SADS NEWS
SADS FOUNDATION

Supporting families. Saving lives.

Spring 2022

SADS FOUNDATION VIRTUAL 2022 ANNUAL CONFERENCE JULY 16-17

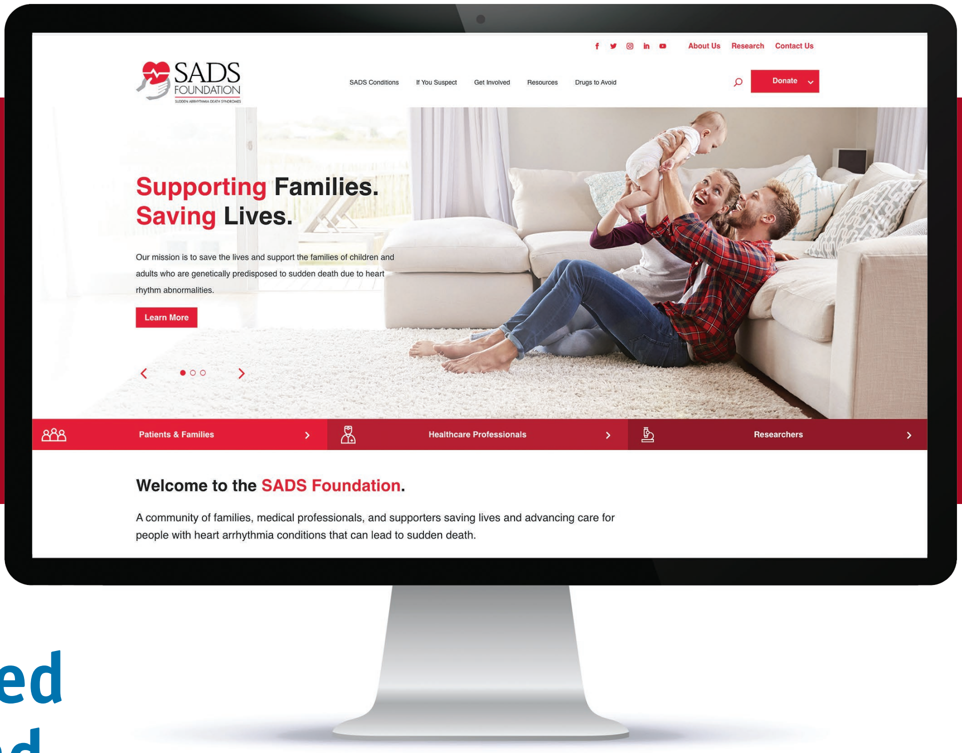
This year we're holding our third Virtual International Conference in mid-July 2022. Because it's virtual, families like yours across the globe can attend right from your living room, and watch global experts give presentations on the newest in research and treatment – plus, it gives you a chance to meet others with your condition, and form lifelong connections!

"The SADS conference is the gateway that has provided us the opportunity to meet other families who share our journey – we're very thankful for them," says Anthony Lucatuorto, member of the SADS Board of Trustees.

A few highlights from last November's virtual family conference include "Exercise/Sports: Can I Still Play?" by Dr. Michael Ackerman, "What is Gene Therapy?" by Dr. Greg Webster, "Raising a Child with SADS: Top 10 Tips for Families" by Dr. Jennifer White, and "What's on the Horizon for ICDs?" by Dr. Charles Berul.

You can register for this year's Virtual International Conference today by going to **SADS.org/Newsletters.** Missed last year's conference? You can sign up to watch the recordings at the same link!

Say Hello! To Our New Website Designed with You in Mind



Supporting Families. Saving Lives.

Our mission is to save the lives and support the families of children and adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Welcome to the SADS Foundation.

A community of families, medical professionals, and supporters saving lives and advancing care for people with heart arrhythmia conditions that can lead to sudden death.

We're excited to announce the launch of our brand-new SADS Foundation website! We've received lots of feedback from families like yours, and incorporated your suggestions – and we can't wait for you to start exploring.

You'll notice lots of exciting new features, including updated pages about each condition, with tailored resources; updates to pages on information like sports & exercise, our COVID hub, and information for parents and schools; and resources that make it simple for new families joining our community to find resources, including more information about preparing for your doctor's appointment, genetic testing, and a detailed roadmap on what to do next.

Can't wait to dive in?
Go to **SADS.org/Newsletters** to start exploring today.

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.

International SADS Volunteers and Groups

SADS conditions occur in all populations around the world and people are concerned about raising awareness and helping families receive the best care available. The silver lining of not being together in person for the past two years is that we have been able to reach far more individuals and families, globally, with our virtual educational webinars and conferences.

SADS International is a small group of organizations that have joined with us to focus on saving young lives. SADS Canada, SADS UK, SADS Hong Kong, SADS Mexico, SADS Spain, SADS Taiwan, Italy, and many other small groups and volunteers.

Visit **SADS.org/Newsletters** to learn more about our international SADS affiliates.

2021 Volunteers of the Year

Congrats to this year's Volunteer of the Year Awardees: Dr. Prince Kannankeril for his efforts in educating medical professionals about SADS conditions; Meredith Loveless and her daughter Alexis for spreading awareness by telling their story; and to the O'Donnell, Speece and Weidler families for raising more than $100,000 through the Ryan Weidler Memorial Golf Tournament.

Congratulations to Brynn Dechert-Crooks on her HRS Board Appointment

SADS Foundation Board of Trustees member, Brynn Dechert-Crooks, pediatric nurse practitioner, electrophysiology at C.S. Mott Children's Hospital Congenital Heart Center, Ann Arbor, Michigan was recently elected to the Heart Rhythm Society Board of Trustees, the primary international medical society for electrophysiology. Her HRS board term begins May 1. We're proud of you, Brynn and HRS is lucky to have you!

"Throughout my involvement with the SADS organization, I recognize how much they give to patients and families. They are advocates and pioneers in bringing awareness of these conditions and prevention of sudden cardiac death. I am proud to be a board member of the SADS foundation and so proud of the work they do."

SADS COVID-19 Hub

Stay up to date on the latest on COVID-19 and SADS conditions!. Our COVID-19 hub includes our vaccine statement, parents' guidance for school and Q&A with an infectious disease expert. Read more on our COVID-19 hub at StopSADS.org

Watch for Our Digital Annual Report

This year, our Annual Report is digital only – which means we had lots of room to include extra stories and facts about how the SADS Foundation makes an impact!

Make sure to sign up for our eNews so you don't miss it. Visit **SADS.org/Newsletters** to join our list!

SADS Foundation Celebrates 30 Years

Did you know that Dr. Michael Vincent founded the SADS Foundation 30 years ago? A few years later, he published an article in Reader's Digest and went on ABC to talk about LQTS – and we started hearing from tons of families like yours.

In 1998, we started to branch out to international affiliates, beginning with SADS Canada; and in 2002, we held our very first family conference in London.

It's amazing to see how far we've come since then. We've seen some real triumphs in scientific advancement – like the fact that genetic testing is now more widespread and affordable, and that treatments are improving every year. And our community has grown exponentially!

This year we're exploring where we started, where we are now – and where we're headed in the future. Visit **SADS.org/Newsletters** to learn more!

SADS 30 FOUNDATION YEARS
YESTERDAY • TODAY • TOMORROW

Your Stories In Action

Over the past year, we've had over 70 volunteers from across the globe volunteer to be a part of our media campaigns, and tell their story to their local media stations to help spread awareness.

Katherine Standefer, author of Lightning Flowers (about her experience with LQTS and an ICD, wrote an op-ed in the Los Angeles Times about how the Academy of American Pediatrics screening guidelines could have detected her and her sister's conditions much earlier, and helped prevent them from having life-threatening episodes.

We've also had great TV clips from volunteers like Meredith Loveless and her daughter Alexis, who is a 15-year-old dancer. Their clip on WLKY news in Louisville, Kentucky featured Alexis's story of her return to dance.

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

Meredith & Alexis Loveless at Mayo Clinic

SADS Live – Now with over 90 Episodes!

We started SADS Live as a way to bring you the most up-to-date info during some very trying times—and it's incredible how much it's grown, thanks to our amazing viewers!

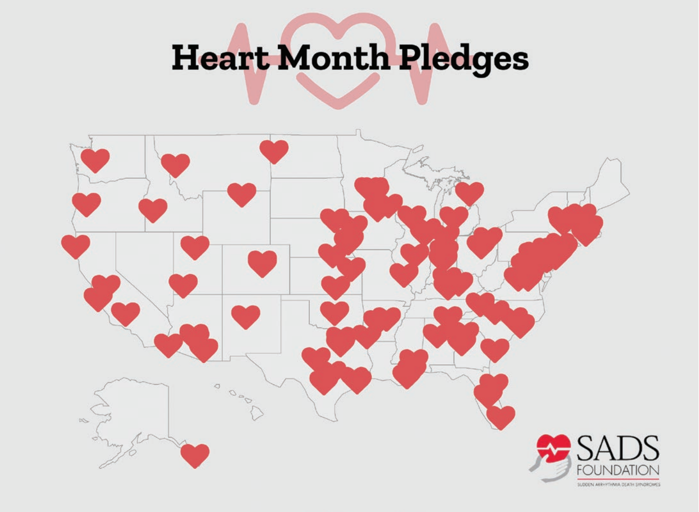
We've discussed cutting-edge papers, shared stories, and provided an ongoing space for you to ask your questions with Dr. Michael Ackerman. Some of our most popular episodes this year included an episode on sports participation with Dr. Rachel Lampert, the newest updates on Brugada and ARVC research with Dr. Robert Hamilton, and our Heart Month episode with volunteers Nora Lambert and Annie Lucatuorto.

You can catch up on this year's episodes of SADS Live, and get updates on new episodes, by visiting **SADS.org/Newsletters**.

Our Community is Growing – Join Us Today

We saw a huge growth in our social media channels in 2021 – thanks to your help! Our Social Media Volunteers helped us spread important awareness messages, and led to a huge increase in shares and engagement. For Heart Month, we had over 100 volunteers from 45 states join us to spread awareness – and many came from social media!

We've also teamed up with other organizations like Parent Heart Watch, HCMA, Project ADAM, and SCAF to amplify important messages about topics like CPR and AED awareness, and worked with hospitals including C.S. Mott's, Mayo Clinic, and Children's National Hospital to share stories about our SADS community.



Join our social media channels to get the latest on what's happening at SADS, and read stories of families like yours – or join our Social Media Volunteer team to help us spread the word – at **SADS.org/Newsletters**.

Pledges we received for Heart Month 2021 – more than 100 volunteers from 45 states

Website Sneak Peek – Sports & Exercise

Here's a sneak peek of our updated Sports & Exercise page from our brand-new website!

If your child is asymptomatic and taking beta blockers, it's fine for them to participate in non-competitive sports, PE classes, play, and recreational activities in moderation. However, if palpitations, light-headedness, weakness and/or blurry vision occur, the exercise or activity should immediately stop to prevent progression of symptoms. Adult supervisors need to be aware that a child should never be pressured to perform, and needs to feel free to stop whenever they think it's necessary.

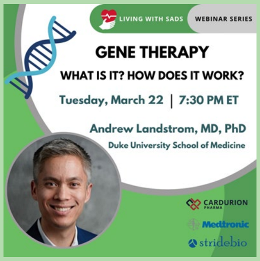
We have some amazing athletes with SADS conditions in our community, like Kati Wildhagen, who experienced SCA in church when she was a teenager. She now has an ICD and is a fitness coach. "For me, it's been a practice in self-care," she says. "Doing what I know what's mentally right for me, which is moving my body, but also respecting my limits and my device."

To read more from our new Sports & Exercise page, visit **SADS.org/Newsletters**.

FAMILY WEBINAR SERIES

Living With SADS

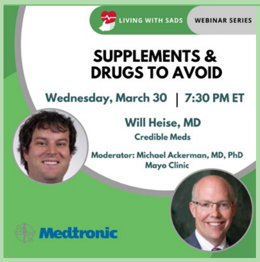
Experts explain YOUR SADS condition and answer your questions in these webinars.



We had record numbers of families and healthcare professionals for our gene therapy webinar on March 22! Andrew Landstrom, MD, PhD of Duke University School of Medicine covered the basics of **Gene Therapy – What is it? How does it Work?**

One of our participants, Molly, said: *"Thank you for making an extraordinarily complex process understandable. We have 25+ in our family with LQT type 2 and are excited for these medical advances."*

Stay tuned for **Gene Therapy – Part II** in April - and you can still watch Part I! Visit SADS.org/Newsletters to register.



We answered your questions about supplements & drugs to avoid for LQTS and Brugada syndrome at our webinar on March 30 with Dr. Will Heise of CredibleMeds. Visit SADS.org/Newsletters to view the recording. Have a question that wasn't answered? We'll be hosting another Q&A webinar on supplements later this year!

SADS Support Groups are Thriving

Join us in one—or more— of 3 monthly support groups: Adults with ICDs, Adults with SADS conditions, Kids/Teens with SADS conditions.

Facilitated by your peers, these groups are a great chance to meet others with similar conditions, share stories and challenges, and discuss common topics of interest. We have over 170 people currently registered for our groups!

"Being a facilitator and participant in the monthly ICD support group has been one of the most rewarding and beneficial experiences of my Long QT journey. Being able to share my experiences and hear the experiences of other SADS patients is very healing. I look forward to it every month!"

-Genevie Echols

Family Fun on Friday Nights

We have a great new opportunity for you and your child (and siblings and other family members too!) to engage in live, interactive play and online activities with other families and kids who have rare conditions.

Join SADS and others in Project Sunshine's Rare TelePlay for trivia and games: visit **SADS.org/Newsletters**.

ARVC Seminars and Groups

SADS was pleased to partner again on the Johns Hopkins virtual ARVC Seminar in March. Families learned about research and were able to meet virtually. And to learn more from the experts, be sure to watch our Living with SADS webinars on ARVC and on Sympathectomies and Ablations.

Monthly Support Group

"I have the wonderful pleasure of facilitating the ICD support group for those diagnosed with ARVC on behalf of SADS. SADS has created a supportive and safe environment for us as we each navigate the peaks and valleys of our lifelong disease." – Deena Edwards

For more information, and to register for our seminars or support groups for ARVC, visit **SADS.org/Newsletters**.

Help Us Save Lives in Our Schools

Join us to help your community learn the warning signs of SADS and prevent sudden death!

Reach out to your local PTA or Home & School Club, get on the agenda of their virtual meeting – and plan to share your story to kick it off. We can provide you with a medical expert and someone to discuss SADS conditions and warning signs.

Renee Maler gave our first presentation at her son's high school, Dougherty Valley High School, in November 2021. When her son, Jordan, died suddenly in his sleep, she wanted to prevent the same tragedy from happening to other families.

"I fed off Jordan's energy, and my immense love for my son, and the best thing I could do was go straight to our local school system to spread awareness," she said.

If you're interested in learning more about the SADS Prevention Program, visit **SADS.org/Newsletters**.

28th No Ball at All Campaign

Brian was a junior and on the dean's honor list at the University of Wisconsin-Madison, studying biomedical engineering and computer science. It was just a normal day in the life of a college student during exam week, Brian was in his apartment all day studying on and off for a test. He had been complaining of what he thought was an abscessed tooth. He still had one more final exam, but it became very painful. He called home complaining it was getting worse.

I called his doctor to get him an antibiotic to help until he got home. They rightfully refused as he was too far away to be evaluated. I then urged Brian to go to the immediate care, but he thought it could wait. I also urged him to call his doctor which he did as we noticed that they were his last three phone calls on his cell phone. Brian's roommate was studying in the next room and after we contacted him, he went to check on Brian and found him sitting up in his chair, already gone

We are so grateful for the help we have received from the SADS Foundation. They were our lifeline, helping us navigate next steps for evaluating Brian's younger brother. They continue to be here for us through informative e-newsletters, educational family webinars, and the virtual conference where we hear from world experts and engage with other SADS families. Visit **SADS.org/Newsletters** to read Brian's full story and to donate in his memory.

Sonny Jude Pancake Breakfast

The newest volunteer fundraising event for the SADS Foundation was hosted by Samantha (Sam) Becotte and her friends on February 19 in Syracuse, New York, in memory of her son Sonny Jude who passed away in October.

The SADS Foundation is truly touched by Sam's support to help us to help others not to experience the loss that she has felt. We could not be more grateful for the time and effort everyone put in to make this event a huge success. Visit **SADS.org/Newsletters** to read her full story.

2nd Annual Jazz Night for SADS

The 2nd Annual Jazz Night for SADS is slated for Sunday, August 28, in Salt Lake City, Utah. Once again John Lambert who is from one of our SADS families will be playing with his band Take 5 at Carolyn's Garden. The evening will feature refreshments, drawing items, and enjoying a summer evening of music and friends. And… just in case you do not live in Salt Lake City, we will be livestreaming the concert on our Facebook Page. Be watching for more details – we hope you can join us in the garden or online!

Your Legacy Will Ensure the SADS Foundation's Future

When you include the SADS Foundation in your will or other planned gift, you ensure the future of the SADS Foundation. We will be able to continue to eliminate sudden cardiac deaths due to SADS conditions. Your gift will help us to strengthen our ability to campaign for awareness, deliver comprehensive support to affected families, expand knowledge within the health care community, and magnify the influence of patients and families on research.

You can prepare to leave a lasting legacy through your will, revocable trust, charitable trust, charitable gift annuity, life insurance, or retirement account. We invite you to contact your legal counsel or the SADS Foundation to learn about estate planning and how to realize your vision for future generations of children with SADS conditions. Visit **SADS.org/Newsletters** to learn more.

An Interview with Dr. Charles Berul, SADS Board Member

What caused you to enter this field?

I enjoy taking care of children. But I also enjoy the complexity and the technical advances and engineering involved with pediatric electrophysiology and device development.

What are you most excited about in current research?

My current research is on miniaturization of devices to make them less invasive and less painful, not only for children, but for anybody who needs an implanted device.

How and why are you involved with the SADS Foundation?

The people involved in the SADS Foundation, including people like me, who volunteer to be part of the SADS Foundation, are interested in making things better for families, both in terms of their medical care and in helping them understand what the diseases are.

To read more about Dr. Charles Berul, visit SADS.org/Newsletters.

Courts K. Cleveland Jr.

2021 Young Investigator Awards in Cardiac Channelopathy Research

To encourage the next generation of researchers studying SADS conditions, the SADS Foundation received 12 applicants for the 2022 Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research. Applications were reviewed by the Pediatric and Congenital Electrophysiology Society (PACES) Research Committee. Thanks to the chair, Dr. Prince Kannankeril of Vanderbilt Children's Hospital for his coordination and administration.

The following institutions and mentors are represented among the applications:

Shubhayan Sanatani, MD, BC Children's Hospital
Andrew Landstrom, MD, PhD, Duke University
Robert Hamilton, MD, Hospital for Sick Children
Hugh Calkins, MD, Johns Hopkins
Michael Ackerman, MD, PhD, Mayo Clinic
Mario Delmar, MD, PhD, New York University
Elijah Behr, MD, St. George's, Univ of London
Dan Roden, MD; Bjorn Knollmann, MD, PhD, Vanderbilt University

Basic Science Winner

The winner of the Basic Science award is Marta Perez-Hernandez of New York University; Mario Delmar, MD, PhD, sponsor; "Loss of nuclear envelope integrity and increased oxidant production cause DNA damage in adult hearts deficient in PKP2: a molecular substrate of ARVC."

Clinical/Translational Science Winner

The Clinical/Translational Science award winner is Leonie Kurzlechner of Duke University; Andrew Landstrom, MD, PhD, sponsor; "Signal-to-noise analysis can inform the likelihood that incidentally identified variants in sarcomeric genes are associated with pediatric cardiomyopathy."

2022 Houston CME Conference & Family Seminar

November 11-12

Texas Children's Hospital®

Third time's a charm! The International Conference in Houston has been delayed two years due to COVID-19 restrictions. Dr. Jeff Kim has planned an outstanding CME-accredited program for medical professionals on Friday, November 11, 2022 at Texas Children's Hospital, Houston. On Saturday morning, November 12, we will have a ½ day family seminar with lunch. Families will have lots of time to ask questions of the docs and mingle with other families. Visit **SADS.org/Newsletters** for more information.

Help Power SADS Research

Do you want to help power SADS research – and improve treatments for future generations of SADS families? We have a lot of exciting upcoming research opportunities for our SADS community!

The Jones family, who's been with the SADS Foundation for four generations, can see firsthand how SADS research has made a difference. "We have a little baby who's just joined our life – my granddaughter," says Deby Jones. "And there's so much less fear attached to a diagnosis for her. There's been so much progress, thanks to organizations like SADS."

To learn more about how you can be a part of advancing research and making a difference for future generations of SADS families – and to view our currently open studies (including research for LQTS, ARVC, Brugada syndrome and CPVT) – visit **SADS.org/Newsletters**.

New Scientific Papers

Oral Contraceptive Use in Women with LQTS

In a study of over 1,600 women from the Rochester LQTS Registry, researchers concluded that progestin-only oral contraceptives should not be administered in women with LQTS without simultaneous beta blocker therapy. Also suggested that oral contraceptives should be used with caution in women with LQTS type 2.

An International Multicenter Study on Beta-Blockers for the Treatment of Symptomatic Children with CPVT

329 symptomatic CPVT patients from 2 International CPVT Registries were studied to determine whether beta-blockers would reduce events. The study concluded that Nadolol, or propranolol if nadolol is unavailable, should be the preferred beta-blocker for treating symptomatic children with CPVT. They also stated that Nadolol, which is not universally available, should become and continue to be available in all countries for the treatment of these patients.

Psychosocial Symptoms of Ventricular Arrhythmias

Patients with SADS conditions are at risk of anxiety and depression. Those with ICD's and frequent shocks have particular challenges as do those with exercise restrictions (like ARVC patients). Parents of patients with SADS conditions may also be affected. Education about their condition and treatment, support groups and counseling may improve the quality of life for these patients/families.

To read these—and more—scientific articles on SADS conditions, visit **SADS.org/Newsletters**.

SADS Advocates Talk to Congress

SADS staff and volunteer advocates participated in Rare Disease Week in February and met with Congress people to show our support for bills we think will help the SADS community.

As you know firsthand, SADS families must sometimes travel to receive specialized care. Bills that expand access to telehealth help SADS families access appropriate experts remotely.

And the development process for rare disease therapeutics takes an average of 15 years— a timeline far too long for the needs of the SADS community. That's why we support bills like the STAT and BENEFIT Acts, which can help close that gap.

To become a SADS advocate— or just to get updates or read more about the bills we are supporting in Congress, visit **SADS.org/Newsletters**.

Volunteer Spotlight: Regina – Group Moderator & SADS Advocate

Regina Welkie joined the SADS community in 2020 – and she's been super involved with us ever since!

"I initially got involved with the SADS Foundation as a way to connect with others, particularly others in the ARVC community," she says. Now she's one of the moderators for our SADS Connection and ICD Support groups, where she helps support other families with ARVC.

She's also involved as one of our amazing SADS advocates, and uses her voice to help support rare disease legislation that could make a huge impact for SADS families. "We have a condition that's not common, and I was really interested in raising awareness, and being a part of the SADS advocacy campaigns."

To learn more about Regina, and learn how YOU can become a SADS Advocate, visit **SADS.org/Newsletters**.

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Updates to CredibleMeds and LQTS Drugs to Avoid

Based on the available evidence, **Levoketoconazole (Recorlev)**, a newly approved drug to treat Cushing's Disease, has been added to the Possible Risk of TdP category of QT drugs.

Clofazimine (a drug used with rifampin and dapsone to treat leprosy) was moved from the Possible Risk of TdP category to the Conditional Risk of TdP category.

Check out the new list of medications that may be good options for different common ailments (like pain, acne, or a cold) titled **"Therapeutic Options Not on QT drugs List."** And to help answer your questions about supplements and drugs to avoid, we held a webinar on March 30 with Dr. Will Heise of CredibleMeds, which you can view (along with the list) at **SADS.org/Newsletters**.

CREDIBLEMEDS®

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

Read More About SADS!

Want to learn more about what you read in this newsletter? Scan this code or visit **SADS.org/Newsletters!**

For Healthcare Professionals: Brugada Syndrome Webinar

Join us on **May 5, 2022** for the latest research and clinical management for individuals diagnosed with Brugada syndrome presented by **Arthur Wilde, M.D., Ph.D.,** one of SADS scientific advisors. Objectives include:

1. Newest studies regarding genetics and pathophysiology
2. Newly developed risk score and typical presentation and treatment/management

For more details about this webinar, visit **SADS.org/Newsletters**.

Get the Latest News on Your Condition

Have you signed up for our eNews? Each month, you'll receive a calendar of upcoming events (both in-person and virtual), and an email with the latest stories & research on SADS conditions. And as we get to know more and more about our community, we'll even start sending you eNews specifically about your condition.

To join over 8,000 other SADS families who receive our eNews, visit **SADS.org/Newsletters**.