



# SADS FOUNDATION

SUDDEN ARRHYTHMIA DEATH SYNDROMES

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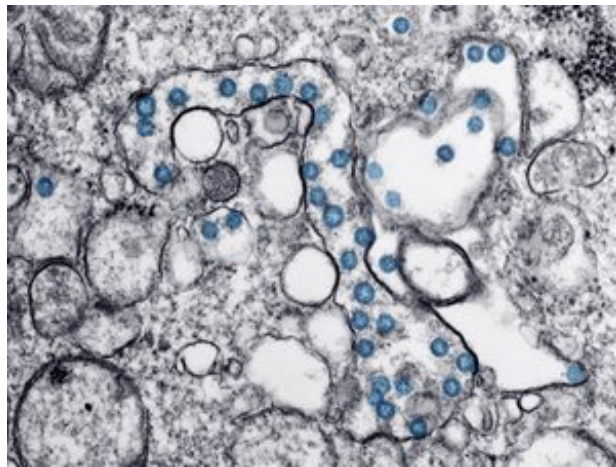
Editor: Jan Schiller

Contributors: Alice Lara, Marcia Baker, Erin Waite, Rachel Goss, Mikayla Viny

## Contact Our Support & Resource Center

Our support and resource center is available Monday-Friday to answer your medical and support questions and help you find knowledgeable medical professionals. Contact the support center at 801-946-0946 or email [sads@sads.org](mailto:sads@sads.org).

## SADS COVID-19 Resource Page



Some of our Scientific Advisors have collaborated with us to bring you the best medical information on COVID-19 in relation to our community. We are complementing this with guidance to help you cope with the added stress and anxiety that this situation is causing. All current and future updates and resources related to COVID-19 can be found on our [Resource Page](#).

## Survey: COVID-19 and SADS Conditions

We want to learn more about if and how our families are impacted by COVID-19. Please help by completing this survey which should take less than five minutes. Please [complete one survey](#) for yourself and one for each person in your family.



We will summarize the answers and let you know the results. And our Scientific Advisors will also take a look at the results and help us provide answers to meet your needs.

## #SADSathome

Stuck at home? So are we. Share with us your experiences at home. Just use #SADSathome and tag us. Here are some ideas for you to share.

## Upcoming Events

May 2, 2020

### [2nd Annual Hops for Hearts](#)

Schwenksville, PA

May 17, 2020

### [5th Annual Gertsberg Memorial 5K](#)

Farmington, CT

October 3, 2020

### [Christie's 15th Annual Heartoberfest](#)

Saratoga Spring, NY

October 10, 2020

### [5th Annual Rachel's Race](#)

Janesville, WI

November 14-16, 2020

### [American Heart Association Scientific Sessions](#)

Dallas, TX

November 28, 2020

### [Brittany's Trees](#)

Carol Stream, IL  
Libertyville, IL

#### Quick Links



1. Get creative! Pull out the arts and crafts - paint something unique, draw on the sidewalk with chalk, even take a picture of anything that makes you happy. We want to know what you and your family are doing to keep busy at home!



2. Make a short video - share with us anything you have learned (like a new hobby), how COVID-19 has affected your life, words of wisdom, or anything you would like to share with the SADS community.
3. Write for the SADS Blog - share your experiences by answering some questions about how you have learned to adapt to new situations.

Still out of ideas? Answers these short questions for our blog or short video. Click [here](#) to watch videos we have already received :-)

#### Blog/Video Questions

- Name
- Age
- SADS condition
- How has COVID-19 impacted your way of life?
- What is something you have learned with your time spent at home?
- What activities do you and your family do for fun?
- If you could give anyone one piece of advice, what would you say?
- How has the SADS Foundation helped you during these times?

We'd love to have you brighten our day and we'll share the love!

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## Celebrate National DNA Day on April 25th



Click [here](#) to check out the games, genetic lessons, and activities for the DNA Day Celebration.

Additionally, as part of your DNA Day Celebration, you can watch the amazing series on PBS [Ken Burns presents The Gene: An Intimate History](#). The Gene: An Intimate History weaves together science, history and personal stories for a historical biography of the human genome, while also exploring breakthroughs for diagnosis and treatment of genetic diseases and the complex ethical questions they raise.

The series tells the story of the rapid evolution of genetic science from Gregor Mendel's groundbreaking experiment in the 19th century to CRISPR, and the hope that newfound powers to alter DNA with pinpoint precision will transform the treatment of some of the world's most complex and challenging diseases. The series also tackles the daunting ethical challenges that these technologies pose for humankind.



Excerpt from the documentary: Dr. Wendy Chung at Mt. Sinai, New York City, examines a patient with a rare genetic disease

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## Online Resources for COVID-19

### Experts Answer Your Questions on Facebook Live

Join the SADS Foundation Facebook Live presentation weekly on Fridays (and some Mondays) at 2:20 pm Eastern.

### Virtual Support Groups

Let's get together - online Zoom meetings! Want to chat, or just be a part of an online group that understands the special challenges of our community during this time? Join us weekly at any of the following.

### International Heart-to-Heart

Join us on Fridays at 4 pm Eastern. To get the Zoom or call-in details, register [here](#).

### Kids/Teens Chat

Join us on Thursdays at 6 pm Eastern. To get the Zoom or call-in details, [please email sads@sads.org](mailto:sads@sads.org). Next Thursday, April 23, a special guest, Dr. Susan Etheridge, will join us for questions.



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## #GivingTuesdayNow on May 5th!





[Donate](#) to [#GivingTuesdayNow](#) scheduled for May 5th as we raise funds to protect the services of the SADS Foundation into the future. Together, we will ensure accurate diagnoses, improve patient care, and find an eventual cure for SADS conditions.

#### **What Else Can You Do?**

As a supporter of the SADS Foundation, we also ask you to be part of [#GivingTuesdayNow](#) team by creating a [Classy.Org Fundraising Page](#). Then share it with your family, friends, and colleagues for the special [#GivingTuesdayNow](#) on May 5th. We are grateful each of you who create a fundraisers and appreciate donations of any amount.

Please contact [jan@sads.org](mailto:jan@sads.org), should you have any questions or need further details.

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## **Deepest Appreciation for Facebook Fundraisers**



Deepest appreciation being sent to the following **6** family members: **Ashley Claudio, Pamela Hoy-Head, Patricia Keegan, Bill Roberts, Tom Sutch, and Tiffany Watkins** who all hosted a Facebook Fundraiser for the SADS Foundation during the month of March!!

Each Facebook Fundraiser helps the SADS Foundation provide life-changing and life-saving services for SADS families! If you would like to do this also, visit [www.facebook.com/pg/SADS-Sudden-Arrhythmia-Death-Syndromes-Foundation-194665999753/fundraisers/](https://www.facebook.com/pg/SADS-Sudden-Arrhythmia-Death-Syndromes-Foundation-194665999753/fundraisers/).

If you have any questions, contact Jan at 801-272-3023 or [jan@sads.org](mailto:jan@sads.org).

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## CredibleMeds



On December 26, 2019, the antipsychotic drug, chlorprothixene (Truxal®) was added to the Known Risk of Torsades de Pointes (TdP) list.

The antidepressant, clomipramine (Anafranil®), was moved from the list with Possible Risk of TdP to the Conditional Risk list in the following conditions: hypokalemia, hypomagnesemia, overdose and when taken with other drugs that prolong the QT interval.

The antipsychotics, Lurasidone (Latuda®) and Lumateperone (Caplyta®) and the anticancer drug, Tazemetostat (Tazverik®) were added to the Possible Risk of TdP category.

Cesium chloride, an ingredient in some "dietary supplements" was added to the Known Risk of TdP list.

The following three appetite suppressants were added to the Special Risk category and the Drugs to Avoid in CLQTS category: Diethylpropion (Tenuate®), phendimetrazine (Bontril®) and benzphetamine (Didrex®).

Obtain the CredibleMeds mobile app for free by clicking the following links: [Apple App Store \(iOS\)](#), [Google Play \(Android devices\)](#) and the [Windows Mobile Device](#) store.

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SADS Foundation | 801-272-3023 | [www.StopSADS.org](http://www.StopSADS.org)  
4527 South 2300 East, #104  
Salt Lake City, UT 84117