Medical Education, I left my position at the SADS Foundation in the fall for a new opportunity. It was not an easy decision by any means. My time at SADS has given me amazing

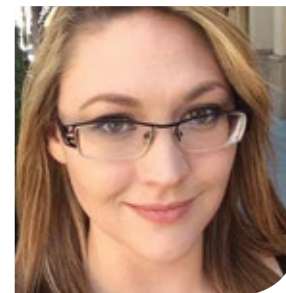


opportunities to work with remarkable patient families, volunteers, and health professionals. Meeting many of you at the conference in New York and presenting about the organization gave me the opportunity to inform others about the work SADS does after learning it firsthand from patients and families like you. I am proud of the work I was able to accomplish, and I look forward to continuing to watch as the SADS Foundation grows and supports each and every one of you.

Corinne Maynes

Office Manager

When I came across the SADS Foundation, I knew it's where I wanted to be. I've always had an interest in the medical field and am excited to work for such a wonderful cause. I received my Associates Degree from Salt Lake Community College and am working towards my Bachelor's Degree. In



my personal time, I enjoy reading, learning new things, video games, hiking, camping, crafts, home repair, and tinkering with electrical equipment.

The SADS Network in Action:

For Medical Advice

One of our SADS members with LQTS called with concerns about a drug that had been prescribed to him by his surgeon. He was in quite a bit of pain, but he checked and saw that the prescribed drug was on the list of Drugs to Avoid for LQTS. He called us for advice, and our CEO Alice Lara emailed the SADS Network of Scientific Advisors. Within hours, responses came in from both national and international experts on LQTS. The recommendations were passed along to our SADS family member, who was grateful for the help. We are thankful for our knowledgeable and supportive network of Scientific Advisors!

For Outreach to potential SADS Families

Thanks to a recent tip to SADS Staff from a family member, we were alerted to the sudden death of a healthy young man in Florida. Because SADS Staff

have attended meetings of the National Association of Medical Examiners (NAME) for the last seven years, we had the contact information for the local Medical Examiner. In addition to contacting the ME, we notified a local SADS Referral Physician who was available to answer questions, we contacted the media regarding a follow-up story about SADS conditions, and we sent a message to the family in order to provide support for them and answer any questions. Unfortunately, the first indication of SADS conditions for many families is an unexpected death. We know this is an important opportunity to save the lives of at-risk family members, which is why we have our Sudden Death Response Plan (StopSADS.org/Awareness/Sudden-Death-Response-Plan).

What can you do?

If you hear of a death or if you see an obituary of a sudden death in a young person that seems to fit the profile of a SADS condition, please send the information to sads@sads.org or call 801-272-3023.

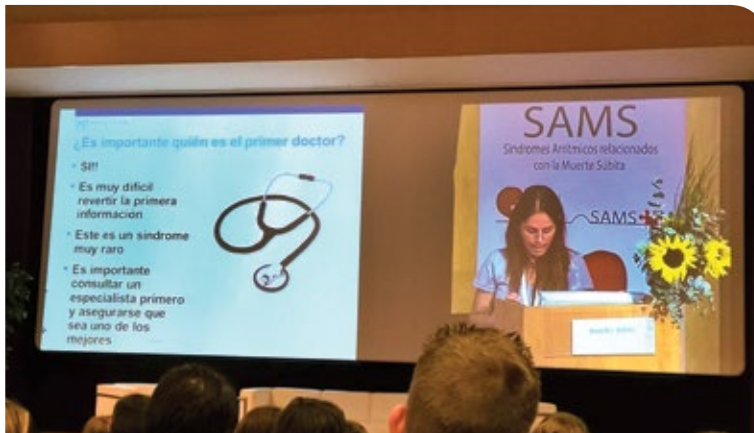
Heart Safe Schools Make A Difference!

Hopkinton High School in Contoocook, NH was planning its steps toward Heart Safe School Accreditation when a 15-year-old athlete collapsed at a basketball game. The movement in his chest had stopped, there was no pulse, and his face was slowly turning blue. The responders in the gym worked as a team, with one person doing CPR, one cutting his shirt off, another getting the AED and someone else calling 911. Coach Dan Meserve, the Athletic Director who initiated the compressions, had just completed his CPR recertification a few months prior to the game. The staff knew where the closest AEDs were located, in the accordance with accreditation standards. The AED delivered 2 shocks before the student's heart began to beat again. The young man now has an implanted defibrillator and is doing well.



And the story gets better. Our CEO Alice Lara learned about the “save” from the Chief Medical Examiner of the State of New Hampshire, Dr. Tom Andrew, because Dr. Andrew was the one who initiated the HSSA for the school! She talked with him at the NAME (National Association of Medical Examiners) Conference in North Carolina two weeks ago, where the SADS Foundation has been educating MEs for the past six years.

For the coach's riveting story and a story on the family visit StopSADS.org



Family Support Meetings

The Baltimore/D.C. Area Family Support Meeting was a great success! Planned by Andy Golden and sponsored by SADS and the Johns Hopkins Children's Center, SADS families had a chance to meet with each other and share their stories. Genetic Counselors Brittney Murray and Rebecca McClellan were on hand to provide information and answer questions. Be on the lookout for another meeting in the future!

SADS Talk in Barcelona

Jennifer White, MD, spoke at a patient and family conference in Barcelona, Spain on “Where do we go from here – the American experience” – how can people live and thrive with LQTS? Dr. White is an emergency room physician and has LQTS herself. Jennifer's talk was a big hit-and she did it in Spanish!

Standout SADS Foundation Volunteers!

Rachel Flores

The SADS Foundation extends its deepest appreciation to Rachel Flores for all of her efforts on behalf of the SADS Foundation and awareness of SADS conditions!

During this past year she was part of the a San Diego fund-raising committee that hosted Find the Caymus bringing in support for all of our programs and services – it was a great evening with other committee members Scott Dailard, Jennifer Paul and guests.

For more than a year, Rachel has been coordinating Heart Safe School Accreditation (HSSA) at her children's school Old Town Academy. Just his past November, they held their CPR and AED training receiving coverage from ABC



10 News. Final accreditation will be received in the near future.

And on top of all of this, Rachel was a committee member for the Emergency Cardiovascular Care Update conference this month in San Diego and hosted a booth for the SADS Foundation and HSSA on the opening day.

Thank you so much Rachel!



Angela Parrott

SADS Foundation member Angela Parrott did a fantastic job volunteering to represent SADS at Missouri's 23rd Annual Coordinated School Health Conference December 3-5th. She got a lot of positive feedback from the attendees, approximately 175 healthcare professionals. Angela has done many events in the past to raise awareness about SADS conditions, but said it was a “whole different world” sharing with healthcare professionals. “They completely understand the importance and it makes it easy to share info with them.” Thank you, Angela!



Super Heroes are our Neighbors

On April 5, a little boy should be celebrating his 6th birthday. Instead, the Ciciarellis will be having a Super Hero pizza party at Myers Park Baptist School in his memory. The Ciciarelli family lost their energetic 5½ year old on November 24, 2015 due to complications from Timothy Syndrome, an extremely rare and poorly understood genetic condition associated with Long QT Syndrome. Lee was diagnosed with this condition shortly after his first birthday. His family was given a 2½ year life expectancy. While Lee did die at an early age, his family knew that his life here on earth would be a special one. Lee passionately loved monster trucks, fire trucks, golf, his dog Tahoe, his John Deere tractor, the Carolina Panthers, and playing on the Dilworth tee-ball team Lawn & Mullinix coached by his father, Christian. Most of all, Lee loved being a big brother to his little sister Evelyn Ann.

From the beginning, his parents did not hold him back from doing anything and they treated him “just like any other little boy.” Lee spent a lot of time at his church where he was dedicated and baptized just before his first birthday. He enjoyed 3 years of preschool and attended almost every session of camp in the summers. In August Lee proudly entered

Kindergarten at what he called “the big kids school”. Lee quickly charmed everyone at Selwyn Elementary just as he had done at Myers Park Baptist. For Halloween Lee decided his family would all dress as Superman, making it clear that everyone was Superman—not SuperMom or SuperDad—but Superman. It was just a few weeks later when Lee was in the PICU at Levine Children’s Hospital that #SuperLee quickly spread through social media. We now continue to refer to him as SuperLee, as he truly lived a Super life here on earth. No drug or medical procedure could slow him down, and he’s continued to teach many who have heard his story to be present in each precious moment of life.

Lee’s family has always supported the Sudden Arrhythmia Death Syndrome Foundation (SADS) and in August his mother, Mary Ann, along with Courtney Waller of Wisconsin, and the SADS Foundation co-founded the Timothy Syndrome Alliance (TSA).



The goal is to bring research and awareness specifically to issues that affect Timothy Syndrome individuals. Since Lee’s passing, over \$25,000 has been raised for TSA. To read the Lee’s full story, visit StopSADS.org/healing-wall.

Share Your Story on StopSADS.org!

As we prepare to celebrate our upcoming 25th anniversary, we at the SADS Foundation would like to say how honored we have been to meet many of the families we serve. We’d love to have your story as a part of our 25th anniversary celebration.

To share your story, visit StopSADS.org/Share-A-Story. Be certain to read the stories of others as well, in honor of those living and thriving with SADS (sads.org/healing-wall-honoring) and in memory of those we have lost (sads.org/healing-wall).

For assistance, please contact Jan at 801-272-3023 or jan@sads.org

My Eagle Scout project

Wyatt Benner

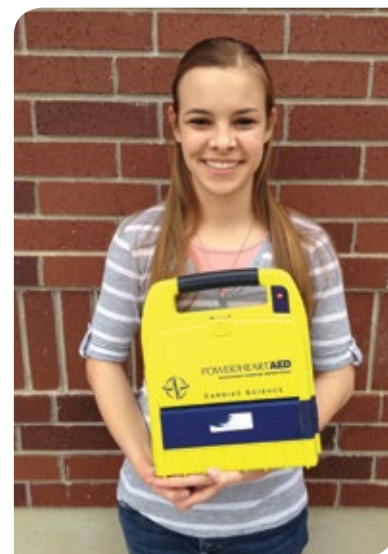
Hello my name is Wyatt Benner and I am 17 years old. I have recently been awarded with the honor of Eagle Scout, the highest rank in the Boy Scouts of America. For my Eagle Scout service project I chose to install an AED in my home church that I attend, and another AED in the church where my Boy Scout Troop meets. Both Churches host a lot of community events and activities and never had an AED on the premises. I chose this project for several reasons and my project has a special meaning to me because my mother has an internal defibrillator implanted because she has SADS. We also have a family friend whose life was saved by an AED. Along with my project I provided a free training session on the use of the AED device for any member in each church who wanted to attend. The fundraising for this project took me over a year to raise all of the funds. However you can never put a price on someone’s life, and although I hope this device is never needed, I am grateful that both churches are prepared to use it if they find themselves with a cardiac emergency.



Amy Taggart

Amy Taggart, a ninth-grader at West Point Junior High, is making a difference. Her English assignment was to write to a community member about a problem. From Amy’s letter: “I feel that students aren’t aware of what Automated External Defibrillators (AED) are and how to use them...I asked 45 jr. high school to high school aged students if they knew what an AED was...Nine of the 45 students had at least a rough idea of what one was and one person out of the nine seemed to feel comfortable in using one...On any day at any time someone in one of the schools, whether it be a teacher or a student, could go into cardiac arrest...having the AEDs in the building means absolutely nothing if there isn’t someone present that knows how to work the AED.”

Amy sent her letter to the district superintendent and the principal. Because of her, they scheduled AED training for the teachers and educated the students about the location of the AEDs on campus, making West Point Junior High a safer school! To read Amy’s letter go to StopSADS.org and click on “Stories: Living & Thriving.”



Extraordinary Ongoing and Brand New Events

The SADS Foundation applauds our volunteer fundraisers who through their dedication and commitment to our mission have been supporting us for several years. The following events are examples from the past few months.

The **11th Annual Brittany's Trees** had its best year ever boasting 18,000 trees lighted in Carol Stream by Jim Guthrie, Tony Valene and team and surrounding areas as well as Libertyville led by the Lentino Family and team!



The **16th annual Brian Price Memorial Jumpathon** was held February 12 and led by Betty Glasheen at Shelton School in Dallas – one of our oldest volunteer fundraising traditions!



Everyone had loads of fun at the **7th Annual Sweet 16** on February 25 hosted by Jeanne Balsam in Winnetka in memory of Rebecca Righeimer.

Additionally, the SADS Foundation congratulates two new volunteer fundraisers for first-time events that are sure to become yearly happenings raising funds and awareness for SADS.

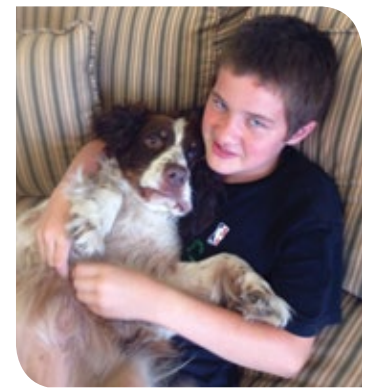


More than 40 participants danced for our mission at a **Zumbathon for Scarlett Manelis** led by Sandy Anderson on February 26 in Rochester.



The Solana Family held the **1st Annual Gray Solana Memorial Roundball Rumble Basketball Tournament** with several local teams playing the sport Gray loved.

To find out more about hosting your own volunteer fundraising event, please contact Jan at 801-272-3023 or jan@sads.org.



Thanks to Belkys and the JPB Foundation

JPB Foundation employee Belkys Porras selected the SADS Foundation for a \$10,000 grant.

JPB Foundation is a private foundation which gives out grants to charitable organizations which fall under its mission areas of medical research, poverty, and the environment. As an employee benefit, staff members get to pick a charity of their choice and donate a \$10,000 staff discretionary grant. Each year, staff members search for a charity that is close to their heart and a cause in which they believe.

This year, Belkys chose a cause that is literally close to her heart – the SADS Foundation. Belkys recently has been diagnosed with Long QT 1 and is in the process of having her children tested. She found the SADS Foundation and now receives our E-Newsletters.

"The more that I read about this silent killer," says Belkys, "the more I believe that there should be more awareness about this syndrome."



No Ball at All 2016

The SADS Foundation is celebrating the 22nd Anniversary of No Ball at All! This year, we are grateful to the Solana Family for allowing us to remember their son and brother Gray who passed away just over a year ago from a sudden cardiac arrest. The Solana Family designated the SADS Foundation as a beneficiary of donations made in Gray's memory at this time. Now they once more ask that you please contribute to the SADS Foundation through No Ball at All to continue to support families and save young lives just like Gray's through awareness and education.

Please visit sads.org/Donate-NoBall to donate online.

Access to Genetic Testing—You Deserve Better!

Since the discovery of the first channelopathy-causative genes in 1992, genetic testing for channelopathies has advanced from basic scientific discovery to clinical application. Today, the majority of channelopathy genetic tests are clinically available, and are extremely useful for diagnosis and screening.

In particular, the value of LQTS genetic testing has been well documented in the medical literature. *Consensus statements and guidelines uniformly recommend genetic testing for all LQTS patients to enable accurate risk stratification, guide therapeutic strategies and to identify potentially at-risk family members.*

So why don't most Medicaid plans cover genetic testing? Why did Tricare (the military insurance plan) drop coverage of more than 100 tests including the tests for Long QT Syndrome and other channelopathies? Why do private insurers

cover (part of, but not all of) the cost of (some, but not all) genetic tests?

You deserve better! Most tests for channelopathies cost thousands of dollars, and we are committed making these tests available and affordable to all of our families. There are many ways we help do this:

- We work with non-profit health advocacy organizations such as Genetic Alliance to petition legislators on our behalf. We want laws to prevent insurers from denying coverage of useful genetic tests (including channelopathy tests) just because they are not cleared by the FDA.
- We work with genetic testing companies to push for increased insurance coverage for channelopathy genetic tests, to make them more widely available and affordable for our families.

- We support research that advances our knowledge of the channelopathies, including identification of new gene mutations, and increased knowledge about the clinical course of known mutations in order to improve risk-stratification and disease treatment.

We believe that with genetic information families can better understand their genetic risks and when necessary, take preventive action. Lowering costs of testing and making tests easier to get will help families everywhere.

We believe that by working to make these genetic tests more available and affordable we are giving families information that will help save lives.

Changes to LQT Drugs to Avoid List

Just a reminder to make sure you check the LQTS Drugs to Avoid list often and especially before you take any new medication.

ADDITIONS to the list: **levomepromazine** (brand names: Nosinan®, Nozinan®, Levoprome®), **delamanid** (Delyba®), **papaverine HCl**, **oxaliplatin** (Eloxatin®), **asenapine** (Saphris®, Sycrest®), **hydrocodone** (Hysingla ER and Zohydro ER), **Osimertinib** (Tagrisso®); **Cyamemazine**, also known as cyamemprozine (Tercian®), **Lenvatinib** (Lenvima®)

CHANGES to drugs on the list: **quetiapine** (Seroquel®), **ziprasidone** (Geodon and Zeldox®) and **gatifloxacin** (Tequin®)



Why is it important to be involved in research?

If you are diagnosed with an illness tomorrow, you will want to go to the pharmacy and pick up the right prescription. However, an effective treatment may not be available yet. Discovering the right treatments requires volunteers to step forward and offer their health information to researchers by using registries or other platforms. Imagine if all of us offered all of our health information so that there was no lack of health data?

Right now health data are not readily available. SADS is working with UCSF the Division of Cardiology on the Health eHeart Study, har-

nessing the power of smart phones, mobile health apps and other technology to learn more about heart diseases. The Health eHeart Study is an ambitious initiative, which will gather "big data" from up to 1 million participants worldwide.

We at SADS are amazed and thankful that so many of you are willing to participate in research. You are the number one group enrolled in Live LQTS study and the number one group who has participated in the pregnancy research. Research like this makes a difference now—and for future generations.

AHA Issues New CPR Guidelines

Bystanders should jump in quickly to give CPR, using breaths if they've been trained in CPR and using mobile technology to speed up the rescue of cardiac arrest victims, according to the American Heart Association's *2015 Guidelines Update for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care*.

Over 326,000 out-of-hospital cardiac arrests and 209,000 in-hospital cardiac arrests occur annually. Despite advances in resuscitation science, **survival rates are only about 10 percent.**

Effective bystander CPR, provided immediately after cardiac arrest, can double or triple a victim's chance of survival.

For more information on the new guidelines visit StopSADS.org/Advocacy/CPR.



Have you been diagnosed with Type 3 Long QT syndrome?

If so, you may be interested in this study. Patients who have been diagnosed with LQT3, and are between the ages of 18-65, may be eligible to participate in a clinical trial whose purpose is to evaluate an investigational drug for use in patients with LQT3.

The study will consist of approximately 6 months of treatment, and will include multiple clinic visits during the course of the study. If eligible, participants may receive compensation

for time and effort. Travel reimbursement will be provided to participants and an optional accompanying companion.

For more information, please visit clinicaltrials.gov and search for this study: NCT02300558 or email LQT3@gilead.com.



International CPVT Prospective Registry and Biobank Study

In order to address the current gaps that exist in our knowledge and management of CPVT, the investigators in this study are collecting health information from patients with CPVT and their immediate family members from around the world into a registry. The information gathered will provide cardiologists and healthcare providers with a better understanding of this condition and lead to more effective treatments for people with CPVT.

The study is currently enrolling individuals diagnosed with CPVT who are 19 years of age or younger and their immediate family members (mom, dad, brother, sister). There is no geographical limitation to participate and participation is completely voluntary. For more information, visit StopSADS.org/research.



New Technology

Drones delivering AEDs to a cardiac arrest site; telemedicine used for genetic counseling, PulsePoint.org for volunteers to get direct notification via their cell phone that someone near them needs CPR; patients recording their own EKGs and bringing them to an appointment with their physician.

Ways new technology is improving our healthcare and helping to save lives.

Volunteers Needed for LQTS and SADS Pregnancy Research Study

In the last five years, much has been learned about Long QT syndrome (LQTS). It is now known that LQTS is more common than previously recognized, and that LQTS can be diagnosed before birth. During pregnancy, the ECG of the fetus is difficult to obtain; however,

a research lab at the University of Wisconsin-Madison uses an extremely sensitive magnetometer to detect the natural magnetic signals of the fetal heart to measure the QT interval.

This test, called a fetal magnetocardiogram (fMCG), is part of an NIH-funded study under the auspices of the principal investigator, Ron Wakai Ph.D., Professor of Medical Physics. Dr. Wakai and his clinical collaborators in Pediatric Cardiology, Dr. Janette Strasburger and Dr. Bettina Cuneo, have been investigating the role of fMCG in the diagnosis and treatment of fetal arrhythmia for over 15 years. The goal of the research is to develop fMCG into a new technique to monitor fetal heart rhythm patterns before birth.

For more information visit StopSADS.org/Research or call the study coordinator, Chris Roginski, at 608-263-4505.



Update on LIVE-LQTS Study! NOW ENROLLING!

LIVE-LQTS is an exciting new study with a goal of determining how lifestyle and exercise impact the well-being of individuals with LQTS. Whether you like to run, walk, play baseball, or sit and read a book, you can participate in this study and help us learn more about lifestyle choices and LQTS.

People age 8 to 50 years old (both exercisers and non-exercisers) and, with or without an ICD can participate. Participation involves a telephone interview and filling out questionnaires online or on the phone. There are no geographic limitations to participation.

It's a 3-year study, with brief questionnaires every 6 months. And a Fitbit, to wear a few weeks per year, which is yours to keep.

For more information, go to livelqts.org



Visit StopSADS.org for links to the full articles
and other information from this newsletter.

We've Moved!

Our new address:
4527 South 2300 East, #104
Salt Lake City, UT 84117

Our new phone number:
801-272-3023



Upcoming Events

May 3	PACES Annual Meeting SADS Young Investigator Award	San Francisco, CA
May 4-7	Heart Rhythm Society Scientific Sessions	San Francisco, CA
May 13-15	Western Society of Pediatric Cardiology Conference	Park City, UT
May 21	Patient Day	Novato, CA
June 11	Family Support Group	Baltimore, MD
June 30-July 3	National Association of School Nurses Conference	Indianapolis, IN
Sept. 30-Oct. 2	9th Annual International SADS Foundation Conference	San Diego, CA