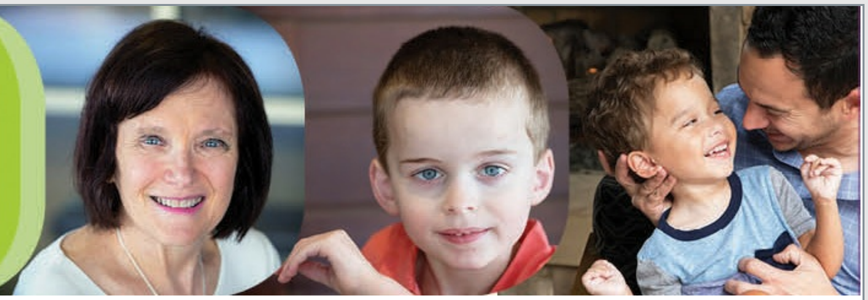
NTSAD

NTSAD Lifeline



We hope that you along with all of our friends, partners, and supporters are managing as best as you can as we live through this unprecedented time.

NTSAD's office in the Boston area remains closed in accordance with the Governor's declaration; however, we want to assure you that the NTSAD staff continues to work remotely to support families and to sustain our important mission.

Remember. We are here for you. Please feel free to contact either myself or Becky for whatever you need. Becky's email is becky@ntsad.org and mine is diana@ntsad.org.

Best,

Becky

42nd Annual Family Conference: Now a Virtual Event!

Even though we cannot be together in person for the conference, we can take advantage of the technology we have to unite virtually for our 42nd Annual Family Conference. ***There is no fee to attend.***

The sessions will take place via Zoom so be sure to download the app to your phone and/or computers. And to get familiar with Zoom, join us on Tuesdays and Fridays. (Links below)

In the meantime, mark your calendars to...

- Join us on **Thursday, May 28th** for the kick-off and support groups!
- Learn more about research on **Friday, May 29th**!
- Gain knowledge on **Saturday, May 30th** as we cover topics on health management, grief and announcing next year's conference location!
- Spend time with us on **Sunday, May 31st** to remember our loved ones and light a candle during our annual commemoration.

We have pared down the conference schedule to respect your time at home with your families, however, we will be offering webinars and chats throughout the year to cover topics we didn't have time for during these four days.

Stay tuned for the full conference schedule and how to register for our first-ever virtual Annual Family Conference.

Keep the Ball Rolling with Your Help

While life on the research front may have slowed down due to the novel coronavirus, there are still ways to keep moving forward including being a part of a natural history study.

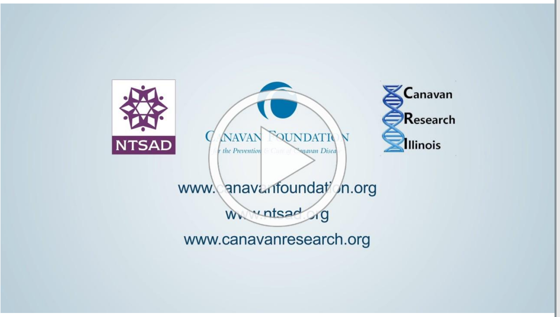
GM1 Gangliosidosis Families

RDMD has launched a program to collect medical records in order to extract anonymized data from them to help paint a picture of the disease. That data will then help researchers - academic or industry - to better understand the many facets to the disease. Watch the webinar to the right to learn more.

Sign up with RDMD **here**. 10 minutes is all you need to give. If you haven't signed up yet, please do today. We're just nine families away from our goal!

Canavan Families

NTSAD has worked closely with Aspa Therapeutics alongside the Canavan Research Illinois and the Canavan Foundation to lend our voices as they develop a gene therapy program for Canavan disease. An important piece of success is having a robust natural history study but that can't happen without families participating in their study. Learn more CANInfom **here** and through this video.



Stay Connected, Stay Empowered and Stay Supported

Technology has allowed us to stay connected via FaceTime, Zoom, Skype, and other platforms. For the 6-7 months we have been hosting weekly Zoom chats to give families a chance to be together virtually. We now have four chats a week at different times to give everyone an opportunity to join us from wherever they are in the world. We hope you take advantage of it and come say "hi"!

Tuesdays at 4:00 pm (Eastern) / 1:00 pm (Pacific) - Link **here**.
We will have speakers for these chats to focus on one topic. If there is a topic you'd like to see explored, let us know!

- **Tuesday, April 28th -** Sarah Mattingly, renowned conference photographer from Soulumination, will share her knowledge on taking photographs as home.
- **Tuesday, May 5th -** Oralea Marquardt, NTSAD parent and social worker, will host a discussion about anxiety and helping your children navigate through this time of uncertainty.
- **Tuesday, May 12th** (tentative) **-** Cindy Erickson, NTSAD parent and artist, will help us make some art in this virtual class!
- **Tuesday, May 26th -** Join us as we review the program, the how-to's, and answer any questions about the Virtual Family Conference.

Tuesdays at 8:00 pm (Eastern) / 5:00 pm (Pacific) - Link **here**.
NTSAD After Hours, a weekly virtual family lounge, to decompress and connect.

Wednesdays at 8:00 pm (Eastern) / 5:00 pm (Pacific) - Link **here**.
NTSAD Late Onset Weekly Zoom Chat with alternating weeks of bingo, discussion, and perhaps a surprise guest or two.

Fridays at 12:00 pm (Eastern) / 9:00 am (Pacific) - Link **here**.
Consider this open office hours for families to stop by, say hello and share what's new.

Helpful Resources

The beauty of our rare disease community is the sharing of resources especially now when we are "alone together." If you find something that helps you, feel free to share in the **NTSAD Family Support Group** on Facebook or on Instagram tagging us @NTSAD.

"Let's be careful out there."
Sargent Esterhaus, Hill Street Blues (1981-1987 series)

Courageous Parents Network

From yoga, articles to recommended podcasts, you can explore what they've shared **here**.

Global Genes

They have links for specific topics ranging from At-Home Teaching Resources, Coverage and Benefits, Exercise, Entertainment to Financial Assistance, Mental Health, Talking to Kids and Virtual Networking among many others. These can be found **here**.

Below we're sharing an episode of Global Gene's RARE on the Run that discusses the impact COVID-19 on clinical research.

Living in the Light and #IStayHomeforRare Campaign

Levi Gershkowitz and his team have created a relief fund for families in the rare community. He's asking you to share who you stay home for with the hopes to shine a light on your stories as the rest of the world becomes familiar with what every day can be like for a rare disease family.

Share your story **here**. And if you need help, apply **here**.

National Organization for Rare Disorders

NORD has curated and shared information on how to be empowered during this unique moment in time. You can access them **here**.

Hear about what the newly released FDA guidelines specific to the novel coronavirus and COVID-19 means for patients and the future of clinical research for the rare disease community. You'll hear from Terry Jo Bichell, PhD, MPH, director at COMBINEDBrain, Andra Stratton, co-founder and president at Lipodystrophy United, and Jason Sicklick, MD, FACS, surgical oncologist at UC San Diego Health.

Caring for an Older Child with a Rare Disease

The **University of Pittsburgh's National Rehabilitation Research and Training Center on Family Support** recently held a webinar addressing family caregiving during this time and the anxieties that arise concerning what could happen if you or your loved one becomes ill. For our community it is especially disconcerting, so having a plan may help mitigate some of the anxiety.

Click here to download a resource page answering a couple of questions along with other helpful resources.

Say their names...
(February 2020 - April 2020)

James Weinbrecht
June 20, 2017-February 28, 2020
Son of Andrea and Greg Weinbrecht

Kinsley Sibley
May 14, 2017-February 29, 2020
Daughter of Abbi Hughes
Daughter of Daniel Sibley

Miranda Sanchez
June 5, 2016-March 20, 2020
Daughter of Martha

Olly Belle Chapman
April 22, 2018-March 26, 2020
Daughter of Lora and Nathan

Maxwell “**Maxie**” Randell
October 9, 1997-April 18, 2020
Son of Ilyce and Michael
Brother to Alex

** If your loved one's name is missing, our deepest apologies. Please send Diana the right information and dates to make those corrections.*

Welcome to the World

Matan Reuben Kamil
Born to Rebecca (Ratner) and Ricky Kamil
on April 14, 2020

Kendalyn Breeze Walters
Born to Ashley and Brian
Little sister to Brielle and Canon
on April 3, 2020

Staff
Sue Kahn, Executive Director
Becky Benson, Conference Coordinator
Susan Keliher, Director of Development
Ingrid Miller, Development & Admin Associate
Diana Pangonis, Director, Family Services

NTSAD
2001 Beacon Street
Suite 204
Boston, MA 02135
info@ntsad.org
www.**NTSAD**.org