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**November, 2014**

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January 16-18, 2015  
Scottsdale, AZ

**PACES 2014**  
**Advancing the Field**



**The Knowles Family Help Make Greece Odyssey Academy Heart Safe!**

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, and look forward to their continued efforts to educate others on being Heart Safe. For more information on the Heart Safe School Accreditation program, click [here](#) or contact Matt at [matt@sads.org](mailto:matt@sads.org) or **800.STOP.SAD**.



**8th International SADS Conference is Fast**

December 12-14, 2014  
Las Vegas, NV



## Approaching!

The SADS Foundation's Board of Trustees, Scientific Advisors, staff members, and volunteers have all been working tirelessly to plan the **8th International SADS Conference** this year in New York City and Long Island. This year

we've also engaged a Family Support Committee of previous attendees and SADS families to help us organize the agenda, determine speaking topics, and organize activities. And while we've kept all of the great things about previous conferences, we're excited to be changing things up a bit to include some new session topics like SADS and the Affordable Care Act; more interactive discussion sections and informal break-out times with a Family Open Mic; and new activities for our Youth and Teen tracks, including a SADS Scavenger Hunt.

We're also very excited to be hosting three conference plenary sessions hosted by **Dr. Silvia Priori**, **Dr. Michael Ackerman**, and **Dr. Arthur Wilde**, respectively. We're still hard at work finalizing the agenda and some of the speakers, but rest assured you won't want to miss it! Registration information is listed below. Be sure to purchase early to take advantage of the Early Bird special pricing!

To register for the conference click [here](#) or for more information on the conference visit our website [here](#) or contact Matt at [matt@sads.org](mailto:matt@sads.org).

### Family Support Conference Ticket Pricing

<i>Adult Ticket Before January 31st, 2015:</i>	<i>\$90</i>
<i>Adult Ticket After January 31st, 2015:</i>	<i>\$120</i>
<i>Youth/Teen Ticket Before January 31st, 2015:</i>	<i>\$40</i>
<i>Youth/Teen Ticket After January 31st, 2015:</i>	<i>\$50</i>

If you are a **health professional** please click [here](#) for information on our CME sessions.

## Thanksgiving and Your Family Pedigree

As we've already alerted you to in the last e-newsletter, Thanksgiving is not only a time to celebrate your





family over a shared meal and stories; it's also National Family History Day. The SADS Foundation encourages you to enjoy your family's company on Turkey Day, but to also learn more about your family by researching your family's health history. By reaching out to your family and documenting the history of SADS conditions in the family tree, you will be not only learning about who has (and has not) been impacted by SADS but also protecting the next generations in your family by being able to trace who might be at risk in the future.

Be proactive this holiday season by analyzing your family pedigree. We here at the SADS Foundation are ready and able to help you along the process. You can get started by downloading our online **Pedigree kit** (found [here](#)) to begin documenting your family's history with SADS. And you can always contact Matt at [matt@sads.org](mailto:matt@sads.org) or **800.STOP.SAD** with questions or if you need tips on how to engage relatives in the process. Happy Thanksgiving!



### **SADS Young Investigator Awardee Part of Team Researching Timothy's Syndrome**

One of our most recent **Young Investigator Awardees, Nicole Boczek, BA** is the lead author on a research paper to be published in the Heart Rhythm Society Journal. The study examines a novel genetic mutation associated with

Timothy's Syndrome, an extremely rare SADS condition with less than 30 total cases reported worldwide. Prior scientific research into Timothy's Syndrome found that most cases are related to mutations in a specific exon, or DNA "spot", found in calcium channels. Boczek and members of the research team focused on a young man who did not have the mutation previously known to relate to the Timothy's Syndrome and found a here-to-fore undiscovered mutation by doing whole exome sequencing (or WES). WES allows scientists a stronger ability to find genetically rare disease-causing genes by looking at the whole genome instead of smaller segments known to cause disease. The research team suggested that, based on their findings, WES might be appropriate for testing people who originally test negative for Timothy's Syndrome to see if there are other unknown mutations that may also cause the disease. We're

very excited to see one of our Young Investigators contributing to the scientific literature and look forward to her next publication. An abstract of the study can be found [here](#).



### **American Heart Association Scientific Sessions 2014**

Once more, President & CEO **Alice Lara** and Director of Medical Education **Christine Rice** have attended the American Heart Association Scientific Sessions. This year, Alice and Christine traveled to Chicago to learn about the latest findings on SADS conditions and took advantage of the opportunity to visit with colleagues and partners about shared goals for 2015. They will be reporting what they learned in the next Enews.

### **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 for study participation, with the goal of comparing the heart rates of



fetuses with a family history of LQTS to heart beats of those who do not have a family history. In the future, this might help physicians better identify babies who may not have a family history of SADS but that still might be at risk of developing a SADS condition. In order to participate, either the mother *or* the father must have a genetic diagnosis of LQTS subtypes 1, 2, or 3. The study is expected to continue over the next five years, and there is compensation for those who participate. Check our website [here](#) for more details on how you might get involved or for more information.



## What *IS* the difference between IEPs and 504 Plans?!

Here at the SADS Foundation, we receive a lot of phone calls and messages

from parents and teachers about how to make sure that their children with SADS conditions can be successful in the K-12 school environment. In many cases, people call because of confusion about whether or not their children can utilize Individualized Education Plans (or IEPs) and/or 504 Plans. Initially designed for children with attention and learning deficits or physical disabilities, IEPs and 504 plans establish “blueprints” that assist children with unique needs in their learning environment in very similar ways. However, each type of plan stems from a different legal origin and has slightly different requirements and processes. In both cases, these types of plans are designed to accommodate kids in their schools to ensure that they have the same opportunities to learn that their peers do. Because these types of plans are more similar than different, it can sometimes be difficult to determine which (if either) of these options is right for your child.

Thanks to one of our Facebook friends, we were alerted to an online resource that shows the similarities and differences between these types of plans in an easy-to-read table format. [Click here](#) to see how IEPs and 504 plans compare, and to find additional links to resources that can guide you in seeing what your options are. Thanks to **Sherri Lynne** from **Facebook** for posting the link on one of the Long QT Support group pages!

## Giving through the workplace

Many ways are available to give through your workplace including the following:



**United Way** – An employee, who works at a company that holds a United Way Workplace Campaign, may write in the SADS Foundation as we are an established 501 (c) (3) non-profit organization. You may give a single gift or through payroll deduction. Our tax exempt ID number is 87-0492100.

**Combined Federal Campaign** – If you are a federal employee you

may give through the Combined Federal Campaign which is run by Federal volunteers across the nation and overseas, it is the largest employee campaign in the world. We are listed as the Children's Heart Syndromes & Death Prevention Foundation with the five-digit code #56112.

Additionally, many companies will match charitable gifts increasing the value of your contribution to the SADS Foundation. Click [here](#) to see if your company is listed for matching contributions or check with your company's human resources department.

Our deepest appreciation is extended to everyone who makes it possible for us to fulfill our mission of supporting families and saving lives. We are truly thankful!

## Volunteers support the SADS Foundation

### A little bit jazz

After five fainting spells and what seemed like endless testing at age 8, **Alex Balagna** was diagnosed with Long QT Syndrome. Years later, he lost his two-year-old nephew Luke to the same condition, which had been overlooked by his doctor. Alex quickly learned the seriousness of LQTS and the importance of spreading awareness in order to prevent other unnecessary deaths.



"After being placed on daily medication and undergoing surgery to implant a defibrillator, I know that I've been extremely fortunate," says Alex, "Now, I would love to give back by donating a portion of the proceeds from this Christmas Album to the SADS Foundation." To find out more about Alex and his passion, visit [www.alexbalagna.com](http://www.alexbalagna.com). We are happy Alex is a part of our family.



### A little bit country

Lola Webb, the daughter of James Robert Webb, had two episodes in a pool – the second being a near drowning. It was after the second incident that her EKG showed mild QT prolongation in the hospital. It was the suggestion of an under-appreciated and overworked resident that led the family to a more complete workup for Long QT

Syndrome. This time, a stress EKG was positive and genetic testing later confirmed that she had LQTS type 1.

James and his family have gotten behind the SADS Foundation. They know that sudden death from cardiac arrhythmias is a huge problem. "The maddening thing as a physician and a parent is, I know the survival rate can be over 99% for these kids if they are identified and properly treated," says James, "Sudden arrhythmia death syndromes like Long QT Syndrome can be treated with survival rates in the high 90s with generic medications and simple avoidance. It just takes screening."

That's why the Webb family believes the work of the SADS Foundation is so important and why James helps partners with us to spread awareness raise funds through his music – even recording PSAs for play on radio stations. To find out more, please visit [www.jamesrobertwebb.com](http://www.jamesrobertwebb.com).

#### **Pottery for fun and funds**

LQTS Research Team at Philadelphia College of Osteopathic Medicine led by Stephanie Felgoise, PhD/ABPP raised awareness for LQTS and SADS conditions on November 14 at Busy Bees Pottery in Conshohocken, Pennsylvania.



Guests painted their own pottery during this event and proceeds were given to the SADS Foundation. We extend our heartfelt appreciation to study coordinators Katherine Corvi and Liz Waldron for all of their efforts and support of the SADS Foundation.



#### **Celebrate Wayne and Conquer SADS**

Shannon Kiss and friends will present the Celebrate Wayne and Conquer SADS Benefit Concert and Silent Auction on Friday, December 12 at 9 p.m. at the [Georgia Theatre in Athens, Georgia](http://www.georgiatheatre.com). This is the 4th annual event in remembrance for Wayne Sawyer to raise critical funding and awareness for Long QT

Syndrome and other SADS conditions. These events have been a tremendous source of personal healing, as well as raising significant funding and awareness for Wayne's family and friends.

Visit <https://www.facebook.com/pages/Celebrate-Wayne-Conquer-SADS> for details about the benefit concert.



**3rd Annual Coconut Creek Luminary Night**

The Halle Family will light up the night for the SADS Foundation. For the third year, Gregory, Kelly, Sydney, and Courtney will bring their

neighborhood together for a festive holiday evening in December that will feature luminaries lining their streets to raise awareness of SADS conditions and funds for the SADS Foundation.

**Brittany's Trees**

Brittany's Trees has been busily taking tree orders and organizing the big delivery day on Saturday, November 29th for tree set-up. If you live in Carol Stream, you still have time to order a tree. If not, you can support the event by purchasing a T-shirt.



For more details, visit <http://www.brittanys-trees.com>.

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