



## SADS Foundation 8<sup>th</sup> International Conference Is Just Around The Corner!

The SADS Foundation has been working diligently on planning what we expect to be our most exciting International Conference to date, with input from prior participants and families in order to ensure that conference activities are engaging, up-to-date and relevant to conference participants. With a great number of folks signing up since we opened registration, we are confident that this will be one of the most well-attended conferences in our history!

Established, popular activities like our Keynote Presentations and Healing Wall are complemented this year with new activities like a Fireside Chat (any and all questions answered) by Dr. Michael Ackerman and Dr. Silvia Priori. New topics in breakout sessions and social activities like a Networking Night Out and a Comedy Improv show will give families in attendance multiple opportunities to get questions answered, network with other families, and learn more about how to manage SADS conditions.

For more information on the conference including copies of the agenda, how to register, and details on how to get involved with different aspects of the program, visit [www.StopSADS/Conference2015](http://www.StopSADS/Conference2015) or contact Matt at [matt@sads.org](mailto:matt@sads.org) or 800.STOP.SAD.

## Speakers Trained for New SADS Speakers Bureau

The SADS Foundation is formally establishing a Speakers Bureau to significantly leverage our growing ranks of committed local SADS experts who will educate front-line health professionals and connect them to these SADS experts.

The first step in developing the Speakers Bureau will be a training session for SADS specialists with Dr. Michael Ackerman. These experts will commit to speaking in their local region to target groups such as Emergency Physicians, Pediatricians, Family Physicians—and all their professional staffs as well as to school nurses.

The trained speakers, with the SADS Foundation and our volunteers, will aggressively seek opportunities to present this life-saving information across the United States so that we may increase the number of young lives saved from a preventable death.



### In this newsletter

*Keeping Kids Safe at Summer Camp*

*Celebrating Volunteers*

*Energy Drinks and SADS*

*Lifestyle and Exercise in Long QT Syndrome*

**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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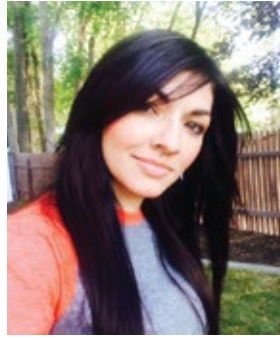
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## Welcoming Amanda

### Family Support Intern

I consider myself incredibly fortunate to become a member of the SADS team in providing information, education, and support for families impacted by SADS. I recently received my BS Degrees in Anthropology and Peace and Conflict Studies from the University of Utah, and am currently in the process of applying to law school. I have a passion for social justice issues and the important work done in the non-profit sector. In addition to my new position here at SADS I also work at the Fourth Street Clinic and the Bateman-Horne Center of CARE (formerly O.F.F.E.R.), providing a variety of services including outreach, fund development, compliance, and advocacy. I look forward to working with children and families in identifying potential risks and/or signs of an underlying SADS condition, and connecting families with medical professionals and supportive services so that children diagnosed with SADS can live happy, healthy lives.



## Christine's Farewell

As I reflect on my four years as the Medical Education Director with the SADS Foundation, I am filled with joy for the passion, commitment, and sincerity of all the folks I have had the pleasure to work with! Though I am leaving SADS to pursue a personal business endeavor, I look forward to hearing about all the advances in the science of SADS conditions and other great work that my colleagues will continue to be a part of! You have taught me so much and it has been a genuine pleasure working with each and every one of you! I wish you all the best personally and professionally and I hope that our paths will cross in future! To all of the SADS staff, scientific advisors, medical education committee members, physicians and healthcare providers, and of course patients that I have had the privilege to work with, you inspire me so much and I will take that inspiration with me into my next adventure and will think of you all fondly! Best wishes!



## Staff Travels

The staff members of the SADS Foundation travel as often as possible to help spread awareness of, educate professionals and community members about, advocate for research of, and support our families with SADS conditions. We hope we meet as many of you in person as possible!

### August 2014

|              |                                                      |                |
|--------------|------------------------------------------------------|----------------|
| Alice Lara   | Pediatric West Conference                            | Sun Valley, ID |
| Jan Schiller | Microsoft Incubation Team Kick Off Fundraising Event | Chicago, IL    |

### September 2014

|              |                                                      |                   |
|--------------|------------------------------------------------------|-------------------|
| Alice Lara   | Health eHeart Alliance Summit                        | San Francisco, CA |
| Alice Lara   | City of San Diego Visit about HSSA                   | San Diego, CA     |
| Jan Schiller |                                                      |                   |
| Alice Lara   | A Night Under the Stars Fundraising Event            | Palos Verdes, CA  |
| Jan Schiller |                                                      |                   |
| Alice Lara   | National Association of Medical Examiners Conference | Portland, OR      |

### November 2014

|                |                            |             |
|----------------|----------------------------|-------------|
| Alice Lara     | American Heart Association | Chicago, IL |
| Christine Rice | Scientific Sessions        |             |

### December 2014

|            |                  |               |
|------------|------------------|---------------|
| Alice Lara | PACES Conference | Las Vegas, NV |
|------------|------------------|---------------|

### January 2015

|            |                                               |            |
|------------|-----------------------------------------------|------------|
| Alice Lara | Children's Hospital of Orange County Seminars | Orange, CA |
|------------|-----------------------------------------------|------------|





## Call to Action: Developing New Materials on College Life

Staff members have recently received a number of questions and requests for more information on how to transition into a college environment with a SADS condition, and we need your help. We're going to be putting together materials specific to navigating college life with SADS, and figured it would be best to go right to the source of time-tested, "front line-informed" strategies: YOU! To that end, we've generated a series of questions and we're looking for your input.

- What have you (and/or your teen) done in the past to prepare for college? What worked? Be as specific as you can.
- Who were the folks you informed first, and how? What would have helped in that circumstance?
- What changes to your daily routine were needed to ensure your safety (if any)?
- What three things did you learn that you wish you'd known before going to college so that you could be prepared?

Please send answers to the following questions to Matt at [matt@sads.org](mailto:matt@sads.org)! Oh, and please use the title "College Questions" in the subject line!



## Heart Safe School Accreditation Survey Results

The first Heart Safe School Accreditation survey results are in! The survey was completed by all schools who have received Heart Safe School Accreditation. Look for a PowerPoint of complete results to be posted on the Heart Safe School Accreditation website soon!

- 31% of schools learned of new students at risk of sudden cardiac arrest.
- 70% of schools made changes to individualized care plans.
- 61% of schools added AEDs to their building(s).
- Confidence in staff to perform CPR and use an AED increased over 50%.
- 100% of school reported an increased awareness of sudden cardiac arrest.
- 100% of schools would recommend the program to other schools.

Join the craze and get your school accredited as a Heart Safe School today

Contact us at [hssa@sads.org](mailto:hssa@sads.org) or 1-800-STOP-SAD to find out how to get your school accredited or visit our website at [www.StopSADS.org/hssa](http://www.StopSADS.org/hssa) for more information.

## Summer Camps: Keeping Kids Safe while Staying Active

When sending your child to summer camp, it is important to be sure that the camp is aware of his or her SADS condition and is properly prepared to respond in the event of an emergency. Summer camp is something everyone can enjoy with a few easy precautions, including making sure staff are CPR trained and that they understand and avoid SADS triggers (startle, stress, etc.) when possible. By making sure camp staff members are aware of your child's medications, AED (where indicated) and care plan, you know that your kids are having fun and making friends in a safe and healthy environment.

You can find a list of special camps for children with congenital heart conditions, implanted devices, etc. on our website at [www.sads.org/living-with-sads/Emotional-Support/For-Kids/heart-camps-for-kids](http://www.sads.org/living-with-sads/Emotional-Support/For-Kids/heart-camps-for-kids). While kids don't need to attend camps that cater to SADS-specific conditions, many families have told us that specialty camps create a unique experience and can help to address support issues that regular camps are not as easily well-equipped for.

If you have a great recommendation



(heart-related or otherwise) for a summer your child has enjoyed, please contact Matt at [Matt@sads.org](mailto:Matt@sads.org) or call 800-STOP-SAD to share; we'll be sure to include it on our website and in potential future e-newsletter articles closer to the summer.



A Project of the Snider Community Heart Watch



## Heart Hero – Nicole Bencie

Seventeen-year-old Nicole Bencie attended the Oxford Royale Academy (ORA) summer school in England two years ago. Nicole had originally been told by ORA staff she would not be able to attend because of her heart condition: she is a SADS patient living with LQTS. At less than three months old, Nicole was diagnosed with LQTS she inherited from her mom, Teresa. Prior to Nicole's diagnosis, her mother was unaware that she had the same condition. Her younger sisters, Nathalie and Noelle, were also diagnosed with LQTS. All three girls take beta-blockers and carry AEDs with them to school.

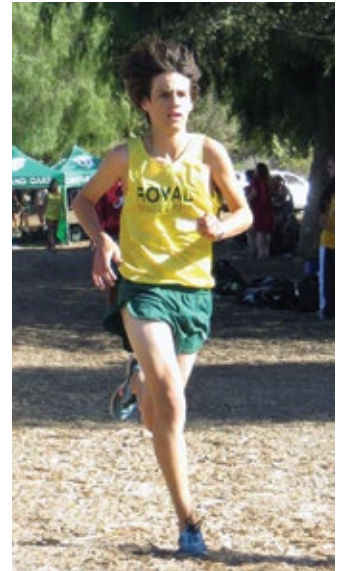
While in Oxford, Nicole spent a lot of time learning about the dynamics and challenges facing the program's directors in regards to having AEDs and trained staff on site. After spreading awareness and understanding, the head program coordinator felt more comfortable with the idea of implementing a safety program that included AEDs in case of an SCA. When the program ended, Nicole coordinated with the SADS Foundation, SADS UK, and her school FIT Club (which she founded in 2012!), to raise money to purchase an AED.

After a year of fundraising, several bake sales, and much effort, enough funds were collected to purchase the AED, which will continue to benefit international students and the staff/faculty at ORA for years to come. We are very proud of you, Nicole!



## The Parks Family and Harrison Hugs

In the early spring of 2014, Harrison Parks died in his sleep from a sudden cardiac death. A junior at Royal High School in Simi Valley, California, Harrison had been working hard to be academically ready for college; assisting with friends and families in need in his community; and maintaining a strong interest in athletics. "Harrison, eternally 16, always had a smile, hug and the desire to help those who needed it, whenever they needed it," according to his mother Kathie. As a result, after his unexpected death the Parks family decided to honor Harrison's legacy of compassion, kindness and giving nature by founding Harrison Hugs.



Harrison Hugs is a non-profit organization that provides education on the risks of sudden cardiac arrest in the young, advocates for basic life support and CPR/AED skills training in schools, and raises funds for AED placement in their community. The organization's long term goal is for all schools in the Simi Valley in California to achieve Heart Safe School Accreditation.

Harrison Hugs has been very successful since its inception last year, and we are happy to report that in November of 2014, the Simi Valley Unified School District Board voted to implement AEDs district-wide into the schools with the help of Harrison Hugs! On behalf of the SADS Foundation, we want to congratulate the Parks family and look forward to continuing in our partnership with Harrison Hugs to prevent sudden cardiac death and save lives.

## Heart Heroes – The Knowles Family

Great friends and supporters of the SADS Foundation, the Knowles family has been busy as advocates and volunteers to ensure that individuals and families know about arrhythmias and what to do in the event of a sudden cardiac arrest. Cameron Knowles, who is currently an eighth grader at Greece Odyssey Academy in New York, survived a pediatric sudden cardiac arrest thanks to his parents (Rebecca and Mark) administering CPR until medical help arrived. Six years later, Cameron and his parents continue to increase awareness and educate their community on how to respond to a sudden cardiac arrest, helping to save young lives.

The Knowles family has recently been working to make Odyssey Academy Heart Safe through the SADS Foundation's Heart Safe School Accreditation Program. This past September over **1,000 staff and students** received Hands-Only CPR training, bringing Odyssey Academy that much closer to receiving accreditation and becoming Heart Safe. We are excited and truly grateful for the hard work of Mark, Rebecca and Cameron in ensuring that both kids and adults are prepared to respond to someone in sudden cardiac arrest!



Each year, a cardiac arrest occurs in 1 in 50 American schools. Educating students in hands-only CPR could save a life. Learn more about Heart Safe School Accreditation by visiting [www.sads.org/hssa](http://www.sads.org/hssa) or emailing [hssa@sads.org](mailto:hssa@sads.org).



## Become a volunteer fundraiser for the SADS Foundation!

Three of our longest-running volunteer fundraising and awareness events: **Oktoberfest** in Colorado in honor of Sally Layton, **Christie's Heartoberfest** in New York in memory of Christie Tolosky, and **Brittany's Trees** in Illinois in memory of Brittany Valene all had their most successful years ever!

Bill and Sally Layton began Oktoberfest in 1998 to bring together family and friends in support of the SADS Foundation after Sally beat the odds and survived a Sudden Cardiac Arrest at Disneyland. Oktoberfest has become a grand tradition at their home each September and brings in more attendees every year.



Craig and Barbara Tolosky started Christie's Heartoberfest in 2006 after losing their daughter Christie due to an undiagnosed Long QT condition. As a result of Christie's passing, several family members have been diagnosed. The event continues to raise funds for and awareness of treatable SADS conditions.

Brittany's Trees is a neighborhood tradition that celebrates the holidays in memory of Brittany Valene who died just before her ninth birthday. Local neighbors decided to keep Brittany's memory alive by placing Christmas trees in their front yards. The first year, 22 trees were placed on neighborhood lawns. It was the beginning of Brittany's Trees which celebrated its 10<sup>th</sup> anniversary selling more than 1,500 trees in 80 towns!

If you want to become one of the volunteers who annually raise awareness and funds through local events, please contact Jan at [jan@sads.org](mailto:jan@sads.org) or 801-531-0937.



## Celebrating Ten Tournaments

The Ryan Weidler Memorial Golf Tournament will celebrate its 10<sup>th</sup> anniversary on July 27<sup>th</sup> in Lansdale, Pennsylvania. Ryan's family and friends will host this event in memory of Ryan who was lost at the age of 26 in the summer of 2005.

In the short years of Ryan's life, he developed an impressive work ethic and was a gifted athlete throughout high school. However, his favorite social sport was golf which he played regularly with family. His summer caddying job gave him an appreciation for the game and enhanced his skills. Ryan would have loved the tournament as an opportunity to challenge himself and as a time to have fun with family and friends.

Finally, Ryan's habit of self-sacrifice would have been

exercised at these annual tournaments. Even though he was, at the time of his death, still a young man climbing the business ladder, he realized the importance of giving to causes greater than himself.

The SADS Foundation is honored to observe this milestone anniversary with the Weidler Family and all those who remember Ryan's altruism through this event.



## No Ball at All

The SADS Foundation is celebrating the 21st Anniversary of No Ball at All! We are honoring Justin Matthew Paul who had an uncertain beginning, but is now a thriving three-and-a-half year old.

"The SADS Foundation is a remarkable organization that has helped us in Justin's journey to thrive as a happy and healthy little boy," says Jennifer Paul, "They helped our family during tough times, helped prepare us for Justin to enter preschool, and to start a local network of SADS families. They do an amazing job in educating, advocating and supporting our community."

Please visit [www.sads.org/Donate-No-Ball-At-All](http://www.sads.org/Donate-No-Ball-At-All) to donate online.



## Vincent Heritage Fund

The SADS Foundation has established a special fund to give tribute to the past and to bestow continuing funds for the future: **The Dr. G. Michael Vincent Heritage Fund.**

It was Dr. Vincent's tireless efforts and compassionate leadership that led to the SADS Foundation becoming an official 501(c) (3) non-profit organization. Since 1991, the SADS Foundation has been "**a better way**" to further life-saving endeavors and family support of children and young adults.

The Dr. G. Michael Vincent Heritage Fund will provide funding to expand the programs of the SADS Foundation as we strive to advance the knowledge, treatment, advocacy, and research of SADS conditions. Be part of "**a better way**" for SADS families all over the world in honor of our founder. Visit [www.StopSADS.org/VincentHeritageFund](http://www.StopSADS.org/VincentHeritageFund) to help fulfill Dr. Vincent's wishes "that families with SADS

conditions will be kept whole to enjoy the future of children, grandchildren, and the rewards that come from active and healthy lives."



## Energy Drinks and SADS Conditions

The SADS Foundation scientific advisors (leading national and international experts in the field of cardiac channelopathies) discussed whether energy drinks are safe for consumption by channelopathy patients. Their expert consensus is that:

- Excessive caffeine intake can lead to many symptoms, including arrhythmia, and should be discouraged for all patients.
- “Moderate” caffeine intake, even of “energy drinks” appears safe.
- No scientific evidence exists linking so-called “energy drinks” or other caffeinated beverages with SCD, but there have been rare cases

of interactions that were suspicious (most often with large exposure doses or short ingestion time)

- Given the incidence of channelopathies in the population and the very high exposure rates (30-50%) of young and middle-aged people to caffeinated beverages, including energy drinks, one would expect to see a high rate of adverse tachyarrhythmia events in new and known patients if there was a relationship, and that just isn't the case.

All of our experts agree that there is a lack of scientific data on this topic and feel it is worth further scientific study.



## Progress with the Medical Examiner Community

SADS staff members attended the National Association of Medical Examiners (NAME) annual conference last September. We were thrilled to hear about even more advances since last year's passing of the position paper on retaining postmortem samples appropriate for genetic testing. During the annual business meeting, NAME members voted in favor of adding this to their autopsy standards. This is a huge leap forward and we are proud to have been instrumental in pushing for this

addition to their standards. In collaboration with the NSGC Cardiac Special Interest Group, we continue to pursue our national mailing campaign to all medical examiners and coroners offices, including a magnet that details this proper sample collection that can be kept on their laboratory refrigerator or freezer. For more information on this project, including how you could help, contact Matt at 801.531.0937 or [matt@sads.org](mailto:matt@sads.org).



## Thank You for Your Action!

We continue to support your interests with our membership on the Heart and Stroke Coalition, our partnership with the American Heart Association, the Genetic Alliance and other national groups who fit our goal “to promote research by advocating for increased funding and patient participation”. Some of our/your most recent actions include:

- Advocating with several large regional Medicare insurance companies to continue to cover LQTS genetic testing. This is important because private insurers look to Medicare for their policy on payments for genetic testing
- Supporting (once again) the Rural and Community AED Act
- Supporting increased funding of the NIH for Heart and Stroke research
- Supporting States who are passing laws to require CPR with AED training as a requirement for high school graduation

Your advocacy actions are critically important to shaping legislation, insurance policy coverage, and increased demands for research on SADS conditions. Make sure you receive these alerts by signing up for E-Newsletters on our website at [www.StopSADS.org](http://www.StopSADS.org). If you hear of a bill that you think SADS should support, please contact Matt at 801-531-0937 or [matt@sads.org](mailto:matt@sads.org).



## Lifestyle and Exercise in Long QT Syndrome

LIVE-LQTS is an exciting new study with a goal of determining how lifestyle and exercise impact the well-being of individuals with LQTS.

LIVE- LQTS is currently enrolling individuals, age 8 to 50 years old (both exercisers and non-exercisers). People with or without an ICD can participate. Participation involves a telephone interview and filling out questionnaires online or on the phone. Since all information is gathered by phone, fax, and/or internet, there are no geographic limitations to participation. It's a three year study, with another brief questionnaire every six months. Participants also receive a Fitbit-type pedometer, to wear a few weeks per year, which is yours to keep. All information is kept strictly confidential. You can be participating in other studies and also participate in this one.

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.

Please see the brochure included in this newsletter for more information.



## Long QT Syndrome in Fetal Life Study is Recruiting!

Dr. Bettina Cuneo of the Colorado Children's Hospital has recently received approval for a prospective study of Long QT Syndrome (or LQTS) in fetal life. Pregnant women are currently being recruited, with the goal of detecting LQTS before a baby is born so that you can provide the best care for your newborn. We know that LQTS babies have a lower heart rate before they are born than babies without LQTS. Now Dr. Cuneo would like to study fetal heart rates from very early in pregnancy until birth in families who have different LQTS mutations:

- To see if the fetal heart rate can predict which baby will have LQTS
- To see if patterns of fetal heart rate can predict whether the baby has LQTS1, LQTS2, or LQTS 3

In order to participate, either the pregnant mother or the father must have a genetic diagnosis of LQTS subtypes 1, 2, or 3. Check our website [www.StopSADS.org](http://www.StopSADS.org) and click on **Research** for more details on how you might get involved or for more information.

## New Research for LQTS Type 3

### Partnership with Gilead Sciences

The SADS Foundation is excited to announce that we are partnering with investigators from around the United States and from around the world, including the Netherlands, Japan and Israel, on a clinical trial of a new drug for LQTS Type 3 patients from Gilead Sciences, Inc.

If you'd like to participate, please contact Matt at 801-531-0937 or [matt@sads.org](mailto:matt@sads.org) for more information.



Check [www.StopSADS.org](http://www.StopSADS.org) for the newsletter  
to find links to the full articles and other  
information from this newsletter.



## Upcoming Events

### Conferences

|           |                                              |              |
|-----------|----------------------------------------------|--------------|
| May 13-16 | Heart Rhythm Society Scientific Sessions     | Boston, MA   |
| May 29-31 | 8th International SADS Foundation Conference | New York, NY |

### Volunteer Fundraising Events

|              |                              |              |
|--------------|------------------------------|--------------|
| April 4      | Devons Beat 5-K              | Lincoln, MO  |
| May 10       | Brian Anderson Memorial 5K   | Sewell, NJ   |
| July 27      | Ryan Weidler Golf Tournament | Lansdale, PA |
| September 11 | Texas Hold'Em                | Folsom, CA   |

## National CPR/AED Awareness Week June 1-7

Help us tell the story of the lives that can be saved if  
more Americans know CPR and how to use an  
Automated External Defibrillator (AED).

**Start Planning Now!** Will **YOU** work with us to  
promote CPR and AED training in your community?

An Easy Way to Give – Donate Your Vehicle!

Visit

[www.sads.org/Get-Involved/Vehicle-Donation-Program](http://www.sads.org/Get-Involved/Vehicle-Donation-Program)  
to find out how easy it is!

