SADS NEWS
FOUNDATION
Supporting families. Saving lives.
Summer 2021

New Living with SADS Webinar Series Receives Rave Reviews!

"THANK YOU SO MUCH for hosting the SADS webinar tonight! This was the first time I have ever joined in…needless to say it will not be the last! A HUGE THANK YOU to all the team!"

In January of 2021, we launched an exciting new family webinar series that's been a huge hit, with over 600 families registering to watch. We brought together medical specialists to share insight on SADS conditions – from webinars on different types of LQTS to Brugada Syndrome and ARVC. We've also added popular topics that YOU requested – like pregnancy with a SADS condition, and life with an ICD.

We've recorded all sixteen of our webinars, which you can view by signing up at SADS.org/newsletter. Make sure to check out our two newest webinars – *Mind Over Body* by Dr. Sam Sears, on living with a SADS condition and anxiety, and our webinar on denervation and LCSD with Dr. Michael Ackerman and Dr. Harikrishna Tandri.

SADS Offers Virtual ICD Support Groups

We're always looking for ways to support you and your family - which is why we introduced our virtual **ICD Support Group** for adults in May. Whether you have an ICD or S-ICD, this is a safe, open space to talk about your experience and receive support from peers who know just what you're going through. Our adult ICD Support Group meets the first Tuesday of every month at 7:30 PM ET.

And we're launching a virtual Youth ICD Support Group on September 14, 2021 – a great way for kids and teens to connect with others around their age group who are also living with a SADS condition and an ICD. This facilitated group will meet the 2nd Tuesday of every month at 7:30 pm ET.

You can register for either group 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.

SADS Welcomes Two New Trustees

We're excited to welcome two new members to the SADS Foundation's Board of Trustees – Genevie Echols and Dr. Charles Berul. Genevie is a SADS community member whose family is affected by LQTS, and is from Austin, Minnesota. Dr. Berul is the Chief of the Division of Cardiology and co-director of the Children's National Heart Institute in Washington D.C. Thanks to Genevie and Dr. Berul for sharing their time and expertise with the SADS Foundation!

Charles I Berul, MD, Chief, Division of Cardiology; Co-Director Children's National Heart Institute, Washington, DC

Genevie Echols, patient and family affected with LQTS, Austin, Minnesota

Get to Know Dr. Susan Etheridge, MD

What caused you to enter this field?
I was very impressed when I was a medical student by how rapidly the field was moving and how things were changing so quickly.

What are you most excited about in current research?
The bench-to-bedside opportunities for the patients and cardiologists. Patients can really participate in research and that research can turn around and improve patient care.

Why are you involved with the SADS Foundation?
The team has brought together true thinkers and clinicians in the field and made them part of the foundation, the international conferences, and the scientific board. I'm more impressed every year by how much visibility this organization has among patients and the medical community.

SADS is my advocacy – it's that arm of my career. It has given back to me and given a great deal to my patients. I would encourage everyone who's reading this to get involved with the SADS Foundation.

To read more about Dr. Etheridge, visit SADS.org/newsletter.

Welcome Anna Goodson to the SADS Team!

Anna is delighted to be joining the SADS Foundation as the Communications Coordinator, and is looking forward to connecting with the SADS community. She holds a B.A. in English from Michigan State University and an M.F.A. in Creative Writing from the University of Maryland. She is originally from Okemos, Michigan. In her free time, she enjoys running, doing crossword puzzles, and spending time with her husband and her dog Bentley.

SADS Brings Virtual Family Conference Right to Your Table.

Our first-ever virtual International SADS Foundation Conference in November 2020 gave us the unique opportunity to bring a SADS conference right to your home! It was great to see so many of you there – we had more than 500 registered participants, a record for SADS Foundation conferences. Rachel Flores, a nurse whose daughter Bella has CPVT (and won a Volunteers of 2020 award at this year's conference), notes that the conferences help foster a sense of community: "There's almost nobody outside the SADS conference who understands your story and the emotional difficulty these conditions carry."

To watch recordings of the conference, visit SADS.org/newsletter. If you want to join us for the next virtual conference in November 2021 – and hear the latest research, connect with your community, and get your questions answered – you can sign up to get your name on the list for early registration at SADS.org/newsletter.

SADS Live – Live Streaming With Our Experts

Since the beginning of the COVID-19 pandemic, we've been live streaming every Friday straight to your home and answering your SADS-related questions! Dr. Michael Ackerman and his guests have provided expert answers to questions about life with SADS conditions – from condition-specific questions to questions about cutting-edge research. In the past year we have had 65 episodes (so far!), and over 150,000 views on Facebook, Twitter, and YouTube.

As things slowly return to normal, we're planning to bring you SADS Live twice a month now (rather than every Friday). If you haven't had a chance to get your questions answered yet, make sure to tune in. Stay up to date on what's happening on SADS Live by signing up for our e-newsletter! Sign up at StopSADS.org or contact erin@sads.org.

SADS LIVE

Have questions about your SADS condition? Get answers from an expert! Join SADS Live for real-time discussion of YOUR questions.

Watch Highlights from the 2020 SADS International Conference

Check out these past sessions with our world experts.

Find them at SADS.org/newsletter

# 6	ARVC with Dr. Hugh Calkins & Brittney Murray, CGC
# 57	Brugada & ARVC Autoantibody Biomarkers with Dr. Robert Hamilton
#67	Dr. Sami Viskin and Brugada Syndrome
#52:	Evaluation of SCA/SCD with Dr. Arthur Wilde & Dr. Martin Stiles
# 11	Dr. Silvia Priori
# 23	Dr. Peter Schwartz
# 60	Dr. Prince Kannankeril on CPVT
# 8	Dr. Christopher Semsarian
# 5	Dr. Elijah Behr

Highlights of the Latest Research

Episode 32	Dr. Sami Viskin, the Associate Editor of AHA Circulation
Episode 47	Dr. Andrew Landstrom, the Assistant Editor of Circulation: Genomic

Join the Conversation – Check Us Out on Social Media!

Have you checked us out on social media? We have a huge SADS community on Facebook, Instagram, and Twitter. Join us to meet other community members and hear their stories, get updates on the latest programs at the SADS Foundation, and share facts about your cardiac condition. You can also stream SADS Live with Dr. Michael Ackerman. We've grown our social media community a ton this year – with the addition of a communications team – so we can get to know you even better. Be part of the conversation – and help us get the word out by sharing our posts – by following us on Facebook, Instagram, and Twitter! You can find links to all of our platforms on our website at StopSADS.org.

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 14 applicants for the 2021 Courts K. Cleveland Jr. Young Investigator Awards in Cardiac Channelopathy Research. Applications were reviewed by the Pediatric and Congenital EP Society (PACES) Research Committee. Thanks to the chair, Dr. Prince Kannankeril of Vanderbilt Children's Hospital.

The following mentors and institutions are represented by these applications:

Arthur Wilde, MD, PhD and Carol Ann Remme, MD, PhD, Amsterdam UMC, The Netherlands

Calum MacRae, MD, PhD, Brigham & Women's Hospital, Boston, Mass.

Gary Tse, PhD, Chinese University of Hong Kong, China

Andrew Landstrom, MD, PhD, Duke University, Durham, North Carolina

Paul Volders, MD, PhD, Maastricht University, The Netherlands

Wen Kwang-Shen, MD, Mayo Clinic, Phoenix, Arizona

Michael Ackerman, MD, PhD, Mayo Clinic, Rochester, Minn.

Jose Jalife, MD, PhD, Spanish National Center for Cardiovascular Research, Madrid, Spain

Prince Kannankeril, MD and Dan Roden, MD, Vanderbilt University, Nashville, Tenn.

Basic Science Winner

The winner of the Basic Science award is **Steven Dotzler** and mentor **Dr. Michael Ackerman** for "Suppression-Replacement KCNQ1 Gene Therapy for Type 1 Long QT Syndrome."

Clinical/Translational Science Winner

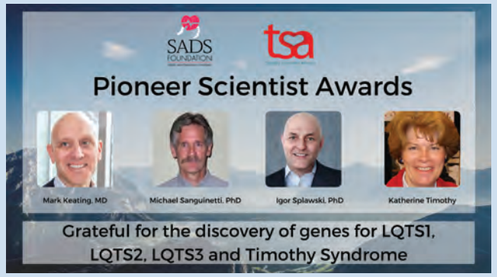
The Clinical/Translational Science award winner is **Puck Peltenburg** and mentor **Prof. Arthur Wilde** for "An International Multi-Center Cohort Study on blockers for the Treatment of Symptomatic Children with Catecholaminergic Polymorphic Ventricular Tachycardia."

Pioneer Scientist Awards

The first Pioneer Scientist Awards were presented by Dr. Michael Ackerman during the International SADS Virtual Conference in November 2020.

In 2003, CACNA1 was identified and in a 2004 Cell paper became the first scientific paper implicating a gene for autism named Timothy Syndrome in Katherine's honor.

Dr. Keating and Katherine Timothy began their LQT research in 1989 and first published in 1991 in Science. In 1992, Dr. Sanguinetti and Dr. Keating began a successful working partnership and in 1993 adding Dr. Splawski for the discovery of h-ERG (KCNH2), SCN5A, KvLQT1 (KCNQ1), and min-K (KCNE1).



Learn More About Professor Peter Schwartz

Tune into the PediHeart Podcast Episode #150 (co-branded with the SADS Foundation) to hear Dr. Robert Pass of Mount Sinai interview Professor Peter Schwartz, who's been working with the SADS Foundation for decades.

He started researching SADS conditions after the sudden death of an 18-year-old-girl during a live TV program in Italy. By chance, he ended up treating her sister (who was experiencing loss of consciousness) – and discovered that she had Long QT Syndrome. At that time, there were only a handful of cases described in the world. Because her fainting always coincided with increased activity, he suggested a sympathectomy. "So we did the surgery, and she never had any other arrhythmic episodes for her life," says Dr. Schwartz. "I was actually the best man at her marriage!"

You can download the episode wherever you get your podcasts, including Apple, Spotify, and Stitcher.

SADS FOUNDATION
SUDDEN ARRHYTHMIA DEATH SYNDROMES

Volunteers of 2020

Advocacy Corner: Make Your Voice Count!

You can make a difference by being a SADS advocate! Learn the legislative process and where the patient voice fits. Represent your SADS condition by sharing your story. If you want to advocate for SADS conditions and improved access to meds and other healthcare issues, sign up online for the first SADS advocate training this August.

Donate to Save Young Lives!

Keona Allen has experienced the unimaginable twice - losing two young children, Elijah and Chloe, to Sudden Cardiac Arrest.

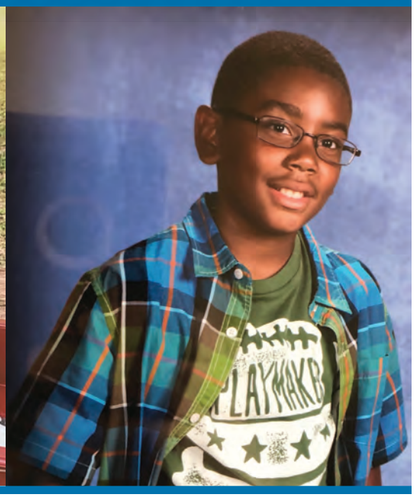
Elijah, 11, loved sports, and liked to play jokes on everyone - and he was really thoughtful and looked out for people. And Chloe, only 5 when she passed away, provided our family with such a sense of hope when we were in such a dark place... she was a very bright light in our family. She wanted to be a mommy when she grew up and have 10 children and drive a purple Ford Expedition.

We know that many of you experience similar grief.

We're honoring and celebrating Elijah and Chloe, and all our loved ones with SADS conditions - the tragedies and the saves. We're honoring families like yours. And we're raising funds to keep our loved ones safe - through educating medical professionals, supporting families, and raising awareness for SADS conditions. Please donate at SADS.org/Donate to support families and save young lives.

Being aware and knowing what you can do can make all the difference! - and YOU can help us make the difference!

- Keona Allen



THANK YOU Fabulous Fundraising Volunteers!

The SADS Foundation would like to extend our deepest appreciation to the families who held a volunteer fundraising event or adapted their annual fundraising events to find a way to support the SADS Foundation during the pandemic. We thank the teams from **Brittany's Trees, Christie's Heartoberfest, All for Al, Holiday Hoop Fest, Brian Price Memorial Jumpathon, Rachel's Race, Ryan Weidler Golf Tournament,** and **Super Lee Charity Golf Tournament** for extraordinary efforts. We also are grateful to everyone who was a part of our Virtual Events including the **Super Heart Bowl, Virtual Comedy Improv Night,** and **Walk for the Beat**

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

Extra Ways to Give

Giving to the SADS Foundation is easy and every little bit helps us support SADS families!

Combined Federal Campaign (CFC)
Pledges may be made by Federal civilian, postal and military employees. Visit www.opm.gov/combined-federal-campaign for more information.

United Way
If your company has a United Way campaign, choose the SADS Foundation for your payroll deduction to be a part of the campaign and support us at the same time.

Workplace Giving and Matching Campaigns
Ask your company if they have a Workplace Giving Program and/or a Matching Fund Campaign. You can easily give through a payroll deduction and make your donation go even further through a company match.

AmazonSmile
Choose the SADS Foundation on AmazonSmile.com every time you shop and donate 0.5% for the services we provide.

Contact Jan at 801-272-3023 or jan@sads.org for assistance.

Get Involved for SADS

YOU Can Be a Facebook Fundraiser Too!

We'd like to say **THANK YOU!** to the **more than 350 Facebook fundraisers** who have raised **more than $100,000** since Spring 2018! Each one has helped the SADS Foundation to provide services for SADS families everywhere! It's easy for anyone to host their very own Facebook Fundraiser. Sharing your story brings in critical funding so that the SADS Foundation can continue to help families live and thrive.

Start a Brittany's Trees in Your Neighborhood

Start a special tradition in your neighborhood this Christmas. Put up lighted trees in honor of your loved one with a SADS condition—and raise money for SADS at the same time. Your neighbors purchase a tree for their front yard and you and your volunteers put them up the weekend after Thanksgiving.

Jim and Tony, who began this tradition in Carol Stream in memory of Tony's daughter, Brittany, will be happy to help you get your event off the ground. Wondering where to start? You can use the manual that Jim and Tony wrote!

You can contact jan@sads.org or go to SADS.org/Get-Involved to find out more. Get involved today – now is a perfect time to help us save lives at the SADS Foundation!

Welcome New Volunteer, Deena Edwards!

We're excited to welcome a new volunteer to the SADS Foundation – Deena Edwards! Read a little more about Deena's ARVC journey below.

"After a number of tests, my doctors started talking about something called Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC). From my hospital bed, I found the team at Johns Hopkins ARVC program led by Dr. Hugh Calkins. I emailed Dr. Calkins directly and he wrote back and agreed to see me to confirm my diagnosis. I was lucky. To be connected to a world renowned program connected to doctors and researchers all around the world, I counted my blessings.

I encourage both patients and caregivers to be as involved as possible with their care and also with organizations like SADS. Having a community of people who understand the journey is so important. For me, I want to make sure I do everything I can do as a patient to help further the science and cardiac medicine, so that there are better management strategies for those that are yet to be diagnosed."

To learn more about Deena's story, visit SADS.org/newsletter.

Newest Updates in Treatment for ARVD/C

Did you know that you can watch TWO recent SADS Foundation webinars on ARVD/C? Check out our Living with SADS webinar all about ARVD/C with Dr. Hugh Calkins and genetic counselors Brittney Murray and Crystal Tichnell of the Johns Hopkins ARVD/C Program!

We then had a webinar just on ablations and sympathectomies focusing on ARVD/C, LQTS and Brugada syndrome with Dr. Harikrishna Tandri, Johns Hopkins ARVD/C program co-director, and Dr. Michael Ackerman, genetic cardiologist, Mayo Clinic. They reviewed when these procedures are the best next step, and what to expect if you're heading into surgery.

It's easy to watch our Living with SADS webinars – just sign up at SADS.org/newsletter.

An Exciting Collaboration with Author Katherine Standefer

We partnered with bestselling author Katherine Standefer this spring for a series of exciting new events. Katherine answered questions at our first-ever SADS book club on her book *Lightning Flowers: The Cost of Saving a Life* – about her journey with LQTS Type 2 – and was featured at a cosponsored event with the King's English Bookshop in Salt Lake City. She was also on a popular episode of SADS Live with Dr. Michael Ackerman, and presented her perspective on life with an ICD at our Living with SADS: Patient Perspectives webinar.

When we asked Katherine about how her ICD impacts her daily life, she gave some great advice on living life with a SADS condition: "A good life is not a flawless life. A good life is one in which we are alive while we're living and not running away from something."

To read more about Katherine and her book, visit our website at SADS.org/newsletter.

First Hybrid Gene Therapy Shows Early Promise in Treating Long QT Syndrome

In a new study published in Circulation, Mayo Clinic researchers provide the first proof-of-principle gene therapy for complete correction of LQTS.

"Gene therapy is an emerging area of interest for treating a variety of genetic heart diseases in general and long QT syndrome in particular," says Michael Ackerman, M.D. Ph.D.

The therapy involves a two-stage process of silencing the genetic error that causes the electrical dysfunction and then replacing it with a protein that works. Researchers demonstrated its potential using beating heart cells reengineered from the blood samples of patients with type 1 long QT syndrome.

If this is successful in an animal, then "gene therapy may be a promising strategy for long QT syndrome in general and in theory almost any sudden death-predisposing autosomal dominant genetic heart disease," says Ackerman.

"Of course, we still have a long way to go from nearly curing a patient's heart cells in the dish to effectively treating the whole person. Nevertheless, we are excited by this first critical milestone and look forward to the next step."

FAMILY WEBINAR SERIES

Living With SADS

Brugada Syndrome	Steven Lubitz, MD, Massachusetts General Hospital, Boston
Undiagnosed/Unknown SCA/SCD/IVF	Elijah Behr, MD, St. George's, University of London, UK & Lisa Castillo, CGC, Northwestern University, Chicago
Arrhythmogenic Right Ventricular Cardiomyopathy	Johns Hopkins ARVC program team: Hugh Calkins, MD, Brittney Murray, MS, CGC & Crystal Tichnell, MGC, RN

Link My Heart BRUGADA PROJECT

We would like to introduce you to a new initiative called Link My Heart—Brugada Project. In partnership with patients, this research project is meant to find new genes and treatments to help Brugada patients live a better, healthier life.

Sign up at SADS.org/newsletter to get the link as soon as the project goes live this summer.

FAMILY WEBINAR SERIES

Living With SADS

Catecholenergic Polymorphic Ventricular Tachycardia (CPVT)	Shubhayan Sanatani, MD, British Columbia Children's Hospital
Long QT Syndrome Type 1	Peter Aziz, MD, Cleveland Clinic, Ohio
Long QT Syndrome Type 2	Andrew Landstrom, MD, PhD, Duke University
Long QT Syndrome Type 3	Arthur Wilde, MD, PhD, Amsterdam UMC, The Netherlands
Long QT Syndrome Type 5	Yukiko Asaki, MD, Primary Children's Hospital, Salt Lake City, Utah

Sign Up for Living with SADS Webinars

Experts explain YOUR SADS condition and answer your questions in these webinars. Scan this QR code or go to StopSADS.org.

Remembering Tom Reubens

When Hal and Linda Reubens lost their son Tom tragically and suddenly, they knew that while they mourned Tom, they also needed to know more about what happened to him to protect the rest of their family. Tom, a history professor and runner who loved horticulture, had recently married his college sweetheart, Katie, at Loon Lake in the Adirondacks, and his unexpected death was devastating.

Tom was intelligent and compassionate, and loved his friends, family, and history. He had lots of interests and was passionate about everything he did – from his love of dinosaurs as a child to his work as a re-enactor at Fort Niagara and his many feats as a high school runner. "When he made up his mind about something, he'd go for it," says Hal. But Tom was also humble, and always gave those around him a leg up – from giving up his spot at a state running event to a friend, to celebrating those around him in his high school Wall of Fame induction speech. "When he'd come in a room, he'd light it up," says Linda, "and I really, really miss that."

After Tom passed away, the Reubens tested their family for SADS conditions, and discovered Brugada Syndrome. They are vocal advocates and spread the word about SADS conditions to prevent other families from experiencing a sudden loss. "We're just trying to get the word out more about this, because it came out of the blue," says Hal.

We'd like to thank the Reubens family for their support, and for raising awareness for Brugada Syndrome and SADS conditions.

Read more at SADS.org/Newsletter

LQTS Drugs to Avoid

The drugs that have been added to the list with a **Possible Risk of TdP** include:

Levetiracetam,
Ozanimod,
Meglumine antimoniate,
Remimazolam,
Sertindole,
Oliceridine,
Ponesimod,
Voclosporin,
Bicalutamide,
Relugolix,
Levmetamphetamine and
Linezolid.

The drug combination Moexipril and Hydrocholorthiazide was **removed** from the Possible Risk of TdP.

CREDIBLEMEDS®

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

Meet Cian Bennett

Meet Cian Bennett, a teen with CPVT who's part of our SADS Connect program – a Zoom session that allows kids and teens with SADS conditions to connect with each other! You can read his full story, and stories of other SADS community members, on our blog at SADS.org/blog.

"Because of my diagnosis, I met a new friend through the SADS Teen Chat Zoom that I now play Fortnite with on my PS4. It is nice to be able to talk to someone who has a similar diagnosis as me.

I would tell anyone diagnosed with my condition that even though I am limited with physical activity and sports, there are other things I can still do. I am also glad there is medication that can help. My mom tells me that I just have to think a little differently about things now. I may not be able to do all I could before, but I can still do other things I enjoy and I try to focus on that."

SADS FOUNDATION
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Wear Awareness On Your Sleeve

Start a conversation that could save a stranger's life! Are you looking for an easy, fast way to spread awareness about your cardiac condition? We've got a great new solution for you – a SADS Awareness T-Shirt!

Our new designs help you spread the word about your SADS condition, including LQTS, ARVC/D, CPVT, and Brugada syndrome. They come in a variety of styles, and we've got sizes for a variety of ages. If you have a specific color or style in mind that you don't see in our store, let us know – we can design a shirt for you. Visit SADS.org/newsletter to order your shirt.

SADS FOUNDATION VIRTUAL 2021 ANNUAL CONFERENCE NOVEMBER 5-7

Read More About SADS!

To read more about the stories in this newsletter, and learn more about our programs here at the SADS Foundation, simply scan this QR code or go to SADS.org/newsletter.