



10th Annual International SADS Foundation Conference

September 22-24, 2017 in Toronto, Canada

We are excited to announce in partnership with the Canadian SADS Foundation the 10th Annual International SADS Foundation Conference on September 22-24, 2017, in Toronto, Ontario, Canada! Our conference will be located at the Sheraton Toronto Airport Hotel & Conference Centre and with easy access to the wonderful attractions in the area.

Registration will open at noon on Friday, September 22nd, with favorites like SADS 101 and several disease breakout groups. Additionally, we will once more hold our signature event Take Steps to Stop SADS and invite everyone to join us to raise funds for our services and have a great time with other families and health care professionals.

Saturday will feature talks for adults on cutting edge research, risk profiles of SADS conditions, a fireside chat, and more breakout sessions on a variety of timely topics. The sessions for youth and teens will highlight topics about the workings of the heart,

treatment and beta blockers, playing sports, and a “no parents allowed” session for teens. Sunday morning will wrap up at noon featuring the topics of pregnancy and starting a family, and ECG screenings.

As in past years, on Friday we will host a full-day accredited continuing medical education program: Preventing Sudden Cardiac Death – Risk Profiles and Red Flags led by Program Directors Drs. Susan Etheridge,

Robert Hamilton, and Danna Spears.

You won't want to miss this special joint conference! Don't forget your passport and see you in Toronto! sads.org/Conference2017



SADS Conference Meeting Leads to Patriots Game

The SADS Staff got a lovely surprise from two of our SADS Families; the Arruda's from Rhode Island and the Bevington's from Maryland. Nick Arruda and Jack Bevington met at our SADS International Conference last fall in San Diego, and wrote to let us know that not only have they have they stayed in touch, but Nick and his dad Ray invited Jack to join them at a recent Patriots game. The boys went to the game, visited the Patriots Hall of Fame, met players, cheerleaders, and had a really great time. This is proof of how WONDERFUL our SADS families are, and how WORTH it is to come to the International Conference! Thanks for sharing this great story!



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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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Welcome Staff Member

Chelsey Tufts

I am a recent graduate from Utah Valley University, where I earned my undergraduate degree in political science. I have always wanted to work for a non-profit, and spent a great deal of time researching the best ones to apply to.

As a result I found the SADS Foundation, and I am humbled to work with the incredible families within our network. I am excited to work in an environment that has such strong advocacy and community. What drives me is working to develop programs that foster support among all varieties of people. I also enjoy looking at the statistics of programs, and how to further improve effectiveness and reach. I love the human connection that is felt here at the SADS Foundation.

I am lucky to live in the beautiful state of Utah, and in my spare time I enjoy anything outdoors. My favorite way to spend a day is outside in nature with my husband and puppy poodle.



SADS UK Founder Receives MBE from Prince William!

Congratulations to Anne Jolly, Founder and Director of our international affiliate SADS UK, for receiving the extraordinary honor of becoming a Member of the Order of the British Empire (MBE). The award was presented to her by Prince William at a ceremony in Buckingham Palace on February 28th. Anne and her husband John have worked tirelessly to assist SADS families in the UK and to make the UK safer for people with genetic heart conditions.

To read more, as well as view photos, please visit StopSADS.org and search for "Anne Jolly".



SADS Meets to Plan Health eHeart Alliance

The Health-eHeart Alliance Steering Committee met last month at UCSF (San Francisco) to develop our strategic plan for the next three years. As a patient-powered research network the Alliance is led by a coalition of patients and advocacy groups including the American Heart Association, Mended Hearts, StopAfib.org, and the SADS Foundation.

Changes to LQT Drugs to Avoid List

These drugs have been added to the list since our last newsletter:

Pilsicainide (on market in Japan)
Prothipendyl (on European markets)
Terodiline (Micturin® and Mictrol®)
Bethanechol
Pantoprazole
Omeprazole
Esomeprazole
Lansoprazole
Bendroflumethiazide (also named bendroflumazide and brand name Aprinox®)
Ibogaine
Efavirenz (brand name Sustiva®)
Olanzapine (moved)
Terlipressin
Bendamustine
Melperone
Romidepsin
Droxidopa



25th Anniversary Awareness Campaign Takes Off!

Awareness Ambassadors reach 41 states

In celebration of our 25th anniversary year, Awareness Ambassadors have been selected to help spread the work of the SADS foundation. These individuals are scattered across the country, and are currently helping to raise awareness through monthly campaigns in their local communities. In a newly designed system, these ambassadors are subscribed to receive monthly awareness materials automatically to their door.

We have now held four successful campaign months, and have heard nothing but positive reviews from our growing community of volunteers.

For our larger audience: be on the lookout for our new ones, where we will be introducing new campaigns every month in 2017. We are incredibly fortunate for the community that we have, and are excited to continually grow our network of volunteers as we expand past our 25th anniversary.

If you would like to become an Awareness Ambassador please email Chelsey@sads.org. We are always looking to expand our network of awareness.



Another Successful Campaign for National Heart Month

More than 120 SADS volunteers participated in our campaign for National Heart Month in February. They ordered 'Red Kits' to distribute in their local community—which proved to be wildly popular. The kit included awareness posters and wristbands, as well as instructional sheets on CPR. Thanks to everyone who participated in distributing SADS Red Kits! You are making your communities safer.

Flat Bob Returns!

This year, the SADS Foundation is reintroducing the Flat Bob Awareness Adventure Campaign as part of the 25th Anniversary Take Steps to Stop SADS Celebration. In case Flat Bob is new to you this is what you do!

- Take Flat Bob out on the town.
- Take pictures of Flat Bob next to your gym's AED, at the grocery store, at the soccer field-anywhere people might need a little SADS awareness.
- Email your photos to FlatBob@sads.org.
- Follow Flat Bob's SADS Awareness Adventure on our website: StopSADS.org/FlatBob



As you take Flat Bob on his awareness adventures, please make certain to let people know that SADS are genetic heart conditions that can cause sudden death in young, apparently healthy people. These conditions can be treated and deaths can be prevented.

Warning Signs:

- Family history of unexpected, unexplained sudden death under age 40
- Fainting or seizure during exercise, excitement or startle
- Consistent or unusual chest pain &/or shortness of breath during exercise

To order your Flat Bob, please contact us at 801-272-3023 or FlatBob@sads.org.



Martina Aupart

My name is Mauricio Aupart, father of Martina Aupart. On March 20th of last year she died at the age of seven years old of sudden arrhythmia death syndrome. Martina was 5 years old when she started having blackouts when she was exercising. There were occasions in which she fainted but 2 minutes later she was back again running and playing. We took her to a pediatric cardiologist who diagnosed her with dysautonomy. We also saw a neurologist who told us our little girl was in perfect conditions. Both doctors ruled out any life-threatening disease. We did all studies that were asked by the doctors, including laboratory, electrocardiogram, tilt table, encephalogram, among others. We never happened to think that she was in danger of death. On March 19th she attended a children's party of her best friend. She boarded a bungee and once lifted by the game we thought she fainted, but what she really had was a heart attack. We only could do resuscitation



maneuvers at the party. There was neither available an on-site defibrillation equipment, nor a specialist. We took her to the nearest hospital

but regrettably she died the next day. Some months after her death we were advised by another cardiologist she may have had a long QT arrhythmia. Since then, we have been looking for some answers so we found the SADS Foundation. We would like to join the foundation and promote communication for these kind of diseases in our country in order to prevent similar deaths, as the one of my beloved Martina.

We do not know what would have happened if she had been diagnosed with arrhythmia when she was 5 years old. We want to make certain the tragedy that we've been through does not repeat to other parents.

Martina's parents, Mauricio Aupart and Gabriela Castell-Blanch attended our SADS Conference in San Diego last fall, and have founded our newest International SADS Affiliate, SADS Mexico: sads.org.mx

Heart Champion

During the month of February, five-year-old Eden Sollimo was helping her mom plan her birthday party. Eden told her mom she wanted to ask her friends to donate to the SADS Foundation instead of buying her birthday gifts. Well, Eden and her 20 guests had a wonderful time at the party and everyone did donate to the SADS Foundation--raising more than \$1,000! We can only imagine the future Eden has in front of her—what a Heart Champion!



Heart of the Matter—Ask the Experts

The Heart of the Matter - Ask the Experts is your chance to get your questions answered by an expert. Anyone can ask a question! The top-ranked questions will be answered by a SADS physician expert via video, and posted on our website.

Sample questions can be anything, such as:

- What do I need to know before going the dentist?
- Are beta-blockers safe for infants?
- How do I know which cold medicines I can take?
- Are subcutaneous ICDs as good as implanted ICDs?

Please ask a general question today and help us build our library of The Heart of the Matter—Ask the Experts video. Submit a question or view videos of past questions at sads.org/living-with-sads/Heart-of-the-Matter---Ask-the-Experts.

SADS Volunteer Advocates for AEDs

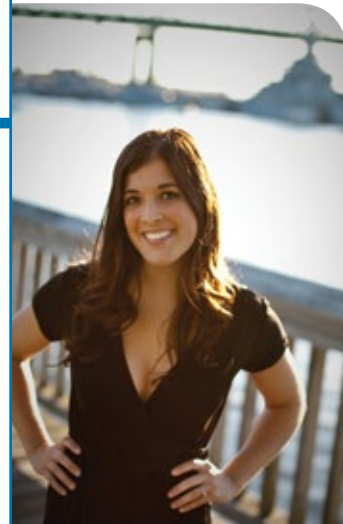
Michaela Gagne Hetzler, school adjustment counselor at Diman Regional Vocational Technical High School in Fall River, Massachusetts, has been a long-time advocate of new Massachusetts Bill S.2449, signed by Gov. Charlie Baker on January 13, 2017, which will require all schools to have AEDs. "It's pretty awesome," Hetzler said. "Quite simply, it saves lives."

Michaela was diagnosed with LQTS at age 15, and after her plans for Division I soccer were derailed, she entered the Miss America pageant, competing as Miss Massachusetts 2006. As far as she knows, she is the first Miss America contestant to compete with an ICD.

The bill requires every school in Massachusetts to have lifesaving automatic external defibrillators on hand by July 2018. Schools that cannot afford a defibrillator can apply for a hardship waiver and receive help with the purchase, roughly \$800 to \$1,000 each.

According to the AHA, a child has a sudden cardiac arrest every three days in the United

States. About 20 percent of the U.S. population is at a school on any given day, whether for work, classes, professional or parent visits, plays, voting, or other programs.



SADS/NYU Family Seminar

The SADS & the NYU Langone Medical Center's Cardiovascular Genetics Program was held at NYU's Langone Medical Center on Saturday, April 29th. The topic was "Arrhythmias: Recent Advancements in Therapies and Diagnosis", and speakers included our CEO, Alice Lara, as well as experts Dr. Glenn Fishman, Dr. Rachel Lampert, Dr. Marina Cerrone, Dr. Steven Fowler, and Dr. Larry Chinitz. After an informative morning program, our families participated in a Q&A session with the speakers, followed by lunch and a volunteer presentation.

Begin a Take Steps to Stop SADS Event in Your Hometown

Right now is the perfect time to start thinking about hosting a Take Steps to Stop SADS walk or run in your hometown. This newly-established signature event for the SADS Foundation has been designed to raise funds for the SADS Foundation and awareness of SADS conditions.

A packet of tips, instructions, and promotional materials have been developed for your use and can be reviewed and downloaded here. Please reach out to Jan at 801-272-3023 or jan@sads.org, if you have any questions or need



further details. She will be happy to walk you through the planning and marketing process to make certain your Take Steps to Stop SADS event successful!

In addition to the tools on the SADS Foundation website, you may use our event website at www.crowdrise.com/take-steps-to-stop-sads to set up your personal fundraising page for friends and family to donate to the SADS Foundation and be recognized as one of your supporters. Make 2017 the year to Take Steps to Stop SADS!

Just-started and Long-standing Events

Just-started

Erin Clark, in honor of her one-year-old son Mason, helped to increase awareness of SADS and raise funds for the SADS Foundation through her CrowdRise page **Keep Little Hearts Beating**. Mason was diagnosed with a LQT 1 after his Pediatric Nurse Practitioner at Mason's two-month checkup thought she heard a faint heart murmur. She immediately referred the family to Children's Mercy Hospital in Kansas City where LQT 1 was diagnosed. We thank Erin for helping us to help other families like hers!

The second annual charity event **Gertsberg Memorial 5K** has been established to commemorate Dr. Mikhail Gertsberg, a respected radiology resident at Hartford Hospital, who suddenly passed away last year. Each year, proceeds from this event benefit a non-profit organization and this year the Sudden Arrhythmia

Death Syndromes Foundation has been chosen. We extend our most genuine appreciation for their support!

Long-standing

The SADS Foundation also wants to recognize several of our long-standing events who together have raised more than \$500,000!! **THANK YOU** to **Jumpathon** hosted by the Shelton School for 20 years in Dallas, Texas; **Oktoberfest** hosted by the Layton Family for 19 years in Colorado Springs, Colorado; **Brittany's Trees** hosted by Valene and Guthrie Families and entire team for 12 years in Carol Stream, Illinois; **Heartoberfest** hosted by the Tolosky Family for 11 years in Ballston Lake, New York; and **Guys and Gals Night Out** hosted by Jeannie Balsam and team for 7 years in Glencoe, Illinois. All of these families just totally rock!



No Ball at All 2017

The SADS Foundation is celebrating the 23rd Anniversary of No Ball at All! This year, we are grateful to the Watschke for allowing us to honor their daughter and sister Abrielle who suffered from a sudden cardiac arrest two years ago. Today, Abrielle is a typical little girl who is outgoing, smiles often, and easily makes new friends. Her favorite things are snuggling, singing and dancing. The Watschke Family proudly supports the SADS Foundation as a crucial resource for families affected by heart arrhythmias and the medical professionals who treat them and asks that you donate to No Ball at All so that young lives will continue to be saved.

Please visit sads.org/Donate-No-Ball-At-All to donate online.



Sustainer of Hearts—One Month at a Time

Join us and save lives in the easiest and most effective way possible by making a monthly pledge as a Sustainer of Hearts! Through donating each month, Sustainers of Hearts support both immediate needs and the expansion of innovative and life-changing programs.

Sustainers of Hearts become part of the SADS Foundation team whose ultimate goal is to eliminate sudden cardiac deaths from SADS conditions. Until we do, we will campaign for awareness, deliver critical support to families, expand knowledge within the medical community, and empower patients and families in the efforts of research.

Become a Sustainer of Hearts at sads.org/ Donate and you will make a difference!

Check out the SADS Foundation Blog

The new official blog of the SADS Foundation is now online! The "SADS Channel" is a collaborative effort between SADS Foundation staff and volunteers, and is intended to be a place for sharing experiences, information, news, research opportunities, and other content related to SADS conditions.

The SADS Foundation wants to thank our Research Committee for all their help in getting the blog started, Rachelle Cook, Jen White and Jasmine Wylie for contributing to our blog, with special thanks to Jasmine Wylie for the many hours she put in to set up our blog.

If you are interested in blogging, please email sads@sadsblog.org. Visit sads.org/blog/ to read our new blog!



The ECG Screening Debate—Things to Consider

The use of electrocardiographic (ECG) screening to detect potentially lethal cardiac disorders is a highly controversial and passionately debated issue. It is important to remember, however, that we all agree on one thing: **we are all passionate about preventing any and all sudden cardiac death in young people.** The ECG controversy centers only on how best to screen. (If ECG screening was perfect, the debate would have ended years ago!). The SADS Foundation believes that there are at least 10 issues that should be addressed before any ECG screening program is instituted. Go to StopSADS.org to access the full paper.



Young Investigator Awards



Mariana Argenziano, PhD
Charles Antzelevitch, PhD
Lankenau Institute for Medical Research



Jerome Clatot, PhD
Isabelle Deschênes, PhD
Case Western Reserve University



Keith Dufendach
Maully Shah, MBBS
Perelman School of Medicine at the University of Pennsylvania



Christopher Follansbee, MD
Gaurav Arora, MD
Children's Hospital of Pittsburgh



Andrew Landstrom, MD, PhD
Jeffrey J. Kim, MD
Baylor College of Medicine



Daniel Matasic
Barry London, MD, PhD
The University of Iowa



Ram Rohatgi, MD
Michael J. Ackerman, MD, PhD
Mayo Clinic - Rochester



Alan Sugrue, MBChB
Michael J. Ackerman, MD, PhD
Mayo Clinic - Rochester



Arja Suzanne Vink, MD
Nico A. Blom, MD, PhD
Academic Medical Center (AMC) in Amsterdam



Ling Xiao, PhD
David Milan, MD
MGH Cardiovascular Research Center

Not pictured:

Najim Lahrouchi, MD
Connie R. Bezzina, PhD
Academic Medical Center (AMC) in Amsterdam

Jerome Montnach, PhD
Mario Delmar, MD, PhD
NYU Langone Medical Center

Thomas Roston, MD
Shubhayan Sanatani, MD
University of British Columbia

SADS Foundation Sponsors Forum at Harvard Medical School

The SADS Foundation sponsored an educational forum focused on Inherited Arrhythmia Syndromes at Harvard University Medical School. Hosted by Dr. Dominic Abrams and the Inherited Cardiac Arrhythmia Program at Boston Children's Hospital. The forum brought together clinical experts to present a complete overview of different SADS conditions and provide recent findings and new avenues of research and disease management. The forum's first session focused on updates for inherited arrhythmic disorders including long QT syndrome, CPVT, Brugada syndrome, and arrhythmogenic cardiomyopathy. The second session provided case discussions with an expert panel from Brigham and Women's Hospital, Massachusetts General Hospital, and Boston Children's Hospital. The forum was such a great success, that the SADS Foundation and Boston Children's Hospital are looking forward to doing it again in 2017!

We extend our thanks to corporate sponsors: Invitae and Medtronic. And also extend thanks to our expert speakers: Dominic Abrams (Boston Children's Hospital), Calum MacRae (Brigham & Women's Hospital), David Milan (Massachusetts General Hospital), John Triedman (Boston Children's Hospital), Neal Lakdawala (Brigham & Women's Hospital), Steven Lubitz (Massachusetts General Hospital), Robert Padera (Brigham & Women's Hospital), Elizabeth DeWitt (Boston Children's Hospital), Robyn Hyland (Boston Children's Hospital), Shannon Hourigan (Boston Children's Hospital), Virginie Beausejour Ladouceur (Boston Children's Hospital).

Genetic Privacy at Risk with HR 1313

The “Preserving Employee Wellness Programs Act”, H.R.1313 threatens to take away genetic privacy protections put in place with the Genetic Information Nondiscrimination Act (GINA) of 2008. According to GINA, employers can't use genetic information to hire, fire, or promote an employee, or require genetic testing, and health insurers can't require genetic tests nor use results to deny coverage. However, HR 1313 gets around these restrictions by allowing genetic testing to be part of a workplace “wellness program.” The bill could allow employers to impose hefty penalties on employees who choose to keep their genetic information private and decline to participate.

The SADS Foundation is among the nearly 70 organizations, including the American Academy of Pediatrics and AARP, who sent a letter to Congress last year and again in March of 2017 stating that the legislation, if enacted, would undermine basic privacy provisions of the Americans with Disabilities Act and the 2008 Genetic Information Nondiscrimination Act, or GINA.

We are monitoring the progress of this bill, and will continue to keep you informed—especially if there is some action you can take. Watch your email for the notice.

LIVE-LQTS Study Expanded to Age 60!

Thanks to you, **more than 1/3 of the enrollees in the LIVE-LQTS study are from the SADS Foundation**, more than from any individual medical center! The goal is 2,000 participants and we're almost at 1,000. So don't wait – sign up today!

The goal is to determine how lifestyle and exercise affect the well-being of individuals with LQTS. This study is funded by the National Institutes of Health.

For more information, go to stopSADS.org.

New Sudden Death in the Young Case Registry Website

The Sudden Death in the Young (SDY) Case Registry Data Coordinating Center is pleased to announce that the SDY Case Registry website, designed specifically as a resource for families, is now live! Check it out at SDYRegistry.org.

The SDY Case Registry is currently active in San Francisco, Delaware, Georgia, Minnesota, New Hampshire, New Jersey, Nevada, Tennessee, the Tidewater Region of Virginia and Wisconsin (Fond du Lac, Forest, Kenosha, Milwaukee, Oneida, Racine, Vilas, Waukesha, and Winnebago Counties). The SDY Case Registry began collecting data and samples in these funded jurisdictions in January of 2015.

The SDY Case Registry is collaboration between the NIH and CDC to gather and store information about sudden child deaths to help:

- Count the number of sudden deaths in infants, children and young adults from birth up to age 20
- Understand the causes and risk factors for the deaths
- Inform strategies to prevent future deaths

What can you do?

- If you have suffered a young sudden death in one of the funded jurisdictions after January 1, 2015 and you have not been in contact with the SDY Case Registry, please contact us.
- If you come into contact with families in funded jurisdictions, please share what you know about the SDY Case Registry.
- Even if your state or jurisdiction is not currently funded to participate in the Registry, please encourage the Medical Examiners and Coroners in your area to use the SDY Case Registry tools (which are available on our website) and save blood and/or tissue for DNA banking and/or future genetic testing.

For more information:

Website: SDYRegistry.org

Email: Info@SDYRegistry.org

SADS Webinar Library—New Webinars for Families

The SADS Foundation is pleased to announce that in addition to our webinar series designed to educate healthcare providers, we have launched a webinar series for families. Our first webinar, presented in partnership with Ambry Genetics, “Genetic Counseling and Testing—Your Questions Answered” took place in April, and is available to view on our website: sads.org/living-with-sads/Webinar

Our current webinar series for healthcare professionals, presented in partnership with Invitae, includes the Latest Diagnosis and Treatment



Strategies for AVR/D/AVRC, LQTS, and CPVT. The final webinar featured internationally recognized CPVT expert Professor Silvia Priori, MD, PhD. Professor Priori's webinar was very well attended and provided an excellent capstone for the series.

The SADS webinar series for healthcare professionals is always available for viewing at: sads.org/Medical-Professional-Education/Webinar

Life Insurance for LQTS Type 1

A major life insurance company, Metropolitan Life, will consider offering life insurance to some adults with Long QT Type 1. To be eligible for consideration a person with Long QT must be:

- Over age 30
- Have Type 1 Long QT
- Not have an ICD (implantable cardioverter defibrillator)

At this time, SADS is not aware of any other life insurance offers for those with SADS conditions. For more information or to apply: Lee Slavutin, MD, CLU at 212-536-6025 or LS@sternslavutin.com.

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

New CredibleMeds® Mobile App Available

The Apps are synced to the
CredibleMeds drugs lists and are
therefore always an up-to-date
resource for you to search
for drugs of interest.

CredibleMeds Mobile
Apps are now
available free for
Apple or Android
phones!



Upcoming Events for 2017

May 1	Understanding Sudden Unexplained Death in Childhood Conference	New York, NY
May 10-13	Heart Rhythm Society Scientific Sessions	Chicago, IL
May 21	Gertsberg Memorial 5K	Farmington, CT
June 10	SADS Foundation Family Support Picnic	Baltimore, MD
July 13-16	Healing of the Heart Retreat	Ossining, NY
September 22-24	10th Annual International SADS Foundation Conference	Toronto, Ontario, Canada

Awareness Activities

May	Medical Red Kit	August	Family Video Celebration
June	CPR/AED Awareness Week	September	SADS Safe Schools
July	Virtual Walk	October	Share your Story for SC