



SADS Remembers Dr. Michael Vincent

The SADS Foundation sadly announces that on February 12, 2020, our founder, Dr. G. Michael Vincent passed away peacefully after a life lived with humility, grace, and inspiration. We honor his service to the mission of the SADS Foundation through the momentous contributions he made in the medical field, through the care he gave to thousands of families and the thousands of young lives that were saved. We will miss Dr. Vincent's guidance and generous heart as we continue to bring his vision to life.

"Michael was such an important part of our pediatric EP community even though he was an adult EP. He really put LQTS 'on the map' and went beyond that by founding the SADS Foundation to help support families, patients and



physicians who care for patients with inherited arrhythmias. Along with researchers at the University of Utah including Mark Keating and Katherine Timothy he helped us understand the genetic nature of LQTS and opened the door for further discoveries in inherited arrhythmias. Despite his worldwide recognition and illustrious career he was a humble, incredibly kind and generous man. He really was a role model for me as to how to be successful with grace. He is the reason I became interested in this population of patients. I will miss him."—Dr. Susan Etheridge

"I am saddened by the loss of my good friend and colleague, Dr. Michael Vincent. Michael created and ran the SADS Foundation for many years—helping hundreds of families around the world

to 'live and thrive' with long QT syndrome. And he supported and trained so many physicians who care for patients with genetic arrhythmia syndromes. When he retired, he allowed me to continue and build upon his work with SADS, which was a deep honor."—Dr. Michael Ackerman

"One of the most gracious people I ever had the pleasure to meet and know. He made me feel like one of his own family. What a great honor for me."—Dr. Robert Campbell

Read more about Dr. G. Michael Vincent's life and accomplishments at StopSADS.org. You can also make a donation in Dr. Vincent's honor and leave a message of condolence.

If you wish to leave a message of condolence for Dr. Michael Vincent please visit the memorial Facebook page.

The SADS Foundation and COVID-19

The SADS Foundation is providing regular updates for our communities. Stay up to date about what you need to know and about all the things the SADS Foundation is doing to help to keep you and your family safe and healthy while we navigate this pandemic. Subscribe to our weekly newsletters at StopSADS.org and make sure you're informed about the latest science.

SADS COVID-19 Hub at StopSADS.org

- FAQs on SADS Conditions and COVID-19
- Videos with Dr. Ackerman & SADS Scientific Experts
- Information about the upcoming weekly, Facebook Live sessions
- Virtual Support Groups

Continue to be Cautious!

After a few months of sheltering in place, some states have begun lifting restrictions. Please continue to be cautious and follow the CDC guidelines to remain safe: frequent hand washing, physical distancing (the 6-foot rule) and wearing a mask when out in public. And please call your doctor or 9-1-1, just like you would have before the coronavirus. They are available and want to take care of you.



International SADS Foundation Conference 2020

Save the Date: Nov. 7

Houston has been postponed until 2021. We're taking our family program online this year—on Saturday, November 7, 2020. Plans are

-THE SADS FOUNDATION-	EDUCATE
INTERNATIONAL CONFERENCE	EMPOWER
November 7, 2020	ENGAGE

afloat for a question and answer session with Dr. Ackerman and another SADS Scientific Advisor as well as other topics requested by the SADS community. There will be plenty of time to "meet" others in the popular disease breakouts, all virtual.

Sign up for SADS newsletter to be the first to get all the details at StopSADS.org!

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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Congratulations to our SADS Taiwan Founder

An original research article was just published in AHA Circulation: Genomic and Precision Medicine titled Validation and Disease Risk Assessment of Previously Reported Genome-Wide Genetic Variants Associated



with Brugada Syndrome: SADS-TW BrS Registry with Dr. Jimmy Juang as first author. You can find the full article on our website.

莊志明 **Jyh-Ming Jimmy Juang, MD, MS2, PhD, FAPHRs**

台大醫院心臟科主治醫師
台大醫學院醫學系副教授

Attending physician, Department of Cardiology, National Taiwan University Hospital

Associate Professor, Department of Medicine, National Taiwan University School of Medicine

SADS Foundation Welcomes New Summer Intern

SADS Foundation is thrilled to have Sophie Thatcher volunteer this summer as the Communications and Awareness Intern. She just completed her freshman year at Virginia Tech.

Read Sophie's Story on the SADS Blog (StopSADS.org).



Our First International Family Chat



SADS International Affiliates of UK, Mexico and USA connect on Zoom.

Awareness

Congratulations Mikayla

Our Awareness and Outreach Coordinator, Mikayla Viny, recently graduated with her Bachelor of Science degree in Public Health! Mikayla has been with the SADS Foundation since May of 2019 and has



helped create and implement awareness campaigns such as SADS Safe Schools, National Heart Month, and CPR & AED Awareness Week. This summer Mikayla will be starting a new job as a Research Analyst at the University of Utah and will continue to work part-time with the SADS staff on social media. We look forward to continue working with Mikayla while she pursues her goals in public health research!

Wishing Rachel a Great Career in Social Work!



Rachel Goss, Program Coordinator, will be leaving the SADS Foundation to complete her Masters in Social Work at the University of Utah. Rachel started working at the SADS Foundation in November 2017 as the Office Manager. She took on other roles as the Family Support Coordinator and absolutely enjoyed the time she spent helping families within the SADS community. Over the last year she has focused on updating the Physician Referral Network and improving our organization's relationships with the medical community. We wish Rachel well on her new journey as a Social Worker.

SADS Facebook Live—Join Us Weekly!

Since mid-March (when COVID19 stay-at-home began), the SADS Foundation and Dr. Mike Ackerman of Mayo Clinic have hosted 22 Facebook Live question & answer sessions with world experts such as Dr. Etheridge, Dr. Wilde, Dr. Calkins, Dr. Shah, Dr. Brugada and many more. The recorded videos on StopSADS.org and SADS YouTube channel have received over 62,000 views as of July 15. Sign up for our enews to receive advanced notice of the topic for our Friday session!

Dr. Ackerman and Dr. Brugada during Facebook Live event



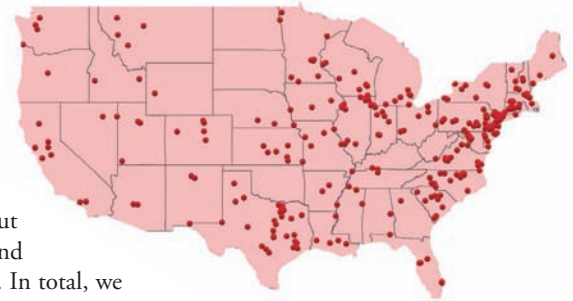
SADS Celebrates CPR and AED Awareness Week: June 1-7

This year, the SADS Foundation did a social media campaign using facts about CPR and AEDs for our families to share with their communities! We also hosted a special Facebook Live session with Dr. Ackerman and Richard Lamphier, RN (Project S.A.V.E.). Thank you to everyone who participated! To watch the Facebook Live session or to sign up for our enews for future programs visit StopSADS.org.



Thank You for the Successful SADS Heart Month!

During February this year we had hundreds of health professionals, parents, advocates and patients help raise awareness about SADS conditions and their warning signs. In total, we shipped out over 350 SADS Red Kits to over 300 cities across the US!



SADSConnect Re-Launches!



The SADS Foundation has re-launched our SADSConnect program for kids and teens. Share your stories, blog questions, games and videos. Check out the pages and let us know what you want!

Get to know your SADS community! Kids and teens share your story in a 30–60 second video. Upload your video and use #SADSConnect for us to feature your story on SADSConnect webpage. You can also email your video to sads@sads.org.

#SADSathome

Staying home and staying safe can get boring. Our SADS families have been keeping busy in creative ways. Share with us your experiences at home. Just use #SADSathome and tag us. Check out Bella and Melissa's contributions—and more on our COVID-19 Hub at StopSADS.org.



SADS Kids Chat



SADS hosted a weekly kids and teens chat and virtual game night on zoom. They enjoyed connecting, sharing stories and of course playing games.

J.J. Neiman-Brown, 2017-2020

Our beloved son, JJ Neiman-Brown, was a healthy 2-year-old who suddenly and unexpectedly lost his life on February 2, 2020. A sweet, kind, and inquisitive child who loved gymnastics, dancing, animals, and music by the artist Prince, JJ was his usual energetic self until late afternoon that day. By about 4 PM, it was clear that JJ was feeling a bit under the weather: he seemed a little tired, his cheeks were flushed, and he felt warm. His temperature measured at 101.5F. Like the several previous occasions when JJ had run a fever, we gave him children's acetaminophen and then a bath. His temperature returned to normal, and he perked up.

The three of us decided to make the evening a special occasion and



watched Moana together on the couch. JJ was very happy and content and soon fell asleep on my lap. We took him up to his crib and kissed him goodnight. We had a monitor in his bedroom, and we did not hear or see anything out of the ordinary. Around midnight, I went to check on him, a little concerned that I hadn't noticed motion for at least an hour, but not imagining that anything was seriously wrong. I found him lifeless in his crib, where he had died perhaps an hour or two before. The very quiet and peaceful nature of his death hints that JJ might have died of a sudden cardiac arrest. We were devastated by his loss, but we are hoping that our continued efforts to learn more about his death can help other children.

Welcome ARVC/D Families

The Sudden Arrhythmia Death Syndromes (SADS) Foundation is pleased to announce a joint partnership with the Johns Hopkins Arrhythmogenic Right Ventricular Dysplasia (ARVD) & Cardiomyopathy (ARVC) Program, Baltimore, Maryland to support individuals and families living with ARVD. The Johns Hopkins ARVD / ARVC Program is internationally recognized as the largest clinical and research center dedicated to clinical evaluation and research in ARVD/Cardiomyopathy.

Alice Lara, RN, CEO & President, SADS Foundation noted, "We are very excited to partner with these clinical experts in the Johns Hopkins ARVD program to provide enhanced educational content and support to individuals and families living with this rare condition."



JOHNS HOPKINS
MEDICINE

My Story of Brugada Syndrome

Sissy Sullins was diagnosed with Brugada Syndrome at age 39. Twenty-one years later she shares her story about finding a diagnosis and how listening to your body can save your life. Read her full story on our blog at STOPSADS.org and check out our suggested questions for submitting your own story.

Share Your SADS Story!

Do you have an experience with a SADS condition? We would love to hear from you! Email them to StopSADS.org.



During the 12th International SADS Foundation Conference in Atlanta in October 2019, there was an ARVD/ARVC disease breakout group for families, facilitated by Brittney Murray, MS, CGC and Crystal Tichnell, MGC, RN, genetic counselors at Johns Hopkins Hospital in the Center for Inherited Heart Disease and the ARVD/C Program.

A collaborative patient educational brochure is being developed and will be available later this year.

Congratulations to SADS Graduates of 2020!

The SADS Foundation held a virtual ceremony on Facebook Live for the graduate class of 2020. We honored our grads by showcasing a slideshow on Facebook live and an inspiring commencement speech by Dr. Michael Ackerman. You are all living and thriving with SADS! Visit STOPSADS.org to read more about each grad.

SADS Graduates of 2020

Jaeger Ackerman
Mitchell Bemenderfer
Phillip Breen
Carter Chiaventone
Miranda Dailard
Brooke Davis
Alfredo Delossantos
Britnee Hatch
Rebecca Knowles
Kam Kotraba

Maria Mansfield
Jenna Marie
Taylor Mundondo
Shaleigh Reilly
Morgan Elizabeth
Righeimer
Elizabeth Renzi
Nyah Stahl
Brittan Sutphin



26th No Ball at All Campaign

My name is Nicholas Arruda. I am 15 and live in Rhode Island with my family. At just five years old, I collapsed on the floor. My uncle called 911 and he and my dad did CPR on me. Fortunately, I woke up before the ambulance arrived. It was determined I had ectopic atrial tachycardia and needed a beta blocker.



When I turned 11, we decided to take me off the beta blocker as I had no symptoms. My parents asked for me to have a stress test to make sure I was ok without it. On the treadmill, my heart rate went up to 300 bpm. It was determined I needed a beta blocker and a medicine called flecainide. After a genetic test, it was discovered I have CPVT.

Since then, I have had two heart monitors implanted and a denervation procedure. I still take nadolol and flecainide and cannot take part in competitive sports. I have to take my AED with me whenever I am going to be active – it stinks to have to be so careful.

The SADS Foundation has helped us in many ways. We have attended three conferences where we met wonderful families going through the same things we do. They have provided resources to educate family, friends, teachers, and coaches about CPVT. Most importantly, they have given me a better understanding of my diagnosis and how to live with it. Please support the SADS Foundation at sads.org/NoBall# where you can watch a video clip from me and my family members.

Fabulous Fundraising Events

The SADS Foundation would like to THANK ALL OF THE FAMILIES who hosted the following 16 FUNDRAISING EVENTS: Brittany's Trees, Heartoberfest, All for Al, Celebrating Samantha's 40th Birthday, Gertsberg Memorial 5K, Holiday Hoopfest, Hops for Hearts, Shelton School Jumpathon, Kaleb Echols' Eagle Project 5K, Kristi's Day Event, Rachel's Race, Rob Kaas Memorial Golf Tournament, Rocks for Ryan, Ryan Weidler Golf Tournament, Super Lee Charity Golf Tournament, and the Stevie Grieshammer High School Swim Preview Meet!

Because of this support, the SADS Foundation keeps SADS hearts beating!

Walk for the Beat

Join us for the First Annual Virtual Walk for the Beat that's happening right now. Use our Walk for the Beat event website on Classy.org to set up your fundraising page and tell your story. Share this page on all the other social media platforms to let everyone know how important supporting families and saving young lives with SADS conditions is to you. Pick a day to walk or walk throughout the month and ask your family, friends, neighbors, and colleagues for their support.

Walk for the BEAT!
StopSADS.org



Everyone who participates will receive a cooling athletic headband to wear on your walk and a pop socket to proudly display on your cell phone. Free 2021 Conference Registration will be given to the person or team with the most donors or the most funds raised. The Walk for the Beat Celebration, Thursday, September 10, on Zoom will conclude this event with an evening of laughter, entertainment, and surprises.

Visit StopSADS.org or contact jan@sads.org for further details.

Be a Facebook Fundraiser—It's Easy!

We'd like to send HUGE THANKS to the nearly 258 Facebook Fundraisers who have raised \$92,000 since Spring 2018! Each one has helped the SADS Foundation to provide life-changing and life-saving services for SADS families everywhere! During this time of uncertainty, our vital services are needed more than ever. Visit www.facebook.com/fund/SuddenArrhythmiaDeathSyndromesFoundation/ to start your own Facebook Fundraiser and join us as we go online with our services during the COVID crisis.

Please contact Jan at 801-272-3023 or jan@sads.org, should you have any questions.



Comedy Improv a Huge Success!

The SADS Foundation extends its deepest appreciation to everyone who helped to make our July Matching Campaign and our First Virtual Improv Comedy Night a success! Featuring the Cherub Improv team with long-time SADS supporter, Shelly Savoca, we had some great Thursday night laughs. Thanks to the Legacy Circle Members for our Matching Fund. And thanks to all who supported the SADS Foundation helped us to double our goal—we so appreciate it!

Thank You, Healthcare Workers and Scientists!

Several of our families have shared personal experiences as healthcare workers. Here are just a couple!



Greg Totero, RN, in New York City



Jen White, MD, an emergency physician in Philadelphia working the front line. Thank you for all your hard work!

SADS Foundation Webinar

Big Data Approaches to Evaluating the Variant of Uncertain Significance (VUS) was fantastic—with over 135 people watching live! It is now available on **StopSADS.org** or on the **SADS YouTube** channel. Featuring Dr. Roden, Professor of Medicine, Pharmacology, and Biomedical Informatics and Senior

Vice-President for Personalized Medicine at Vanderbilt University Medical Center and Dianalee McKnight, PhD, Medical Affairs Director, Emerging Clinical Omics, Invitae. This webinar was supported by educational grants from Invitae and Medtronic and is well worth your time.

Submit Patient Questions or Difficult Cases to SADS Foundation Scientific Advisors

Diagnosing and managing patients with potentially life threatening channelopathies can be challenging. Our expert Scientific Advisory Council can help!

Please use our SADS Foundation Scientific Advisors for any questions that may come up with patients you are seeing in this pandemic. You can email alice@sads.org with your question or submit a case in a PowerPoint format to include HPI, family history (including pedigree if available), clinical course including current management, supporting studies (EKGs, MRI, echo, genetics), and

specific questions. We will reply promptly with great advice from our Scientific Advisors. Who knows? Your case may be published in HeartRhythm Case Reports.

"This was so, SO helpful! I was heartened to see that some of things I worried about were noted by your amazing scientific advisors."

-From a submitting physician

SADS Foundation Screening Position Statement - Updated

An updated screening position statement has recently been published by the SADS Foundation

Medical Education Committee.
Visit StopSADS.org to read the full statement.

Follow SADS on Facebook, Twitter, Instagram and LinkedIn

The SADS Foundation has stepped up our activity on social media and our following has grown by 24%, with a total of 8,000+ followers across Facebook, Instagram, and Twitter! Follow us now to stay up to date on virtual events, new research, Facebook Live sessions and more.

2020 Young Investigator Awards

WAY TO GO SADS Foundation Courts K. Cleveland Jr. Young Investigator Awardees! Too bad we couldn't present the awards in person in San Diego. But we had a wonderful Facebook Live presentation for the winners: Aravind Gade, PhD, and his mentor Geoffrey Pitt, MD,



Dr. Kannankeril of Vanderbilt University announces the basic science category winner, Dr. Aravind Gade (below left) with his mentor Dr. Geoff Pitt (lower right).

PhD, of Cornell Weill Medicine, New York City, for basic science and Yukiko Asaki, MD, and her mentor, Susan P. Etheridge, MD, of Primary Children's Hospital/University of Utah, Salt Lake City, for clinical/translational science category. Read more on StopSADS.org.



Dr. Kannankeril and Dr. Ackerman congratulate clinical science YIA winner Dr. Yuki Asaki and her mentor Dr. Susan Etheridge.

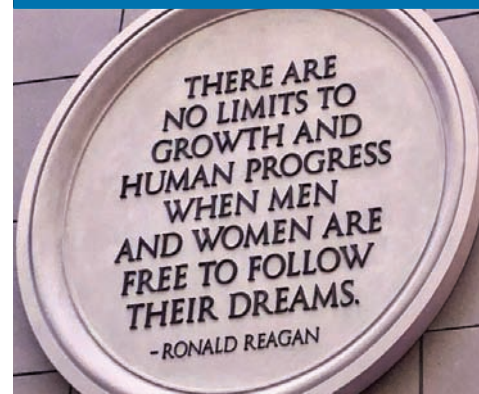
Rare Disease Week Highlights

The purpose of Rare Disease Week is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. This year, one of our own rare disease advocates, Samantha Wilder, attended Rare Disease Week on Capitol Hill in Washington, D.C. Here, patients and advocates alike attended events that included

caucus briefings, rare disease documentary screenings, lobbying, and meeting with members of the House and Senate to advocate for improved policies. Huge thanks to everyone who contributed during Rare Disease Week, whether from Capitol Hill or your own community!



SADS advocate and heart bowl winner Samantha winner attended Rare Disease Week. Read about her experience and story on the SADS blog at sads.org/blog



ARVC Research Study

Make a Difference and Help Advance Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) Research from Home



SADS Recruits ARVC/D Patients for New Drug Study

The SADS Foundation assisted Sanguine Biosciences and Cydan to enroll individuals diagnosed with Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) or Arrhythmogenic Right Ventricular Dysplasia

(ARVD) in a research study for a new drug treatment. We want to thank all of you who volunteered to enroll in this study!

To make sure you know about future studies, sign up for our newsletter at StopSADS.org.



SADS Safe Schools

Keeping your family safe is the number one priority for the SADS Foundation. If your child goes back to school, download or order our Back-To-School Checklist and our SADS Safe School Packet from StopSADS.org. If your child is schooling at home, download our emergency go bag list of items. And

make sure you're on our email list to receive any updates.

New this year! Kids and teens can get help with their About Me talk for school! SADS will provide some slides for you to use when talking to your class about your SADS condition.

Win an AED during SADS Safe School Month.

Get your tickets to win AED with its case donated by One Beat CPR & AED. You will receive one ticket for a \$5 donation or five tickets for a \$20 donation. Donate through the month of September at sads.org/Donate/AEDdrawing to make certain you have the chance to win this special prize!

Upcoming Events

Month of August	Virtual Walk for the Beat
September 10	Virtual Walk for the Beat Celebration
August & September	SADS Safe School Campaign
August & September	Tickets Available for AED Drawing
October 2	Drawing for AED to be held
November 7	SADS Foundation Virtual Conference
November 28	16th Annual Brittany's Trees

Don't miss out on the fast-changing news. Sign-Up for Our eNews now!

If you enjoy receiving our newsletter, you'll love receiving our eNewsletter! Our eNews gives you information about newly published SADS-related research, upcoming educational programs and fun events.

Sign-up by emailing erin@sads.org or visit StopSADS.org.

