SADS NEWS
FOUNDATION
Supporting families. Saving lives.
Fall/Winter 2024

Updates from the 2024 SADS Foundation International Conference

Imagine an in-person meeting bringing together the foremost international experts in SADS conditions at the same time and in the same place!

That's exactly what we did this November at Lurie Children's Hospital in Chicago, IL.

Visit **SADS.org/newsletter** or scan the QR on this page to learn more and register to watch the recordings from our conference.

Insights from the Experts

SADS experts joined us from all around the world, presenting cutting-edge info on the best practices and newest research for our conditions.

This included the latest on clinical trials and research; updated guidelines on sports participation; a live Q&A with Dr. Michael Ackerman; and information about why genetic testing is so important for your family.

You can watch all of these sessions by registering online.

Celebrating Our Community

Over 80 families joined us in Chicago - and we had a wonderful time celebrating our community in-person.

"Thank you for this opportunity! The adults and kids in our group left with more knowledge and new friends, plus we connected with friends we've met along the way. What a great conference!" said Melissa, whose children, husband, and parents all attended as well.

Kids and teens had fun and learned a lot! They participated in sessions that included extracting DNA from strawberries, CPR relays, music therapy, and visits with therapy dogs!

We would be remiss not to mention those who couldn't be with us at the conference, but we carry them in our hearts - and we honored their memories through pictures on our Wall of Lights.

Thank you to our conference sponsors!

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In This Issue

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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SADS Welcomes Two New Staff Members

Allie Hoth, Social Media Coordinator

In December of 2023, my family's world was turned upside down when my 16 year old brother went into cardiac arrest. This led to him being diagnosed with CPVT as well as three other members of my family being diagnosed, myself included. During this time I relied heavily on the SADS social media platforms to understand this new condition that we were coming to terms with. I am so happy to be a part of this Foundation and the Communications team

Jennifer Berko, Community Engagement Coordinator

In January 2023, our 16 year old son suffered a sudden cardiac arrest, was pronounced dead, and then came back to life. Thanks to immediate genetic testing, we learned he and I have CPVT. Genetic testing also revealed our 10 year old son had passed away four years earlier due to undiagnosed CPVT. The world-renowned electrophysiology team at Texas Children's Hospital were the first to tell us about SADS. Immediately, I saw my purpose. I volunteered for SADS and shortly thereafter became an employee. This is not a job for me, but a passion to get others like me and my family the information, testing, and treatment they need before it's too late.

Active Clinical Trials for SADS Conditions

This is an exciting time for those with SADS conditions because there's so much new research happening along with a greater push for new therapies!

Choosing to participate in a study is an important personal decision. Before you participate in a study, know the risks, potential benefits, and discuss all options with your health care provider and other trusted advisors. You can also reach out to SADS with any questions - we're here to be your advocate as research advances.

ARVC/ACM: Lexeo HEROIC-PKP2 Gene Therapy Trial for PKP2-ARVC

This gene therapy, called LX2020, aims to deliver a working PKP2 gene to your heart cells to restore PKP2 protein levels, and to potentially improve the outcome for patients with PKP2 ARVC.

ARVC/ACM: Tenaya RIDGE-1™ Gene Therapy for PKP2-ARVC

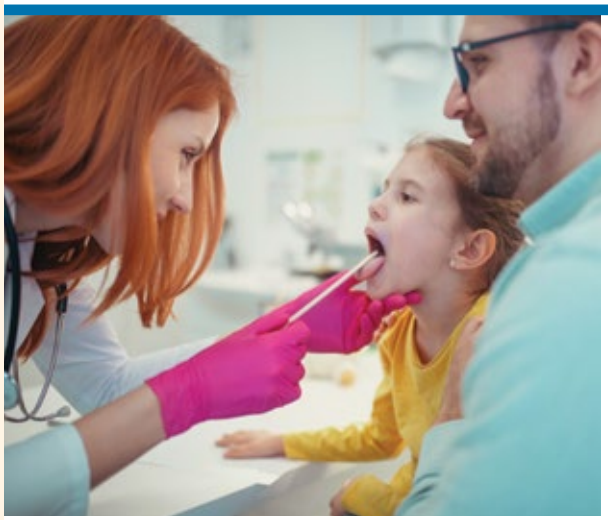
The RIDGE-1 clinical trial will assess the safety of TN-401, an investigational gene therapy intended to address the underlying causes of ARVC.

Cardurion Clinical Drug Trial for the Treatment of CPVT

This is a clinical study of CRD-4730 administered as single oral doses to participants with Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT). The study will have 2 cohorts in which participants with CPVT will participate. Each participant will receive 2 different doses of CRD-4730 and 1 dose of matching placebo.

Clinical Study for Long QT Syndrome Types 2 & 3

Thryv Therapeutics Inc. is conducting a clinical study to evaluate the safety and tolerability of an investigational medicine, LQT-1213, in people with Long QT Syndrome Type 2 or Type 3. This trial is currently not enrolling; check back soon for updates.



Know Your Family Gene

Did you know that genetic testing is the standard of care in 2024?

The information derived from genetic testing helps your doctor accurately determine which medication will be most effective for you and contributes to their decision of whether or not to recommend an ICD or other treatment. Getting genetic testing can also help identify which other family members might be affected.

Genetic testing allows you to share the name of your genetic mutation with the SADS Foundation, so we can reach out to you if you're eligible for upcoming, groundbreaking research and trials. Visit **SADS.org/newsletter** or scan the QR on this page to learn more.

For Your Family, For Your Community - and #ForSarah

Since she was a little girl, Sarah Katz was involved in CPR and AED awareness advocacy – and always wanted to help others learn how to save a life. Sarah passed away suddenly at the age of 21 from Sudden Cardiac Arrest.

Sarah is deeply missed by her friends, parents, and community - who believe her message of CPR and AED awareness is more important than ever. In honor and memory of beloved Sarah, order free, informational cards and put them up in YOUR local community so we can create a community of lifesavers: for you, for your family, and #ForSarah.

So far we've sent 2,770 cards to 39 states - even Hawaii - resulting in over 39,000 people engaging and learning more about Sarah's legacy. Order your cards by visiting **SADS.org/newsletter** or scanning the QR on this page.

Upcoming Chances to Spread Awareness

The next few months are packed with great opportunities to help us on our mission to spread awareness. Here's how you can jump in and join us for the rest of 2024:

November - Family Health History Month

How you can help: use our free online resources to contact your potentially affected family members so they know about their heart risk.

December - Worldwide Candle Lighting Day

How you can help: share your loved one's memory with us to be included in our yearly video. Then, share our video so the faces of those we lost too soon inspire others to take action.

December - Year End

How you can help: make a donation of any amount - and share our cause with friends & family! There's no greater holiday gift than helping save a life by supporting SADS.

Friday Night Football Goes Red

Have you ever wanted to host a community event for SADS?

A small town in Utah did just that! They turned a regular Friday Night Football game into a SADS Awareness Night - and a whole week of awareness at their high school.

Amy Phillips, a mother of multiple children with CPVT, pitched this event to her local high school after her son suffered a SCA (Sudden Cardiac Arrest). The administration and school's Student Council came together to help plan a whole week of SADS-based activities and awareness. The community showed up by flooding their small stadium wearing red, one of SADS' main colors. Intermountain Healthcare brought a CPR booth and their life flight was able to deliver the game ball. This small idea became an event for the whole community.

Sometimes the idea of holding a SADS awareness event might seem daunting, but SADS is here to help you - and so is your community.

Supporting Families Who've Experienced Loss

Bella Gonzalez brightened the lives of everyone she met. Her very favorite activity was dancing; she joined her first dance class at three years old.

"We can go on for hours and hours about the joy Bella brought into our lives and anyone who came in contact with her," says Amanda. "The outpouring of love and support of people she didn't even know just shows you the beautiful soul she is and will always be. Now she will always be our forever dancing angel."

Bella was just 12 years old when she passed away in June 2022. Families like Bella's are the reason we've developed new Grief and Mental Health Resources - which we continue to grow and expand each year. Learn more about Bella's light and legacy, how you can share your loved one's memory with us at SADS, and get support for your grief journey, at the QR code.

Join a Virtual Support Group

Here at the SADS Foundation, we're always looking for ways to support you and your family – that's why we hold two support groups each month: our **ICD Support Group** for any adult with an ICD and our **SADS Connection Support Group** for those who are newly diagnosed and want to connect with people who can relate.

Join our support groups by visiting **SADS.org/newsletter** or scanning the QR on this page.

Updated Pregnancy and Exercise Resources

We've recently updated our website with the newest information on two highly-requested topics: exercise and pregnancy. Here's a sneak peek of what you'll find. View our new information and resources by visiting **SADS.org/newsletter** or scanning the QR on this page.

Exercise

During Heart Rhythm Society 2024, a new consensus statement on returning to play with SADS conditions was released (the authors include Drs. Rachel Lampert, Dr. Michael Ackerman, Dr. Susan Etheridge, Dr. Cynthia James, Dr. Andrew Krahn, and Dr. Maully Shah).

Research has not shown an increased risk of continuing sports for those with LQTS, CPVT, and Brugada Syndrome who have had a risk assessment and are being treated. A return-to-play, shared decision making model is appropriate and is a huge step forward for our families.

Pregnancy

We know that having a heart condition while considering starting a family, or while pregnant, can create extra challenges for our SADS families. You may be looking for resources to help educate your doctor or answer questions like, what are the chances my child might have a SADS condition? And, is it safe to continue my medication while pregnant and breastfeeding? Look no further than SADS for support and answers.

SADS Supports Your Family

Wherever you are in your SADS journey, we're here to help at the SADS Foundation.

Elliott was diagnosed with Brugada Syndrome in 2020. He found the SADS Foundation soon after his diagnosis and connected with a specialist at Johns Hopkins – Dr. Andreas Barth, a medical expert volunteer for the SADS Foundation. Dr. Barth confirmed Elliott's diagnosis.

After an S-ICD implantation, Elliott joined the SADS ICD Support Group. "For the first time in almost four years since my diagnosis, I met someone else with my condition," says Elliott. "I didn't feel alone, or lost, or like it was all in my head. It really breathed new life into me."

Our SADS Family Support team is a resource for our whole community – whether you've just discovered the SADS Foundation, or you've been with us for years. We're here to offer support, answer your questions, connect you with other families who've been through similar experiences, and help you find appropriate care in your area. Learn more about our Family Support resources and Elliott's story by scanning the QR code on this page.

What Your Donation Supports at SADS

Gratitude is the only word that describes the feeling every donation generates here at SADS. Your donation tells us you believe in the work we've been doing together since 1991! Like the four chambers of the heart, our focus continues in four main areas: Awareness & Prevention, Patient & Family Support, Medical Education, and Research & Advocacy. Thanks to you, each of these areas is experiencing significant growth. Just look at the numbers to see how far your donations have helped us go:

- A **$25** gift provides a SADS Safe School Kit - allowing school staff the ability to help a child in the event of an emergency.
- A **$100** gift equals five physician referrals to newly diagnosed families in need of an expert.
- A **$500** gift gives a family one-on-one support as they navigate living with a SADS condition.

We are so thankful for every donation we receive – big or small – for making a difference in the lives of SADS families everywhere!

No Ball at All

Frankie Berko was at the heart of our annual No Ball At All campaign this year. Frankie left his earthly body at just ten years old, but his family continues to feel his giving energy fuel them to help families like theirs. It took 4 years and their oldest child having a cardiac arrest to learn their family has CPVT. With the help of SADS, they say they received a full education, "We learned that SADS funds research, awareness, family support, and medical education. Today, SADS is helping us ensure Frankie's memory and spirit of giving live on."

You can donate in Frankie's memory, and learn more about his story, at **sads.org/newsletter** or by scanning the QR below.

Make a Gift of Thanks to SADS

This Thanksgiving we're most thankful for YOU, our SADS family, for your commitment to awareness, new and improved treatments, family support, and fundraising.

We hope you'll remember the SADS Foundation this Thanksgiving.

With an end of year gift...

- You save lives by powering awareness efforts.
- You drive research for better treatments.
- You give more families the support they need.
- You bring top-notch education to medical experts.

Brighter futures are up to you. We can't do it alone. Please donate today at sads.org/yearend or using the QR code.

Have You Planned Your Legacy?

SADS families are constantly planning for the future, but have you planned your legacy yet? Nearly 67% of American adults don't have a will!

Using FreeWill, our free, online will-writing tool, 100% of our SADS community can protect the people and causes they love by creating a will. Find peace of mind knowing your giving heart will be your legacy. In just 20 minutes you can find a sense of security knowing you've protected your family, dictated important decisions, and made a lasting impact by supporting SADS for years to come.

FREEWILL

2024 International Conference for Healthcare Professionals

Jointly provided by Lurie Children's Hospital, Northwestern University Feinberg School of Medicine and Sudden Arrhythmia Death Syndromes (SADS) Foundation

Our comprehensive, state-of-the-art conference addressed the management of patients with cardiomyopathies and channelopathies. Healthcare professionals had an opportunity to ask questions of experts in the field in real time – including appropriate treatment of patients with Long QT syndrome, use of cardiogenetics with gene-specific data, diagnosing and treating arrhythmogenic cardiomyopathies and managing complex single-gene clinical cases.

Visit **SADS.org/newsletter** or scan the QR on this page to view the recordings.

Thank you to our conference sponsors!

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Heart University and SADS Collaborate to Educate Physicians

SADS Foundation has started a new partnership with Heart University, a virtual library featuring evidence-based educational materials for healthcare providers specializing in pediatric and adult congenital cardiology.

We have offered three collaborative webinars so far in 2024, including **Developing Gene Therapies for Cardiomyopathies** with Dr. Andrew Landstrom, **A Patient & Physician Perspective on Inherited Arrhythmias in the Fetus** with Dr. Janette Strasburger and Tia Hansen (SADS Family Support Coordinator), and **State of Genetic Testing for SCD-Predisposing Channelopathies and Cardiomyopathies** with Dr. Michael Ackerman. Visit **SADS.org/newsletter** or scan the QR on this page to register and learn more.

Heart UNIVERSITY

2024 Courts K. Cleveland Jr. Young Investigator Award Winners

During the PACES annual meeting at HRS, the SADS Foundation presented its 2024 Courts K Cleveland, Jr. Young Investigator Awards

Basic Science Winner

The Basic Science winner is Chantal van Opbergen, PhD with sponsors, Mario Delmar, MD, PhD and Marina Cerrone, MD of New York University School of Medicine for her study, *AAV-Mediated Delivery of Plakophilin-2a Arrests Progression of Arrhythmogenic Right Ventricular Cardiomyopathy in Murine Hearts: Preclinical Evidence Supporting Gene Therapy in Humans.*

In Research. Both award winners, and their mentors, are studying gene therapies for SADS conditions (ARVC and LQTS)

Clinical Science Winner

The Clinical Science winner is Sahej Bains with sponsor Michael Ackerman, MD, PhD of Mayo Clinic for *AAV9-Mediated KCNQ1-Suppression-Replacement Gene Therapy in Transgenic Rabbits with Long QT Syndrome Type 1.*

Pushing the Field Forward for LQTS & CPVT

Thank you to all who participated in our meeting to inform the FDA, healthcare professionals and researchers about LQTS and CPVT. This meeting was impactful because of your vulnerability and commitment to making a change. **The FDA has already started taking action based on your insights.**

The Voice of the Patient Report is now available, which contains a summary of what we heard during our EL-PFDD. Here are a few highlights:

- We heard about how **mental health** is a huge challenge for our families, including anxiety, depression, and PTSD resulting from ICD shocks and cardiac arrests.
- Though many people's symptoms are well-controlled by devices and medications, they often have **severe side effects** - which is one reason we need better, improved treatments.
- Dr. Ackerman and Dr. Wilde helped us see, from the clinician's perspective, why **the status quo is not good enough** in terms of treatment for LQTS & CPVT.

Watch our EL-PFDD and read the Voice of the Patient Report by visiting **SADS.org/newsletter** or scanning the QR on this page.

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"Today, we made history for our families with LQTS and CPVT. I trust the FDA will hear loud and clear that the status quo is not good enough for our patients. They need and deserve for us to search for and find better solutions."

- Dr. Michael Ackerman, Mayo Clinic

Why I Joined a Clinical Drug Trial for LQTS

"Recently, I had the chance to weigh the risks and benefits and decided that I felt very safe participating in a drug trial for a medication that I hope one day soon will help keep my daughters, my mom, my cousins, me and everyone else with Long QT safer.

I lost my sister to Long QT back in 2005. And I have two daughters with Long QT. I thought to myself: I can actually help usher in the future of treatment for this condition. I can make my daughters' futures safer.

Not everyone can make it work, and not everyone will be comfortable with the risks. It's a personal decision. Personally, I feel proud to be one of the first ten people with Long QT to have tested a medication that could be a game-changer for us.

It was only going through a clinical trial, though, that I realized how much I didn't know about clinical trials to begin with. So, let's shed some light on what it's really like to participate in a drug trial."

Read Melissa's story at **SADS.org/newsletter** or scan the QR on this page.

"I look forward to the possibility that this new medication will one day be available to me, my daughters and the rest of my family. I'd do it again in a heartbeat to speed up that timetable."

Research Updates in 2024

2024 has been an exciting year for research in all our conditions. New treatments - including gene therapies - are on the horizon. Here are just a few of the research highlights we saw for our SADS conditions this year:

LQTS

1. Exercise guidelines are being updated for LQTS.
2. Gene therapy is in progress for LQTS.
3. Risk assessment can help determine if you really need an ICD.

ARVC

1. Gene therapy for PKP2-ACM (ARVC) shows promise in stopping progression.
2. Shared decision making is a good model for exercise & ARVC.
3. AI might make it easier to diagnose ARVC.

CPVT

1. Two new clinical drug trials are in progress for CPVT - and gene therapy is on the horizon.
2. Exercise guidelines are being updated for CPVT.
3. Researchers emphasized the need to weigh the risk vs benefit of ICD implantation in symptomatic children with CPVT.

Brugada Syndrome

1. New research might help more accurate diagnosis of Brugada syndrome
2. Knowing your variant can help you know your risk.
3. Ablations are a potential treatment for some people with Brugada.

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Updates to CredibleMeds and LQTS Drugs to Avoid

Alert for our LQTS families! AZCERT's Scientific Review Committee for the QTdrugs List has found substantial evidence that the following medications are associated with the development of QT prolongation but lack convincing evidence of torsades de pointes (TdP):

- Moclobemide (antidepressant)
- Gepirone (antidepressant)
- Motixafortide (Multiple myeloma therapy)
- Givinostat (Duchenne muscular dystrophy therapy)
- Isoflurane (general anesthetic)

Therefore, these medications have been added to the Possible Risk of TdP category (PR) and the List of Drugs to Avoid in patients with Congenital Long QT Syndrome (DTA List).

Also, the Committee found substantial evidence that **Ivabradine** (antianginal drug), previously in the Conditional Risk of TdP category, is associated with QT prolongation and TdP when used as directed. Therefore, Ivabradine has been changed to the Known Risk of TdP category. In addition, **Quizartinib** (leukemia therapy) was added to the Known Risk of TdP category.

CREDIBLEMEDS®

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

Sign Up for Upcoming Events

Worldwide Candle Lighting Day
December 8
Join us virtually

SADS Exercise & Movement Challenge
January 2025
Join us virtually

National Heart Month
February 2025
Join us virtually

No Ball at All
March 2025
Join us virtually

Wear Awareness on Your Sleeve

One great way to spread awareness is by ordering one of our brand-new SADS t-shirts! These are a great way to start a conversation about your condition – and spread awareness wherever you go. They come in tons of sizes, colors, and styles.