



NTSAD Lifeline



## OUR FIRST-EVER, VIRTUAL FAMILY CONFERENCE

May 28 - May 31, 2020

**REGISTRATION DEADLINE - Midnight, Friday, May 22.**

**REGISTER NOW**

The **NTSAD Virtual Family Conference** is for you and your family. Despite the distance between us, we hope our virtual conference will sustain our community until we can be together again. Things to remember:

**Please register** to receive the passcode for the Zoom links to the conference sessions. The deadline is 11:59pm (PDT), May 22, 2020.

**For the best conference experience possible for all**, please share the sessions you plan to attend with us by **filling out this survey [HERE](#)**.

**If you're a bereaved family**, and want to honor your loved one for the Commemoration ceremony on Sunday, May 31st, please email a photo along with your loved one's name and dates to Bonnie Davis [here](#).

Be sure to **download this tip sheet** to help make attending sessions easier and **visit this blog post** for more tips.

**For a general overview of the conference**, **[join our Zoom chat](#) on Tuesday, May 26th at 4:00 pm (EDT) for the Conference 411**. We'll review the conference, what to expect, the schedule and suggestions to make attending the conference virtually easier for you and your family.

### **New to Zoom? Need Help?**

Practice your Zoom Skills on one of our Tech Checks! Join us on Zoom **[Tuesday, May 26th from 6-8 pm \(EDT\)](#)** and **[Wednesday, May 27th from 12-2 pm \(EDT\)](#)** to practice on Zoom before the conference on Thursday, May 28th.

**If your family is participating in more than one session at a time**, please be sure to have all of your devices charged, and the Zoom links easily accessible on all devices before the conference begins.

**Please note all sessions are hosted in English**. After the conference, we will post the recorded sessions on the NTSAD website where there is an auto-translate feature for your preferred language.



Our thanks to lead sponsor **Sanofi Genzyme** and all of our valued sponsors for their continued, generous support.

## Sibling Virtual Family Conference Sessions

### Special Genetics Session for Senior Youth Group

**Learn more about genetics** with NTSAD Board President, Staci Kallish, DO on Friday, May 28, 2020 at 4:00pm (EDT). The Zoom link can be accessed via the mobile app or conference website.



**Virtually interact with other NTSAD siblings and have a little fun along the way!**

We have two virtual Youth Groups set up; one for our younger participants – Junior Youth Group (ages 8-12) and one for our Senior Youth Group (ages 13-18).

Use the links below to stay connected throughout the conference weekend.

Junior Youth Group ages 8-12 <https://padlet.com/NTSAD/junioryouthgroup>

Senior Youth Group ages 13-18 <https://padlet.com/NTSAD/senioryouthgroup>

Marco Polo: <https://onmarcopolo.com/groups/AqzKXwYwglCo/ntsad-siblings>

## Friday, May 29th - Research Day

**It's been a robust year in research.** We have knowledgeable speakers in every aspect of the conference--from the opening presentation to the individual breakouts for Canavan, GM1 Gangliosidosis, and GM2 Gangliosidosis (Sandhoff and Tay-Sachs).



**In the opening presentation at noon (EDT), NTSAD Board member, Gerry Cox, MD, PhD,** will provide a general overview of the clinical trial process. Following Dr. Cox, two speakers from the Food & Drug Administration (FDA) will address the FDA's role in drug development and gene therapy.

As we do every year at the conference, we have individualized sessions for each disease. Researchers and industry members are presenting in separate, virtual break-out Zoom rooms. They will be recorded and posted in the future on the NTSAD website for your convenience. Visit [here](#) to see the full schedule including the Research Breakouts.

## Let's Stay Connected!



Stay connected and follow us on social media using **#NTSADVFC2020** and **#AlwaysConnected**.

We also encourage you to select the NTSAD Virtual Family Conference frame for your Facebook profile picture.





**Sue Kahn**, Executive Director  
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