



25 Years of The SADS Foundation

In 1991 a group of scientists inspired by Drs. G. Michael Vincent and Mark T. Keating at the University of Utah discovered the first gene for Long QT Syndrome (LQTS).

This was a landmark development in the study of unexplained sudden death.

The genetic finding helped physicians to identify who had the disease before they had symptoms and to treat them with preventative medications.

This pre-symptomatic treatment proved effective, and **is the key to preventing sudden death.** As doctors learned more about prolonged QT intervals, it became clear the abnormality was widely misunderstood



and often misdiagnosed. Dr. Vincent's team was frustrated by the number of young people with LQTS who remained undiagnosed and untreated, and at risk for dying of the disorder. Despite publishing their research in medical journals, it appeared that too few physicians were familiar with or tested for LQTS. Dr. Vincent stated "there must be 'a better way' to spread information about LQTS, and save the lives

of these children and young adults."

The Sudden Arrhythmia Death Syndromes (SADS) Foundation became "the better way."

The SADS Foundation, a nonprofit 501(c)(3) charitable organization, was established on December 12, 1991 by Dr. Vincent and several dedicated colleagues for the purpose of preventing sudden and unexpected cardiac death in children and in young adults.

Today the SADS Foundation continues the original vision of the founders: to prevent sudden death and support families and patients who are genetically predisposed to sudden death due to heart rhythm abnormalities. With affiliates in countries around the world, The SADS Foundation is uniquely able to provide cutting edge information and leadership for SADS conditions.

To learn more about our history, to view pictures of our beginnings, and to learn how YOU can be a part of our 25th Anniversary celebration, please visit our website at StopSADS.org or contact Jan at jan@SADS.org.

2016 Conference a Huge Success!

The SADS Foundation staff came home exhausted and excited after our wonderful 9th Annual International SADS Foundation Conference! The CME Session for medical professionals on Friday was the "best ever" with experts presenting state-of-the-art treatment as well as cutting edge research. Families loved our Research section and Take Steps to Stop SADS event on Friday, and the lectures

from experts, Q&A sessions, and anew disease-specific breakout groups on Saturday and Sunday.

We are looking forward to our 10th Annual conference in Toronto, Canada, Sept 22-24th, 2017. Make plans to join us!

Visit sads.org/conference2016# to look at our gallery of conference photos.



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 New Board Members

Ian Law, M.D.

Dr. Ian Law is a Pediatric Cardiologist and Electrophysiologist, and the Division Director of Pediatric Cardiology in the Department of Pediatrics at the University of Iowa Children's Hospital. His primary area of interest is treating children and young adults who have abnormal heart rhythms, spanning from fetuses with arrhythmias to adults with congenital heart disease in their sixth decade of life, having been born with complex heart disease and later developed arrhythmias as a result of their heart disease or heart surgeries. While his work is primarily focused at the University of Iowa, he performs clinics and procedures in four different states.

Dr. Law is the past President of the Pediatric and Congenital Electrophysiology Society and has been a member of the executive committee for four years.



Brynn Elena Dechert-Crooks, NP

Brynn is a Nurse Practitioner at the University of Michigan Congenital Heart Center and immediate past Vice President of the Pediatric and Congenital Electrophysiology Society (PACES).

A SADS supporter and
SADS Medical Education



Committee member, Brynn Dechert-Crooks, has been a major contributor to our education programs for both families and health professionals. We look forward to working with her and getting the benefit of her experience and expertise as we continue to serve our SADS community.

Mary Ann Ciciarelli

Mary Ann is a Director of Product Marketing for Early Learning at Houghton Mifflin Harcourt. She has been a huge support of her son and also the SADS Foundation starting in 2010 through November 24, 2015 when Lee passed away from complications from Timothy Syndrome. Now Mary Ann continues her valuable work as one of the founders of a Facebook Support Group for families who have members with Timothy Syndrome. This has been a place for educating, sharing, and being there for each other in celebratory and difficult times. To expand upon the purpose of this support group, Mary Ann, Courtney Waller, and Katherine Timothy with the SADS Foundation have established the Timothy Syndrome Alliance (TSA). This organization is charged with bringing more research, awareness and support to Timothy Syndrome. In conjunction with this new role, Mary Ann is a new trustee on the SADS Foundation Board of Trustees representing the TSA. We are genuinely grateful for the extensive efforts of Mary Ann on behalf of Lee and all other children with Timothy Syndrome.



KL2 Award Helps Former SADS Young Investigator Awardee Pave His Career Path

David Auerbach's interest in pursuing a scientific career began during a hockey game his first year of college, when a teammate - who turned out to be a chief medical examiner - asked Auerbach if he would like to observe a case.



Now Auerbach's career is taking a major step forward with a two-year KL2 Mentored Career Development Program award from the University's Clinical and Translational Science Institute. The two-year program designed to support the early career development of

multidisciplinary scientists, helping them transition to an independent career as a clinical and translational investigator.

He is now look at establishing an independent line of research, Auerbach decided to approach the problem in reverse: are people with long QT syndrome - a classically studied genetic cardiac disease that causes arrhythmias - also at an increased risk of seizures?

David Auerbach was award the Courts K. Cleveland SADS Young Investigator Award in 2013. We are so proud of his continued accomplishments.

Family Seminar

The Baltimore/D.C. Area Family Seminar on November 19th was a great success! Planned by Andy Golden and sponsored by SADS and the Johns Hopkins Division of Cardiology, more than 20 SADS family members had a chance to meet with each other and learn from the experts. Dr. Jane Crosson, Pediatric Electrophysiologist, Dr. Gordon Tomaselli, Adult Electrophysiologist, Genetic Counselors

Brittney Murray and Rebecca McClellan and Ligia Jordao, RN from Johns Hopkins all spoke and answered questions. Breakfast and a hot lunch were provided by sponsors Gene Dx and Invitae. For more information and to register for future meetings, please contact Andy Golden at alexandandy3@verizon.net.



Heart Safe Accredited

Tristan Leonhard, the Assistant Director of Recreational Sports, at Valparaiso University, has worked hard to get accreditation for his university. On November 17, in Chicago, Tristan and his wife Eryn were presented the award by Dr. Michael Ackerman. Valparaiso University is the first university to be accredited as Heart Safe.

Changes to LQT Drugs to Avoid List

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

Amphotericin B (brand names Fungilin®, Fungizone®, Abelcet®, AmBisome®, Fungisome®, Amphocil®, Amphotec®)

Bendroflumethiazide (also named bendrofluazide and brand name Aprinox)

Buprenorphine (brand names Butrans®, Belbuca®, Bunavail®, Buprenex®, Suboxone®, Zubsolv®)

Capecitabine (brand name Xeloda)

Efavirenz (brand name Sustiva)

Esomeprazole (Nexium)

Ezogabine (an anticonvulsant also known as retigabine) (brand name Potiga® or Trobalt®)

Flupentixol (Depixol® or Fluanxol®)

Fluvoxamine (brand names Faverin®, Fevarin®, Floxyfral®, Dumyrox® and Luvox)

Ibogaine

Lansoprazole (Prevacid)

Loperamide (Imodium® and many OTC and Rx brand names)

Olodaterol (brand name Striverdi Respimat®)

Omeprazole (Prilosec)

Sultopride (brand names Barnetil®, Topral®, Barnetil®)

Zotepine (brand names Losizopilon®, Lodopin®, Setous® and Zoleptil®)

These drugs have been moved:

Atazanavir, Ranolazine, Roxithromycin, Solifenacin, Tiapride

Special Note: Avoid LQTS App. The SADS Foundation has become aware of an "LQTS" App for Drugs to Avoid that is NOT accurate and is NOT recommended for use by our families. (There is another app we previously evaluated, "EP Tools", that is also not recommended.) We will keep you updated if we learn of an app that is useful.

International SADS Affiliates Meet in San Diego

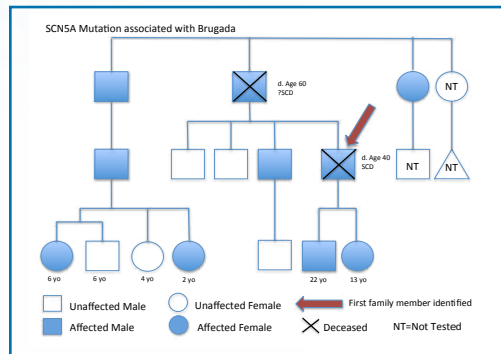
International SADS Affiliates gathered for the first time after the SADS Foundation Conference in San Diego concluded. Affiliates represented include: the SADS Foundation, SADS UK, SADS Canada, SADS Hong Kong, SADS Mexico, and about-to-be-established SADS Argentina. All of us will continue to be in touch with one another about international issues and look forward to meeting again after the conference on September 22-24, 2017, in Toronto, Ontario, Canada.



The Tenhundfeld Family and Friends take on Brugada Syndrome!

Four members of Bridget and Troy Tenhundfeld's family pictured here have been diagnosed with Brugada Syndrome. Not pictured are brothers, sisters, and cousins living in other states who have also been diagnosed with Brugada Syndrome. On October 18, 2015, Bridget's husband, Troy, was napping on the couch next to her when he had a Sudden Cardiac Arrest, from which he did not recover. At the time, he was a healthy 40-year-old man with no prior symptoms.

Through the advice and assistance of The Cincinnati Children's Hospital Genetic Department, Troy's immediate family members as well as their children were tested for the Brugada Syndrome mutation. They also actively reached out to extended family members and their genetic



counselors. One year later, the family has identified at least 7 members with the SCN5A gene, and three family members have been implanted with ICDs (see pedigree).

"Brugada has changed our entire family forever", says Bridget. "However, the death of my husband, Troy, has in turn saved our family from losing another member which makes him a hero. Awareness of Brugada is the only way to stop the cycle."



TEDx Talks Features 16-year-old Sarah Skinner

Sarah Skinner was diagnosed with Long QT when she was 5 days old. She is now 16 and entering her junior year of high school. Last fall, she was invited to do a TEDx Youth talk and she chose to share her viewpoint on living with an invisible disability. The video is available on Youtube. We extend our congratulations to Sarah for doing such an amazing job! Watch her video by searching on our website "Living with an Invisible Disability | Sarah Skinner | TEDxYouth@Dayton."



Barb Almendinger Was Met with a Surprise on the First Day of School This Year

The Utica Junior High's eighth grade language arts teacher was surprised by the faculty with a plaque in honor of a recent accomplishment: self-publishing a book. The book, titled "A Heart in Pieces: A Journey from Grief to Grace," stemmed from coping with the death of her daughter Mary, who died suddenly when she was 8 years old in 2003.



After Mary died, it took six months to figure out her cause of death, which was Long QT syndrome... find the full story on our website: stopSADS.org and searching "Barb Almendinger."

Toni Scarbrough is Totally Dopey!

Excerpted from article by Bob Dalton for the Peachtree City Running Club Newsletter

That's right. New member 44 year-old Toni Scarbrough took the Dopey Challenge and ran a 5K, a 10K, a Half Marathon, and a Full Marathon all in the span of four days at Disney World this past January. But that's not what makes her so unusual. What makes the difference for Toni is that she did it with an Implantable Cardioverter Defibrillator (ICD)!

Toni works in aviation maintaining technical publications and is also a catering supervisor for NASCAR events. Her husband, David, also works in aviation and they have two daughters, Amy (16), and Abby (12). She was born with a heart condition that runs in her family known as Long QT Syndrome. Toni had completed a

65-mile bike ride one weekend and fainted at home the next night. The doctor decided it was time to implant the ICD, so in July 2012, she underwent the procedure. Two months later to the day, she ran a Breast Cancer 5K in Fayetteville and was the first female finisher! "I ran my first marathon one year later (Savannah Rock n' Roll) and haven't stopped since."



She enjoys running because "it relieves stress, is rewarding, has great health benefits, and sets high expectations for my girls (don't quit what you start)."

For future goals, she wants "to do an ultra-marathon this year and do a marathon every 10 years." If there's anything certain about Toni, it's that if she sets her mind on something, she will make it happen, ICD or not!

New and Ongoing Events

Inaugural Rachel's Race

Dave Lancour of Janesville, Wisconsin, never heard of Long QT Syndrome until his 22-year-old daughter Rachel died in her sleep in May 2015. Since Rachel's death, many family members have tested positive. "Prior to Rachel's death, none of us had a clue that we had this," Dave said. To raise awareness, family and friends organized Rachel's Race for Long QT Syndrome on Saturday, October 8, at Skelly's Farm Market featuring a walk or run on scenic country roads. Organizers hope to make it an annual event.



was never diagnosed with the Long QT, even after going through testing since her grandfather, mother, sister, and niece all have an ICD."

10-Year-Plus Events Rock On!

19th Layton/Hanss Oktoberfest, September 17, Colorado Springs, CO

11th Christie's Heartoberfest, September 24, Saratoga Springs, NY

12th Brittany's Trees, November 26, Carol Stream, IL



Wells Fargo Community Support Campaign

Javier Torres, Branch Manager with Wells Fargo Bank in Whittier, California, chose the SADS Foundation as his district's charity of choice in memory of his wife Maribel who passed away on May 18, 2016. "This is something that is truly important to me, especially under the circumstances," says Javier, "My wife



Ways to Give Throughout the Year

Celebrate the 25th Anniversary of the SADS Foundation with a New Year's 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.

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

Autopay from Financial Institution: Add the SADS Foundation through your bank's or credit union's bill pay option.

Recurring Payment from Credit Card: Contact us to set up credit card payments on the date of your choosing.

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.

Take Steps to Stop SADS

The SADS Foundation extends our heartfelt gratitude to EVERYONE who helped to make the first Take Steps to Stop SADS event held on Friday Evening, September 30, 2016, at the 9th Annual International SADS Foundation Conference in San Diego, California a huge success!

Special thanks to our sponsors Cardiac Insight and Brotherhood Crusade, special guests Dwayne Polee Jr. and his mom Yolanda Kenon, and event committee members



Scott Dailard, Rachel Flores, and Jennifer Paul. Together, we raised nearly \$17,000!

Our first signature event Take Steps to Stop SADS is designed for you to be able to plan an event in your hometown. We created materials (t-shirts, banners, brochures, etc.) and a Crowdrise page for local organizers to use. To learn more, contact Jan at 801-272-3023 or jan@sads.org or visit sads.org/Get-Involved/Take-Steps-to-Stop-SADS where you also may view photos from the first event.



SADS Foundation's Webinar Series

Offered in partnership with Ambry Genetics and Invitae

The SADS Foundation has produced a webinar series designed to educate genetic counselors, physicians, and other healthcare providers about the care of families with inherited arrhythmias.

The Pregnancy Journey with Inherited

Arrhythmia – Dr. Bettina Cuneo (University of Colorado), Dr. Teresa Caldwell (University of Colorado), Julia Wynn, MS, CGC (Columbia University), Robin Jenkins, RN

The Family Experience with Sudden Death –

Brynn Dechert-Crooks, MSN, CPNP (University of Michigan), Mary Hardies, RN (Community Mental Health), Julianne Wojciak, MS, LGC (UCSF)

Cardiovascular Genetic Testing Practices

around the World – Dr. Michael Ackerman (Mayo Clinic), Dr. Sylvia Priori (University of Pavia), and Dr. Robert Hamilton (University of Toronto)

Latest Diagnostic and Treatment Strategies

for ARVC/ARVC – Dr. Hugh Calkins (Johns Hopkins), Brittany Murray, MS, CGC (Johns Hopkins)

Diagnostic and Treatment Approaches to Long QT Syndrome (LQTS) – Dr. Michael Ackerman (Mayo Clinic)

SADS Foundation's Symposium Series

Offered in partnership with Ambry Genetics, Invitae and Medtronic

Our Symposium Series is designed to educate and inform physicians and healthcare providers. The symposiums, featuring world-renowned SADS expert Dr. Michael Ackerman were held in New Orleans, in Chicago and in New York City (coming in Dec.). Other regional symposiums include:

Clinical Update on Inherited Cardiac Arrhythmias

December 8, 2016, 2 pm to 6 pm
The Joseph B. Martin Conference Center
Harvard Medical School, Boston, Massachusetts

Invited Speakers:

t

- David Milan (Massachusetts General Hospital)
- Dominic Abrams (Boston Children's Hospital)
- Elizabeth DeWitt (Boston Children's Hospital)
- John Triedman (Boston Children's Hospital)
- Neal Lakdawala (Brigham & Women's Hospital)
- Robert Padera (Brigham & Women's Hospital)

- Steven Lubitz (Massachusetts General Hospital)
- Robyn Hyland (Boston Children's Hospital)
- Shannon Hourigan (Boston Children's Hospital)
- Virginie Beausejour Ladouceur (Boston Children's Hospital)

A Science Update of SADS Conditions

February 11, 2017
Phoenix Children's Heart Center
Phoenix, Arizona

Invited Speakers:

- Mitchell Cohen, M.D. (Phoenix Children's Hospital)
- Susan Etheridge, M.D. (University Health Sciences & - Primary Children's Hospital)
- Andrew Papaz, M.D. (Phoenix Children's Hospital Heart Center)
- Additional Speakers to be Announced

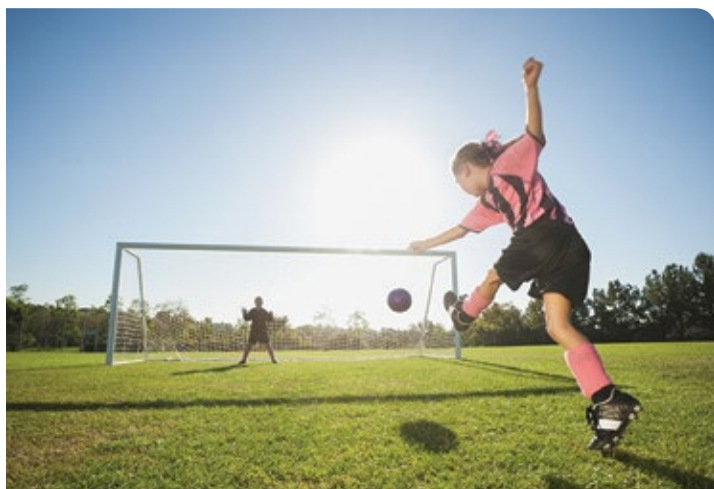
To learn more about our symposium series and our webinar series (and to view the sessions that were previously held), visit sads.org/seminars.

Shared Decision-Making Allows Some Athletes with CPVT to Compete

"Shared decision making supported by evidence-guided medical therapy and incremental interventions lays the foundation for a more permissive approach to not only allowing, but potentially encouraging participation in physical activity, including

competitive sports," the authors said who include our very own Board President Dr. Michael Ackerman and Scientific Advisor Dr. Shubhayan Sanatani.

To read the full article, visit StopSADS.org and look for the news articles.



Just-Released Policy Statement About Nadolol

On September 20, the Heart Rhythm Society (HRS) released a policy statement titled "Beta Blocker Therapy for Long QT Syndrome (LQTS) and Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT): Are all beta blockers equivalent?" to reinforce the importance of appropriate beta blocker therapy for the treatment of these two genetic disorders. Writing committee members unanimously agree that nadolol is a front line and efficacious agent for LQTS and CPVT among patients of all ages at risk of sudden death.

In the HRS press release: "As the primary patient advocacy organization for the families of children and adults who are genetically at risk for sudden death due to heart rhythm abnormalities, we know our families and their physicians are concerned about recent difficulties in obtaining nadolol. SADS recognizes the importance of

this beta blocker for the families we support and we plan to work with HRS to ensure the availability of nadolol," stated Alice Lara, President and CEO of the SADS Foundation.

SADS is aware of concerns regarding the availability of nadolol, particularly in some European countries, and encourages patients and physicians to have informed conversations about all treatment options. Based on available evidence, SADS and HRS recommend that nadolol remain available for patients with LQTS and CPVT. If you have a question or concern about nadolol, please let Lynn know (Lynn@sads.org).

What is the role of the SADS Foundation in Research?

As a patient advocacy organization, SADS is uniquely positioned to help promote and be involved in research. Specifically, SADS serves the important and crucial role of being the conduit amongst three key aspects of research: physicians, families, and the research itself (Figure 1).

Families & Physicians: Since 1991, SADS has helped patients and families get connected with physicians. As much of research is driven by clinical observations, SADS role in facilitating the dialogue between patients and physicians allows for physicians to a variety sudden cardiac death cases and help ensure no question is left unaddressed.

Physicians & Research: By connecting and immersing themselves within the physician community, SADS is well-positioned

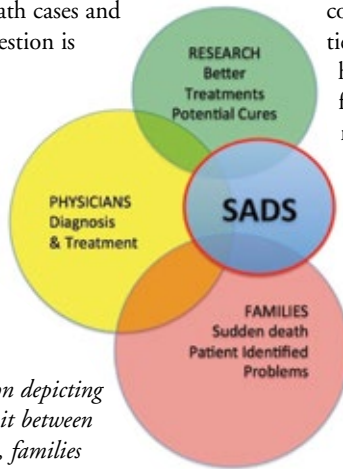


Figure 1: Illustration depicting SADS as the conduit between research, physicians, families

to help physicians be aware of ongoing research. This in turn can help inform physicians of the latest clinical practices and help provide them with the most up-to-date treatments.

Families & Research: The most passionate voices undoubtedly arise from our community of patients and families. But researchers don't have access to patients and patients find it difficult to access research. SADS is the bridge between them and gives advice to both researchers and families who are interested in participating. From enrollment in clinical trials to providing the latest literature, SADS supports families by connecting them with research and opportunities for them to get involved. Conversely, SADS helps provide researchers access to patients and families whose genetic information and unmet needs are invaluable guides towards directing their research studies.

Altogether, SADS serves the important role as a "translator" and facilitator and provides a vital platform from which the voice of the patient can reach the key influencers in research. This enables us all to work towards the common goal of helping prevent sudden and unexpected cardiac death in children and in young adults.

SADS Foundation Participates in AHA Scientific Sessions

SADS Foundation staff members Alice Lara, Lynn Johnson, and Jan Schiller attended the American Heart Association Scientific Sessions on November 11-16 in New Orleans.

They met with several of the corporations who collaborate with us to provide medical education seminars, webinars for physicians and families, and support for our Speakers' Bureau.

We also met with researchers and discussed scientific studies that SADS promotes, such as:

- PI (principal investigator) meeting for the NIH-funded LIVE-LQTS study. They have extended the age limit and you can now be up to age 60 to participate!

- New Late Sodium Channel Blockers for LQT3—this is our Gilead study
- Antiarrhythmic and Gene Therapy in CPVT—we'll be 'advertising' this study in about a year if things go well

Other scientific sessions we attended that hold promise for future treatments included:

- iPSCs (induced pluripotent stem cells) for Personalized Cardiovascular Medicine
- Clinical Outcomes in Timothy Syndrome—an International collaboration facilitated by the SADS Foundation
- Biologic Pacemakers: Is Reprogramming Our Best Hope?

- Big Data: Integrating Phenotype, Genotype, and Pharmacology to Transform Care
- Drugs and Invasive Therapies in Brugada Syndrome

Visit StopSADS.org to sign up for our newsletter and receive research updates as things progress.



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.

2016 SADS Young Investigator Awardees

The winners of the 9th Annual Courts K. Cleveland SADS Foundation Young Investigator Awards in Cardiac Channelopathies were announced at the annual Pediatric and Congenital Electrophysiology Society (PACES) evening meeting by Dr. Shubhayan Sanatani, Chair of the Committee and PACES Vice-President for Research.

Winners of the 2016 Young Investigator Award in Cardiac Channelopathies:

Basic Science Winner

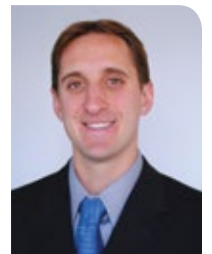
Worawan Limpitikul (Mentor: Gordon Tomaselli, M.D. at Johns Hopkins University School of Medicine)



A precision medicine approach to the rescue of function in calmodulinopathy associated LQTS.

Translational/Clinical Winner

Bradley Clark, MD (Mentor: Charles Berul, M.D. at Children's National Health System)



Minimally invasive percutaneous pericardial ICD placement in an infant piglet model: Head-to-head comparison with an open surgical thoracotomy approach.

Congratulations to both of our winners and all of our 13 nominees!

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

Upcoming Events for 2017

January 20-21	Sports Cardiology & Sudden Cardiac Arrest in the Young Conference	Anaheim, CA
February 11	Prevention and Awareness of Sudden Cardiac Death in Children: An Update for Pediatricians and Family Practitioners Seminar	Phoenix, AZ
March 17-19	American College of Cardiologists Scientific Sessions	Washington, DC
March 22-26	Neo Heart Cardiovascular Management of the Neonate Conference	San Diego, CA
May 1	Understanding Sudden Unexplained Death in Childhood Conference	New York, NY
May 10-13	Heart Rhythm Society Scientific Sessions	Chicago, IL
Date TBD	Latest Diagnostic and Treatment Strategies for CPVT Webinar	

Remember

Discuss your family history during the holiday season!

