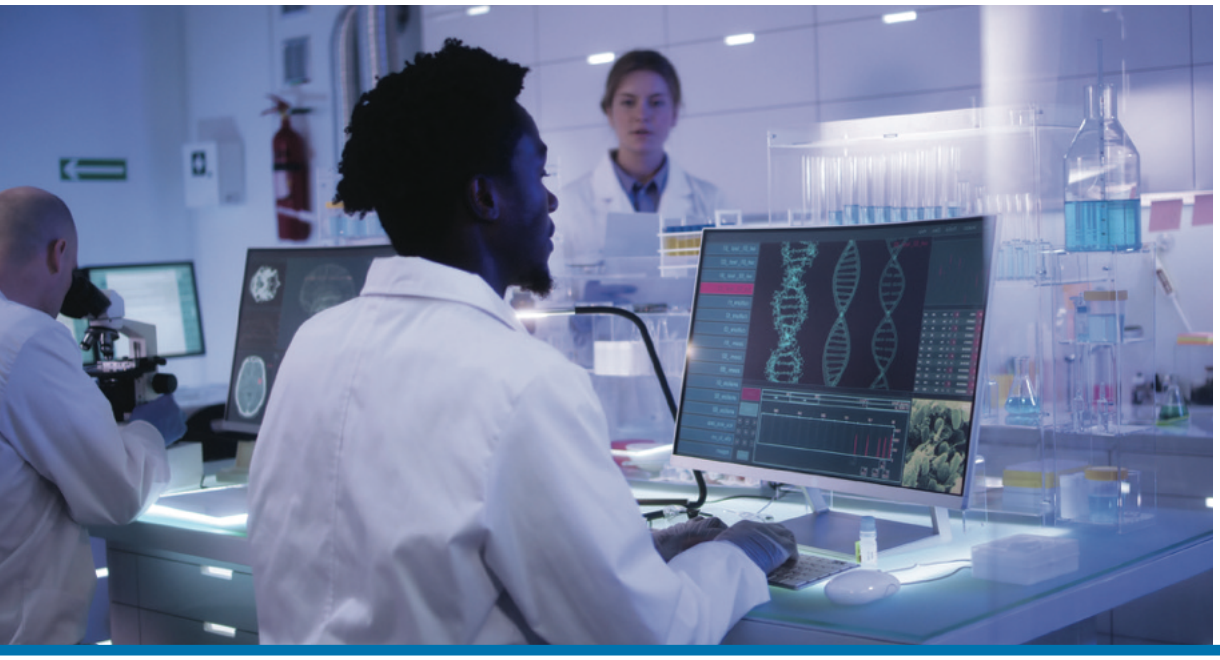
SADS NEWS
FOUNDATION
Supporting families. Saving lives.
Spring 2023

Meet with the FDA and Researchers

Bringing the Voice of the Patient to Research

The SADS Foundation is hosting our first ever Externally-led Patient-Focused Drug Development (EL-PFDD) meeting on June 20, 2023.

This meeting will give the FDA and researchers, biopharma companies, healthcare providers, etc. an important opportunity to hear directly from patients and their families about the symptoms that matter most to them, the impact the disease has on patients' daily lives, patients' experiences with currently available treatments, and patients' priorities for new treatments.



The meeting and participants, including the FDA, will be virtual, however, SADS will be looking for the ARVC/D community to participate in polls, send in comments, or call in live! There will be a brief 10-15 minute overview of ARVC/D, followed by two sessions with panelists, callers, reading of submitted comments, and live anonymous polling.

Your voice matters! We want and need to hear from families with ARVC/D—both with and without therapy (transplant, beta blockers, anti-arrhythmics, ICDs, ablations, etc.), and from all countries. While the primary focus of this meeting will be on ARVC/D, all SADS conditions will benefit by bringing attention to genetic heart conditions and the need for better treatments.

Pre-register to attend live (virtual) June 20th, 2023 from 10-3 pm EDT at SADS.org/Newsletter.

If You Have a SADS Condition then you NEED Genetic Testing!

Genetic testing is considered the standard of care for people diagnosed with a SADS condition—in other words, **a critical part of being properly evaluated.**

Some of you haven't had a genetic test. And some of your family members haven't been tested. Here at SADS, we recommend that EVERYONE with a SADS diagnosis (and their family members) get genetic testing. Take it from Dr. Michael Ackerman, president of our Board of Directors and genetic cardiologist at the Mayo Clinic:

"Genetic testing is the standard of care for any person if their cardiologist is telling them that they have (or might have) one of these SADS conditions."

Genetic testing can change your treatment (personalized medicine) and can help identify other family members. You need genetic testing if you want to **participate in research and in clinical trials for new therapies**. And it is now less expensive than ever before!

Check out the genetic testing resources at SADS.org/Newsletter or scan the QR code on this page.

Take this Genetic Testing Card to Your Doctor

If you haven't yet had genetic testing, use the enclosed card to talk with your doctor. AND share the card with other cardiologists in your area – you can order more at SADS.org/Newsletter.

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.

Staff
Alice Lara, *President & CEO*
Jan Schiller, *Development Director*
Marcia Baker, *Program Director*
Genevie Echols, *Family Support Director*
Anna Goodson, *Communications Director*
Erin Waite, *Technology & Administrative Manager*
Ryan Rodarmer, *Project Manager*
Tia Hansen, *Communications Assistant*

SADS Board of Trustees Welcomes New Members

We're excited to welcome two new board members to our Board of Trustees: Meredith Loveless, MD and Chris DeFrancis!

Meredith got involved with the SADS Foundation after her daughter, Alexis, was diagnosed with Long QT Syndrome. She and Alexis have been part of SADS ever since, working with the media to share their story and spread awareness, and she and Alexis were 2021 Volunteers of the Year.

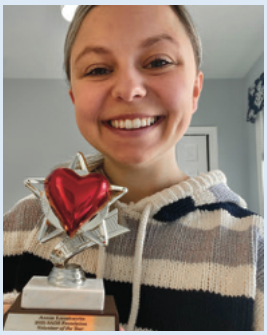
Chris DeFrancis came to us after his son, Oscar, had a Sudden Cardiac Arrest in the middle of an indoor track event. He has been a dedicated member of our Finance Committee and his daughter's 5K helped raise funds for SADS. Welcome to both Chris and Meredith – we look forward to hearing your insights!

Finally, we'd like to thank board member Scott Dailard for nearly ten years of service on our board. He retired from his position as Board Secretary in 2022—although he continues to be a valued volunteer, fundraiser and friend to SADS. During his time on the board he helped guide SADS through ups and downs leading to our substantial growth. He always provided great advice and a special passion for our mission. We appreciate you, Scott, and you will be missed by our staff and board!

And a big thanks to Brynn Dechert, CPNP—who has now taken on the role of board secretary.

2022 Volunteers of the Year

Congrats to this year's Volunteer of the Year Awardees: Deena Edwards for her help in engaging the ARVC community; Sandy Cowin for spreading media awareness; Annie Lucatuorto for helping reach new social media audiences; and the Lancour family for raising more than $27,000 for SADS through their annual Rachel's Race 5K.



SADS Welcomes New Staff

We are excited to welcome three new staff members to the SADS Team!

Genevie Echols, RCIS, is our new Family Support Director, and joined our staff in April of 2022 after years of volunteering with the SADS Foundation. "I was diagnosed with Long QT Syndrome at 16 years old," says Genevie. "My children also have LQTS. The SADS Foundation has been such an important part of my Long QT journey. I feel honored to be a part of this team, and I'm happy to be able to use my experiences to help support SADS families."

We also have two incredible interns working at SADS – Tia Hansen and Ryan Rodarmer. Tia joined the SADS team in November of 2022 as Communications Assistant. "I first attended a SADS event over 20 years ago! Little did I know I'd become part of the team years down the road," says Tia. "I have a Bachelor's Degree in Public Health from Utah Valley University, numerous years spent working in cardiology and my own experience with having a SADS condition."

Ryan Rodarmer, genetic counselor, is a Project Manager for the SADS Foundation. "I'm working with a group of doctors and genetic counselors to ensure that providers interested in helping their patients undergo genetic testing have the resources they need to do so," he says.

To learn more about any of our new staff members, visit SADS.org/Newsletter or scan the QR code on this page.

Your Stories in Action

We've had some exciting new updates to our awareness campaigns like Heart Month, CPR & AED Awareness Week, and Sudden Cardiac Arrest Awareness Month in 2022!

These new ways of spreading awareness mean that we reached 1,135,698 people in 2022 with warning signs, information about each condition, and CPR and AED awareness.

Over the past year, 68 volunteers from across the globe have joined our media campaigns, and helped spread awareness by telling their story to their local media stations.

Are you interested in sharing your story with your local media station? Visit SADS.org/Newsletters to get started.

SADS Goes Big with Billboards

Thanks to volunteers Nora Lambert and Brian Cuyler, we started our Billboard Campaign in 2022 with a simple goal: to make sure that as many people as possible know that fainting can be a potential warning sign of SADS. We want them to ask their doctor about their heart and get a diagnosis— before a tragedy happens.

Our billboard in New Orleans, Louisiana has an estimated reach of over 3,733,000 during its initial one-month run. Our billboard also spread to New York with the help of volunteer Sandy Cowin, with eight additional placements across the city of Binghamton. And volunteer Melissa Russom had a radio PSA placement of this same message in Spokane, WA.

Billboards are a brand-new addition to our awareness campaigns at SADS, and we are so grateful to the volunteers and billboard companies who have made this possible! To learn how YOU can be a part of this campaign, visit SADS.org/Newsletter or scan the QR code on this page.

Learn How We Reached Over 4,000,000 People Last Year

Our 2022 Annual Report is now live online! Read stories about our programs, check out volunteers who made a difference, and learn how we served 407% more families this year and reached over 4,000,000 people through awareness billboards.

You can read it at SADS.org/Newsletter or by scanning the QR code below.

From Hospitals to Nonprofits, SADS Collaborates on Social Media

Last year, we found a brand-new way to spread awareness on social media—through story collaborations with other organizations.

In 2022, we collaborated with 25 other organizations—including Vanderbilt Children's Hospital, Children's National Hospital, LifeSure AED, the National Society of Genetic Counselors, and TikTok and Instagram influencer Dena DNA through stories, facts, and educational videos about SADS conditions.

Visit SADS.org/Newsletter or scan the QR code on this page to see some examples of the work we've done with other organizations across the globe to make an impact! If you want your hospital to be part of our social media collaborations, email Anna@SADS.org.

Each year in the United States, approximately **360,000 Americans** die suddenly and unexpectedly due to **cardiac arrhythmias**.

Have You Lost a Loved One to SADS?

Losing someone you love suddenly and unexpectedly might make you feel like you'll never return to your normal life again. Everything seems wrong, and you're left wondering if you'll ever feel better. If you've experienced the tragic loss of a loved one, please know how sorry we are.Losing a loved one suddenly and unexpectedly is something no one is prepared for. We are dedicated to supporting families after they experience such a loss.

On National Candle Lighting Day 2022, families remembered their loved ones who left this world too soon through a beautiful memorial video.

Establishing a fund at the SADS Foundation in memory of someone who has passed away is a meaningful way to honor and remember your loved one while making a difference. To establish a fund or view the video, visit SADS.org/Newsletter.

If you have lost a loved one and would like to connect with someone else who has experienced a loss, please email Genevie@SADS.org.

FAMILY WEBINAR SERIES

Living With SADS

Experts explain YOUR SADS condition and answer your questions in these webinars.

Our webinar on **Gene Therapy** with Dr. Andrew Landstrom this April covered the basics of how genes are edited and delivered into humans, and the major hurdles to overcome before we can use gene therapy.

You can catch up on this and all of our other Living with SADS webinars at SADS.org/Newsletter

You can watch all the sessions from our 2022 Houston Family Conference as webinars, including Michael Ackerman, MD, PhD on **LQTS: Update & Cutting-Edge Treatment Approaches**—including gene therapy and an upcoming clinical trial for a new drug.

Visit SADS.org/Newsletter to watch all our sessions.

SADS International Virtual Conference in July

We are excited to announce an international focus for our SADS Virtual Conference this summer! We are partnering with SADS Canada, SADS UK, SADS Hong Kong, SADS Taiwan, SADS Germany, Australia, Spain and many others to bring the experts to you.

Stay tuned for July dates and details. To learn more, visit SADS.org/Newsletter

SADS FOUNDATION INTERNATIONAL 2023 VIRTUAL CONFERENCE JULY 2023

Find Your Community

No matter where you are on your SADS journey, peer support is so important when living with a SADS condition! SADS offers support groups for kids and teens, adults living with a SADS condition, and for those with an ICD. Join us to find your community and to help support others. Visit SADS.org/Newsletter or scan the QR code on this page to learn more.

SADS Foundation
ICD Support Group
by patients, for patients

100 Episodes of SADS Live!

We're celebrating 100 episodes of SADS Live! Thanks to Dr. Michael Ackerman, our SADS Live host, we've been able to join you, LIVE, more than 100 times! We've loved "seeing" you online and bringing the experts to you to answer YOUR questions twice a month on Facebook, Twitter, and YouTube.

"I've said to many people, with what other condition can you get access to one of the world's preeminent experts, hear what they're saying, and ask them your questions as they come up? That's huge," says Stephanie, whose family has LQTS.

To watch our special 100th episode celebration—or catch up on any episode of SADS Live from the past three years—visit SADS.org/Newsletter or scan the QR code on this page. And join us LIVE twice a month on our social media pages.

Thanks for being a calm voice at a scary time for so many people. It's like Mr. Rogers became a genetic cardiologist!

- Julie L.

30th No Ball at All

My son, Sonny Jude, stopped breathing and his precious heart stopped beating at six months old. His babysitter performed CPR and resuscitated him. It was then we learned that Sonny Jude has LQTS. In October 2022, when he was 13 months old, I put him down for a nap and he didn't wake up.

I'm trying to transition my grief and devastation into something positive. Sonny Jude was a happy boy, and I want to put some of that positive and loving energy back into my community to bring awareness to arrhythmias, and how important learning CPR is. It was a 16-year-old babysitter that had taken a CPR class who revived Sonny in March 2021. It doesn't matter how old you are when learning CPR, as every second counts when you can save a life.

The SADS Foundation is important to me because they directly help those affected by SADS. They help spread awareness about these issues which is so important. The access to information and resources has been incredibly helpful. SADS has helped me not feel alone. I am grateful for what they do and hope you will visit SADS.org/NoBall to read Sonny Jude's full story and to donate in his memory.

Make Damar's SCA Count

In January 2023, Monday Night Football brought all of us beyond football as we watched the sudden collapse of Damar Hamlin due to a Sudden Cardiac Arrest.

At the SADS Foundation, we jumped into action right away. We provided a virtual support group for families triggered by watching Damar's SCA, and used the momentum of SCA in the news to spread CPR and AED awareness through email, social media posts, and a press kit for the media, which reached over 116,000 people. We also presented a forum for 2,574 school nurses and distributed 1,766 School Nurse Packets – so far!

We know how much you care about preventing another young person's sudden death from SADS. You can help us get the CPR and AED message out, every month, all year long. Join the SADS Foundation's special friends and become a Sustainer of Hearts by giving an automatic monthly gift.

Join our Sustainers to make a convenient monthly contribution AND help prevent sudden death: SADS.org/Newsletter or scan the QR code on this page.

Fabulous Fundraising Volunteers!

The SADS Foundation would like to extend our deepest appreciation to the families who held a volunteer fundraising event in support of the SADS Foundation's mission to support families and save young lives. We thank the teams who have held recurring events that include **Brittany's Trees (Carol Stream, Libertyville, Orland Park), Saratoga Race Club House Box Raffle, Shelton School Jumpathon, Rachel's Race,** and the **Ryan Weidler Golf Tournament!** We also send our heartfelt thanks to brand new events that include **Amelia Runs for Arrhythmia Awareness, SoldierFit Boot Camp, Tap and Growler for Ruben Rodriguez, Sonny Jude Pancake Breakfast,** and the **Adam Wilkens Golf Tournament!**

An Interview with Prof. Peter Schwartz

What sparked your interest in studying SADS conditions?

My interest started with my very first patient in 1971, and the interest for the broader field started in 1973, when I started connecting Long QT Syndrome to Sudden Infant Death Syndrome. And from that moment on, my research life was largely devoted to Long QT Syndrome, and to the group of genetic disorders that go under the name of SADS.

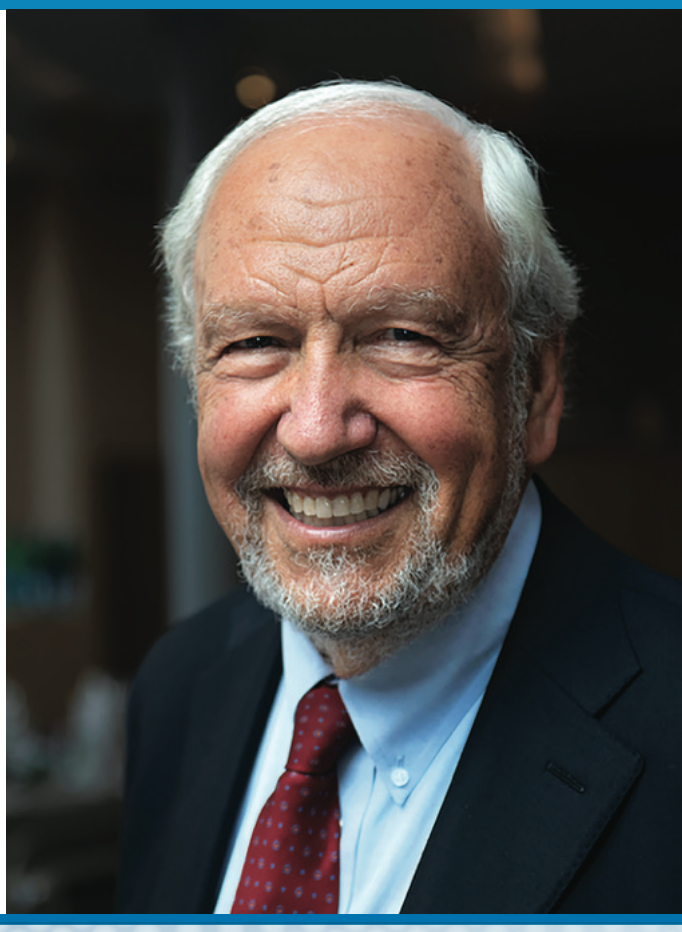
What is one of the current research topics that you think is most promising in SADS research?

Personally, the area that most fascinates me during the last 20 years is the role of what we call modifier genes. Those genetic variants that may either worsen the risk or decrease the risk of sudden death associated with one of these diseases.

What's on the horizon for the treatment of SADS conditions?

With my group, we're very much interested also in repurposing, which means using drugs that are currently used for different diseases and by studying the so called IPS cardiomyocytes from our own patients, we are trying to identify drugs that can be useful in new directions.

Learn more about Professor Peter Schwartz, international SADS expert and chair of our Scientific Advisors at the SADS Foundation! To watch all our interviews with medical experts, visit SADS.org/Newsletter or scan the QR code on this page.



SADS Physician Referral Network

SADS families can't just see their local cardiologist—it is crucial to be evaluated by an expert for proper diagnosis and treatment. And physician referral requests to SADS continue to be one of our most requested services.

We are so grateful for the experts who are part of our Physician Referral Network (PRN) and who provide such wonderful care to SADS families!

If you need a referral please visit SADS.org/Newsletter or scan the QR code on this page.

Welcome New SADS International Affiliates

SADS is increasingly working with families from other countries and helping new SADS Affiliates get started. We welcome our two newest International Affiliates, SADS Germany and SADS Vietnam! They will be a wonderful support to families affected by SADS conditions in these countries

SADS Foundation Courts K. Cleveland Jr.
2023 Young Investigator Awards in Cardiac Channelopathy Research

To encourage the next generation of researchers studying SADS conditions, the SADS Foundation is proud present this award for the 16th year. Thanks to the Pediatric and Congenital Electrophysiology Society (PACES) Research Committee and its chair, Dr. Peter Aziz of the Cleveland Clinic, for helping with us recognize these young scientists. Check our website and enewsletter for the winners out of these 11 applicants.

Clinical/Translational Applicants

Madeline Liu, Mount Sinai; NY; **Amy Kontorovich, MD, PhD**

Arja Suzanne Vink, MD, MSc (EBP), Amsterdam UMC; **Arthur Wilde, MD, PhD**

Weiyi Xu, PhD, Baylor College of Medicine; **Lilei Zhang, MD**

Megan Lancaster, MD, PhD, Vanderbilt University Medical Ctr; **Dan Roden, MD**

Alesseo Gasperetti, MD; Johns Hopkins University; **Hugh Calkins, MD and Cynthia James, CGC, PhD**

Sahej Bains, BS, Mayo Clinic; **Michael Ackerman, MD, PhD**

Mary E. Moya-Mendez, MS, Duke University School of Medicine; **Andrew Landstrom, MD, PhD**

Basic Science Applicants

Ana I Morena-Manuel, MSc, Spanish National Ctr for CV Research, Spain; **Jose Jalife MD, PhD**

David Chiang, MD, PhD, Brigham & Women's Hospital/Harvard; **Calum MacRae, MD, PhD**

Lala Tanmoy Das (Tom), Weill Cornell Medicine; **Geoffrey Pitt, MD, PhD**

Ramin Garmany, BS, Mayo Clinic; **Michael Ackerman, MD, PhD**

Living with ARVC: Jason's Story

On a typical afternoon in April 2020, Jason went out for a jog after work. After only a couple miles, he began to feel off—his heart began racing and just would not slow down. With his medical knowledge from being an EMT and firefighter, he surmised some arrhythmia might be taking place.

After numerous tests and imaging doctors diagnosed Jason with ARVC and placed ICD in his chest to protect him from future arrhythmias. Most importantly, they explained to him that he could no longer run or do any activity that would elevate his heart rate, lest he accelerate the scarring of cardiac tissue on his right ventricle, or risk another arrhythmic episode.

While running and backpacking are off-limits activities now, there are many aspects of Jason's life that he has maintained, making the necessary adjustments to stay safe while doing them. Jason's story highlights the importance of developing new therapies and treatments for ARVC – which we're committed to through holding our EL-PFDD for ARVC in June.

To read more about Jason's story – developed by Living in the Light of Rare Diseases – visit SADS.org/Newsletter or scan the QR code on this page.

Scientific Articles

Genetic Testing Guidelines

Best practice guidelines recommend genetic testing for patients diagnosed with a SADS condition, and yet most patients are not receiving it.

Dr. Kanchan Bhasin and team recently presented their findings from a study of inherited cardiovascular conditions. Of 87,231 patients with a new diagnosis of Long QT Syndrome- only 2,175 or 2.5% received genetic testing.

Gene Therapy Research

Dr. Michael Ackerman, et al., publishing a study in Circulation about suppression-replacement (SupRep) gene therapy in LQT1, LQTS2 and SQT1 showed that using this therapy in cardiac cell models worked by suppressing the disease causing mutation and replacing it with one that is fully functional.

If this therapy is successful, it has the potential to be applied to other SADS conditions!

Potential New Therapy for Long QT Syndrome

A potential new first-in-class therapy from Dr. Ackerman's lab shows promise in shortening the QT interval in human heart cell models. It works by inhibiting serum and glucocorticoid regulated kinase-1 (SGK1), which is an important regulator in the heart.

Importance of Genetic Testing in ARVC

A recent study published in the Heart Rhythm Journal determined that genetic testing is critical when diagnosing ARVC. When genetic testing was not used as part of the criteria, the study found a loss of diagnosis or a > 30-day delay in diagnosis in 10% of the patients in the study who definitely had ARVC.

This study illustrates the importance of genetic testing in SADS conditions.

Read the articles at SADS.org/Newsletter or scan the QR code on this page.

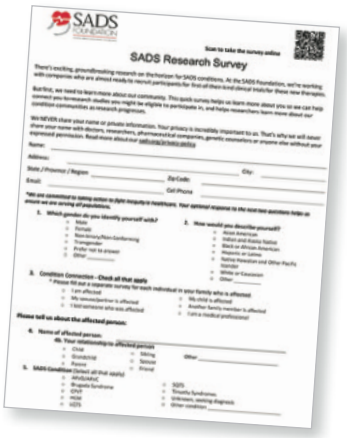
Groundbreaking New Research!

There's new, exciting, and groundbreaking research on the horizon for SADS conditions.

At the SADS Foundation, we're working with companies who are almost ready to recruit participants for first-of-their-kind clinical trials for these new therapies.

But first, we need to learn more about our community. The enclosed ten-minute survey helps us learn more about you so we can help connect you to research studies you might be eligible for and help researchers learn more about our communities as research progresses.

Fill out and return the enclosed survey, visit SADS.org/Newsletter or scan the QR code on this page.


SADS Research Survey

FAQs about CPR/AEDs

How can I tell if someone has just fainted or they need CPR?

Someone who is experiencing a sudden cardiac arrest will be unresponsive, not breathing or not breathing normally, *call 911 and push hard and fast on the center of the chest.* **Don't be afraid; your actions can only help.**

Will I hurt someone if I use an AED on them?

No, if a shock is not needed, the device will not shock the victim (i.e. if there has been a seizure, injury, or another cause for the victim to collapse). In this case, other reasons for the collapse should then be assessed and CPR should be continued if needed.

SADS FOUNDATION
4527 South 2300 East, #104
Salt Lake City, UT 84117

Updates to CredibleMeds and LQTS Drugs to Avoid

Deutetrabenazine (used to treat tardive dyskinesia) and **Perflutren** (a contrast enhancing agent) were **removed** from the Possible Risk of TdP category.

The use of **Remdesivir**, an antiviral drug used to treat COVID-19, is associated with the development of QTc prolongation. **Macimorelin** (used for diagnosis of growth hormone deficiency), **Dexmedetomidine** (a sedative), **Pralsetinib** (medicine for thyroid cancer), **Adagrasib** (medicine for NSC Lung cancer) and **Tebentafusp** (medicine for melanoma of the eye) are associated with the development of QT prolongation but lack convincing evidence of torsades de pointes (TdP). These drugs have all been **added** to the QTdrugs List in the **Possible Risk of TdP category**.

Serdexmethylphenidate, a new prodrug of dexmethylphenidate used to treat ADHD, was **added** to the **List of Drugs to Avoid** in patients with congenital Long QT Syndrome.

Finally, CredibleMeds has updated their website to include a new category, **"Therapeutic Options Not on QT drugs List,"** which is a list of medications that may be good options for different common ailments (like pain, acne, or a cold).

CREDIBLEMEDS®

Remember that the full QTdrugs list is available in the CredibleMeds mobile app or crediblemeds.org.

Sign Up for Upcoming Events

Sign up for our Virtual International Conference, happening this MONTH!

Learn more about our regional family seminars – happening this fall!

Wear Awareness on Your Sleeve

One great way to spread awareness is by ordering one of our Ask Me About SADS t-shirts (modelled here by Patti, CPVT mom)! These are a great way to start a conversation about your condition – and spread awareness wherever you go. To order yours, visit SADS.org/Newsletter or scan the QR code on this page.