New SADS Blog Post: CRISPR Study to Correct Genetic Defect

The SADS Foundation is pleased to share this essay written for us by a genetic counselor on the latest CRISPR research, and what it means for our families.

“This possibly represents the greatest discovery of the century. With this technology, we could end suffering and disease for billions of people.” says Stephen Heitner, M.D., a cardiologist at OHSU in Portland, Oregon, who was a member of the research team who showed that it is possible to correct genetic defects in embryos. As he explains, this breakthrough could ultimately lead to humankind’s ability to end genetic diseases.

The study involved DNA, which is your hereditary material, inherited from each of your parents. Small pieces of the DNA are called genes. Researchers recruited a patient with a gene defect which caused his heart to develop hypertrophic cardiomyopathy, or HCM.

The study team used a technology called CRISPR-Cas9, which works like scissors to DNA. To read the rest of this post go to StopSADS.org and search for “CRISPR”

2017 Conference Wrap-Up

The SADS Foundation and the Canadian SADS Foundation are delighted to have hosted the 10th Annual International Conference on September 22-24, 2017, in Toronto, Ontario, Canada.

Attendees came from 7 different countries, 9 Canadian provinces, and 14 states with more than 60 at CME Sessions, more than 100 at Family Sessions, and more than 20 participating in Youth Tracks.

Just a Few Highlights...

• Keynote Speaker Yvonne Heath sharing her “Just Show Up” message
• Disease-Specific Breakout Sessions including LQT, CPVT, ARVC, and HCM
• Pam Husband, Founder of the Canadian SADS Foundation, receiving the Lifetime Achievement Award for her incredible dedication to supporting families and saving lives of young people with SADS conditions throughout Canada

More highlights on page 4.

SAVE THE DATE - 2018 Conference in Ann Arbor, MI

October 26-28, 2018 in Ann Arbor, MI

In partnership with the University of Michigan and CS Mott’s Children’s Hospital, we already are planning the 11th Annual International SADS Foundation Conference on October 26-28, 2018, in Ann Arbor, Michigan.

Join our interest list by visiting our website. By doing so, you will receive priority registration for this highly-anticipated conference. We will send you an e-mail message when registration opens, before it is announced.

sads.org/Conference2018
Meet Our New Intern

Ashlie Miller

My name is Ashlie Miller and I moved here to Salt Lake City from California for my Master’s program in Genetic Counseling. After receiving my Bachelor’s degree in Molecular Biology, I spent a year volunteering at the Inherited Cardiovascular Disease Center (Stanford) working with a multidisciplinary team, as well as volunteering at a local Crisis Center. My passion for genetics and working with people are well fit for the genetic counseling profession. As a future genetic counselor, I value patient advocacy and providing supportive resources and information to patients and their families. Working here at SADS fits well with my personal values and professional goals.

In my free time, I enjoy spending time outdoors exploring the beautiful scenery Utah has to offer. In my first year here I have visited almost all of Utah’s National Parks and have been blown away by their beauty!

New Committee Members

Phil Howard, SADS Trustee and Finance Committee Member

Phil is a partner in Ernst & Young’s Redwood Shores office (San Francisco Bay Area) and has over 14 years of experience serving life science clients of all sizes. He also has spent time auditing the financial statements of a number of not-for-profit entities.

Phil enjoys spending his free time with his wife of 13 years, Stephanie, and their 5-year-old son, Philip “Cuatro,” and 2-year-old daughter, Pierce. When not working, Phil enjoys cooking with his wife, reading, watching his Arizona State Sun Devils, keeping up on his favorite TV shows and traveling to new places. Phil’s daughter Pierce suffers from an undiagnosed SADS condition.

Lee Cooper, Finance Committee Member

Lee works in Business Development and Strategic Planning at Moderna Therapeutics, a biotech company. He experienced a Sudden Cardiac Arrest in 2016 and subsequently learned that he has Long QT Type 2.

Lee is attracted to education, school programs, partnering with researchers, and Board activities that keep things moving forward. He lives in Boston with his wife who also works in the Boston area Biotech Industry.

Amy Sturm is NSGC’s President-Elect

The SADS Foundation extends congratulations to our friend, and cardiac genetic counselor Amy Sturm, MS, CGC, LGC, for her nomination to be the National Society of Genetic Counselors’ President-Elect.

As NSGC’s Cardiovascular Expert, Sturm can discuss hereditary forms of heart disease, including cardiomyopathies, arrhythmias, familial hypercholesterolemia, familial aneurysms and others.

In addition to her role with NSGC, Amy is a Professor and the Director of Cardiovascular Genomic Counseling at the Geisinger Health System Genomic Medicine Institute. Sturm was also appointed to the ClinGen Cardiovascular Domain - Channelopathies Subcommittee.

She also serves as one of two appointed genetic counselor members of the Sudden Arrhythmia Death Syndromes (SADS) Foundation’s Medical Education Committee and works extensively with the Familial Hypercholesterolemia Foundation.

We send our gratitude for everything Amy does to help our families!
Did you know?

Rob L. Walker Heart Safe School Accreditation Champion Award Winner 2017

The award is named after Rob L. Walker who led the charge in starting the Heart Safe School Accreditation program as the Superintendent of Lancaster City Schools, and who was instrumental in having the Pickerington Local School District become the first school district in the nation to become completely Heart Safe.

The SADS Foundation presented this year’s award to Rebecca Knowles who is a Nurse Educator by trade, however as a mother and responder who saved her son Cameron when he suffered a cardiac arrest, Rebecca has wanted to pay it forward. Rebecca started the HSSA program at Greece Central School District in New York. Rebecca lead the way to accrediting four high schools and four middle schools resulting in 6,000 kids receiving hands-only CPR training. Since this accomplishment, Rebecca has focused on other groups reaching the goal.

As a special note, a local resident who suffered a cardiac arrest at a local baseball game was saved by a principal of a local elementary school who had received his training through HSSA program. What a meaningful reward for Rebecca and the SADS Foundation to know HSSA is working!

For information about this program, visit sads.org/HSSA or contact Jan at 802-272-3023 or jan@sads.org.

SADS Family Member and Nurse Connie Goodwin Spreads Awareness About SADS Conditions and Sudden Cardiac Arrest

For the past three years, Connie Goodwin has been going to Indiana schools to educate school nurses, coaches and teachers to make sure that staff know how to respond to a cardiac arrest when it happens, and know where the AEDs are located. Goodwin knows that many schools have AEDs on hand, but they may not be kept where they can be easily reached—she knows of one school that has an AED, but it’s kept locked in the office of the school nurse who works only two days a week. Goodwin says sports teams also need to have AEDs on hand in the event a student collapses. When a person suffers cardiac arrhythmia, you have only minutes to revive them.

Sudden Cardiac Arrest? Drones Could Come to Your Rescue

From Alan Mozes at HealthDay Reporter Tuesday, June 13, 2017 -- Drones have been proposed for some pretty mundane uses, such as delivering pizzas or packages, but new research suggests the high-flying machines could be used to swoop in and save lives.

Swedish researchers think drones can quickly deliver defibrillators to someone whose heart has suddenly stopped beating.

Each minute that passes after a sudden cardiac arrest decreases the chance of survival by approximately 10 percent.

Highlight on SADS Volunteer Zoe Golden Cardiac Arrest?

Zoe is a high school student from Maryland whose father Andy has been an active volunteer with The SADS Foundation for years. At this year’s annual conference in Toronto, Zoe offered to help out with the Youth Program, and spent three days working with the kids who attended the conference. Not only did Zoe really enjoy the meeting and enjoyed helping us out, but she learned a lot about SADS conditions and is now planning on making a presentation to other students to educate them about SADS. Good job, Zoe, and thank you!
In Memory of Ian Hyzy

Ian was a kind, sweet, caring, giving, and empathetic little boy. He was a very loving son, brother, and friend. Ian’s hugs held all the love he had inside of him and he lit up others’ lives with joy. He was funny and did a great Frankenstein impression that couldn’t help but crack you up. Ian was the best medicine for curing a bad day. Ian was full of life and was always full of ideas. He liked adventure and was curious about everything. He loved Legos, Angry Birds, Minecraft, reading books, playing outside, playing at the playground, drawing pictures or writing little stories, and being with his friends. He had just started learning how to play baseball and was really getting good at the skills required. Ian was an “old soul” and was very mature in his thinking. One day while driving with his mom in the car, the song “If I Had a Million Dollars” came on the radio. He listened to the lyrics and then declared, “If I had a million dollars, I would give it to people who need it. THIS guy just wants to buy himself something!” Another day, while riding the school bus home, he told a fellow student that he “shouldn’t be eating a sucker on the bus because he could choke”. He was always aware of others’ feelings and needs, and put them before his own.

On March 6, 2016, at age 7, Ian passed away from Long QT Syndrome, a rare heart rhythm condition. He had been taking the antibiotic Zithromax, which unbeknownst to his parents, was exacerbating the Long QT. His parents were completely unaware that he had this condition, as he had never shown any symptoms. Genetic testing results eventually confirmed that Ian was born with the gene mutation for Long QT Syndrome.

To honor his life, the Hyzy family held the First Annual Fundraising Walk/Run and Auction called Celebrate Ian on September 30, 2017, to support the both the SADS Foundation and Parent Heart Watch as these two organization help affected families through the SADS journey and prevent the future loss of young lives.

At the SADS Conference, I Learned I Was Not Alone

By Annie Lucatuorto

SADS Blog sads.org/blog

As I sit here on a train to Mineola Station, I know one thing for sure: I am confident. Confident of the condition I was born with, the limits I possess, and the boundaries I can break. Outside the window to my right passes scrawny trees and packed cities.

This sight is nothing compared to Mount Rainier, WA, the first convention I attended. At that time I was anything but confident. It was a year after I learned of my condition and I was lost. Unlike some, I experienced an episode, and as a result I had to give up playing competitive sports. In other words I was very restricted.

That first convention I attended truly changed my life. I learned I was not alone. Which sounds silly when I type it out, but it was comforting to know that there are others out there who have my condition, and there are individuals out there striving for a change. At each conference I attended thereafter I learned how my condition differed from case to case, the different approach every individual doctor took with his/her patients, and how I did not have to be as restricted as I was at first. Most importantly I became confident, and this confidence could not have been achieved without the SADS Foundation, my family, and the individuals I met whose stories changed my life.

If you’re thinking of going to the next convention don’t go because your parents are making you, but go to better understand the condition you possess, and to meet individuals who could change your life too.

2017 International Conference Wrap-Up

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We would like to thank everyone who helped to make it so hugely successful - expert speakers, hardworking volunteers, amazing participants, and our valued sponsors including Ambry Genetics, Audentes, GeneDX, Gilead, Invitae, LifeSure, Abbott, Myokardia, Medtronic, Heather Cartwright, Chris Clark Family, Colin O’Kane Memorial Fund, Peter Kidder & Lynn Johnson.

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Ways to Give Throughout the Year

Start off 2018 with a resolution that makes an impact throughout the year for every family with SADS conditions including yours – set up automatic monthly donations to the SADS Foundation!

Join our SADS families who donate a $5 to $200 gift each month. We rely on these gifts to help us to plan and sustain the critical services we provide to support families and save young lives. When combined with all the other donations, both large and small, they add up to victory for families with SADS conditions.

Authorized Pay from Financial Institution: Just click the Donate Button at sads.org, fill out your information, continue to the payment page and choose ACH Checking or ACH Savings from the dropdown menu.

Authorized Pay from Credit Card: Just click the Donate Button at sads.org, fill out your information, continue to the payment page and choose Credit Card from the dropdown menu.

Payroll Deduction: Ask your employer if they have this option and how to set it up.

And...some other ways to support us:

Vehicle Donation Program: Donate a vehicle and receive a tax deduction. Just contact our office to send you a form for the required information to be sent to Copart who will process the donation for the SADS Foundation.

AmazonSmile: AmazonSmile lets customers enjoy the same services as on Amazon.com except when you shop on AmazonSmile, 0.5% is donated to the charity of your choice. Remember, start each shopping session at smile.amazon.com choosing us as your charity.

iGive.com: Join for free at iGive.com/ SADSFoundation to be part of the largest online network of shoppers who turn everyday online shopping and searching into much-needed donations.

Contact Jan at 801-272-3023 or jan@sads.org for assistance.

SADS Foundation
25th Anniversary
25 Donors Challenge

In order to end our 25th Anniversary Year with a BANG! the SADS Foundation is challenging our family members, friends, and supporters to collect 25 donations per person or family by December 31, 2017!

You may collect 25 donations by cash, checks, or online at our SADS Foundation 25th Anniversary 25 Donors Challenge CrowdRise page. Every person or family who collects 25 donations will be receiving a surprise 25th Anniversary Celebration gift.

For more details, contact Jan at 801-272-3023 or jan@sads.org.

Events Highlights

Repeating Events

20th Hanss Layton Oktoberfest in Colorado Springs, CO - The SADS Foundation extends its heartfelt appreciation to Bill and Sally Layton, their families and friends, and the nearly 700 people who attended on September 16th in Colorado Springs, CO, in honor of Sally Layton to raise funds for the SADS Foundation. This past year’s event broke records raising just shy of $23,000 to bring the lifetime total of funds raised to more than $150,000!! What an outstanding accomplishment made over the past two decades and what an amazing commitment to supporting families and saving lives through the SADS Foundation!

13th Brittany’s Trees in Carol Stream, IL, is once more lighting up thousands of yards in local neighborhoods during the holiday season in memory of nine-year-old Brittany in support of SADS families, SADS research, and the SADS Foundation.

12th Christie’s Heartoberfest in Saratoga Springs, NY, is an annual awareness and fundraising event benefiting the SADS Foundation. Each year 4,000 Americans die suddenly and unexpectedly from SADS condition. Christie’s Heartoberfest remembers Christie Tolosky, who was one of the 4,000 who died suddenly in 2005 at the age of 24 from what was later diagnosed as Long QT Syndrome.

12th Ryan Weidler Memorial Golf Tourney in Norristown, PA, is hosted by Ryan’s family and friends 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. Ryan’s favorite social sport was golf which he played regularly with family. Ryan would have loved the tournaments as a way to have fun while giving back to the SADS community.

2nd Rachel’s Race in Janesville, WI, is a 5k and 10k race that takes place on scenic roads. This race is in memory of Rachel Lancour who died in her sleep on May 20, 2015, and was a victim of long QT syndrome. Funds raised enhance LQTS research, education and early recognition through the SADS Foundation to help prevent further tragedies.

New Events

Lemonade Stand for SADS Foundation in Carol Stream, IL, Christine and her daughter Madeline found out this year that Madeline has long QT syndrome, so they decided to make lemonade out of lemons and sold lemonade and SADS bracelets one Saturday afternoon at a local park that turned out to be a huge success. The SADS Foundation appreciates the support.

Celebrate Jan 5K in East Hamenster, NY, was started this year by the Hyzy Family after they lost their 7-year-old son Ian to long QT syndrome on March 6, 2016. Through this event Ian’s legacy lives on to support organizations including the SADS Foundation that support families and save young lives so that other families to not experience a tragic loss.

Running for Our Lives to Take Steps to Stop SADS in Ionia, MI, began after July 9th, 2016, the day Stephanie Tubergen experienced a sudden cardiac arrest. Her husband Kurt happened to be home at the time and was able to perform CPR and keep her viable until first responders could arrive to administer a life-saving shock with an automated external defibrillator (AED). After many tests, it was found that Stephanie has a condition called Long QT Syndrome. Stephanie with friends and family now participates in 5Ks together in support of the SADS Foundation. It’s so important to me to get information to - early diagnosis can make all the difference in life or death.
It's Time for an Update!

The SADS Foundation is updating our Physician Referral Network—our list of medical professionals who know how to take care of SADS conditions—and we need help! A PRN survey was recently sent to current network members to be updated. Answering the PRN survey is quick, completing the survey should take about ten minutes. Once the information for current network members has been updated SADS staff will be contacting additional medical professionals about joining the Physician Referral Network. For more information or questions, contact our Director of Medical Education William Shiflett at william@sads.org.

SADS Speakers Bureau Expanding to Reach More Healthcare Professionals

After a period of great success we are eager and excited to increase the reach and breadth of The SADS Foundation Speakers Bureau Program. The SADS Foundation Speakers Bureau provides trained professionals to healthcare groups who are interested in having a presentation on SADS Conditions and Treatments.

For 2017, the SADS Medical Education Committee established a goal to increase impact of the SADS Speakers Bureau by 10%. While we are getting close to achieving that goal we still need your help. To increase the success of our Speakers Bureau we need to add new members of the health care community to the Bureau AND identify opportunities to speak. We would love to have you, SADS physician (or patients can ask your physician) join the SADS Speakers Bureau today! To learn more about the SADS Speakers Bureau, including how to become a member and how to notify SADS of an event in need of speakers, contact our Director of Medical Education William Shiflett at 801-272-3023 or william@sads.org.

Heart Beater

Cameron Helps Classmate

In a ceremony held on June 8, the Rochester Police Department of the State of New York presented the Do the Right Thing Award to high school student Cameron Knowles for coming to the aid of a fellow classmate who was having a seizure. All are now fine and the ceremony even ended with pizza and refreshments. Way to go, Cameron!

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! The goal is 2,000 participants and we are over half-way there—we need only 300 more adults and 300 more kids...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, sads.org/research/Studies/LIVE-LQTS

We continue to accomplish a lot together.

- 134,247 participants strong
- 14,601,393,965 steps captured from connected activity monitors
- 16 discoveries accepted by top clinical research journals
- 6 in-progress heart health studies

Thank you for your support in the fight against heart disease!

If you’re not part of the study, visit health-eheartstudy.org/

Action Alert: NIH Funding in Danger!

The National Institute of Health (NIH) is the federal agency that supports the vast majority of the biomedical science conducted here in the United States. The Trump Administration proposed a 20 percent cut to the NIH in 2018. This would be a devastating blow to finding treatments and cures for cardiovascular diseases.

The American Heart Association has set up a campaign to tell Congress to increase NIH funding, not cut it!

Please take a moment to tell your lawmakers to support more heart research today!

Go to http://act.yourethecure.org

There are many ways to get involved with SADS Advocacy efforts. We participate in lots of different campaigns. If you are interested in following Advocacy Efforts and in sharing them with our community via our monthly enews, please let us know by emailing sadsadvocacy@sads.org.
Study Says Coffee Shops, ATMs May Be Ideal Locations For Defibrillators

(CNN) — Coffee shops and ATMs could play a major role in helping reduce deaths caused by out-of-hospital cardiac arrest, researchers say.

Their findings appear in the journal Circulation.

“That’s the problem,” said Dr. Richard Page, chairman of the Department of Medicine at the University of Wisconsin School of Medicine, who provided editorial remarks for the study.

“We don’t know where the AED might be. Just think, if every Starbucks or Bank of America ATM had an AED and was known for this, then there would be an AED nearby many (cardiac) arrests, and the rescuers would know where to find it.”

Frequently, Chan says, people don’t know where to find an AED in public, “but if you asked where the closest coffee shop or ATM, most people would know where that is.”

“We want to create a relationship between these devices and familiar places such as a coffee shop or ATM,” he said.

So why aren’t they everywhere? The portable, lightweight devices come equipped with a powerful computer that can detect and analyze rhythms in the heart and decide to restart the muscle if needed. The technology in these devices isn’t cheap. “There is a cost,” Page said, “and although devices can be under $2,000, the costs would add up, and most would never be used.”

According to the American Heart Association, cardiac arrest is often reversible if treated within a few minutes. “It’s important because every second matters,” Chan said.

And a program that takes the information from this research, Page said, “would save lives.”

Light Tames Lethal Heart Disorders in Mice and Virtual Humans

Using high-tech human heart models and mouse experiments, scientists at Johns Hopkins and Germany’s University of Bonn have shown that beams of light could replace electric shocks in patients reeling from a deadly heart rhythm disorder.

The findings, published online September 12 in the October 2016 edition of The Journal of Clinical Investigation, could pave the way for a new type of implantable defibrillators.

changestolqt.png

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

- Cabozantinib (Anti-cancer)
- Epirubicin (Anti-cancer)
- Palonosetron (Anti-emetic)
- Piperacillin/Tazobactam (Antibiotic)
- Piripendyl (Anti-emetic)
- Prothipendyl (Anti-emetic)
- Pilsicainide (Anti-emetic)
- Soflenacin (Anti-emetic)
- Terodiline (Micturin and Mictrol)
- Necitumumab (anti-cancer monoclonal antibody)

Ribociclib (anti-cancer, kinase inhibitor)
Foscarinet (anti-viral)
Midostaurin (anti-cancer drug)
Eliglustat (Gaucher’s Disease)
Valbenazine (Tardive Dyskinesias)
Deutropabenzine (Chorea with Huntington’s Disease)
Triflurizine/Tipiracil (metastatic colorectal cancer)
Cabozantinib (Anti-cancer), Epirubicin (Anti-cancer) and Palonosetron (Anti-emetic)

Piperacillin/Tazobactam (Antibiotic)

Changes to LQT Drugs to Avoid List

11th Annual SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards

To continue encouraging the next generation of researchers in SADS conditions, the Sudden Arrhythmia Death Syndromes (SADS) Foundation presents its Eleventh Annual SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research.

In May 2017, the annual SADS Foundation Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research recognized two outstanding, original academic works in the field of cardiac channelopathies. We congratulate the BASIC SCIENCE winner Daniel Matasic, BS and the TRANSLATIONAL//CLINICAL SCIENCE winner Najim Lahrouchi, MD.
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!

Upcoming Events

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<td>SCA in the Young Conference</td>
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Sign up for our e-news to stay up-to-date on new research that is coming out of the American Heart Association!