NTSAD Lifeline

Community and Connection for Families and Individuals

February 2021

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Spring is in the Air

As we look toward spring, we're always here to support you on your rare disease journey.

Your NTSAD Family Services Team certainly understands the challenges you face each day. Missing the typical family gatherings and connection with friends due to COVID-19 can be an added hardship on top of our already stressful lives.

Please reach out to us if you need extra support and be sure to check in on our **Family Support Group page** to connect with other families like yours. In addition, the **CDC offers vital patient education on the COVID-19 vaccine here**.

Register Now for the 43rd Annual Family Conference *"Heart to Heart, Home to Home"*

You're invited to register for NTSAD's 43rd Virtual Family Conference where you can attend from the convenience of your own home! There is no fee to attend, but registration is required. Families living in the U.S. who **register** by March 26 will receive a conference gift box with t-shirts and activities for the whole family.

The registration deadline for families is March 26, 2021.

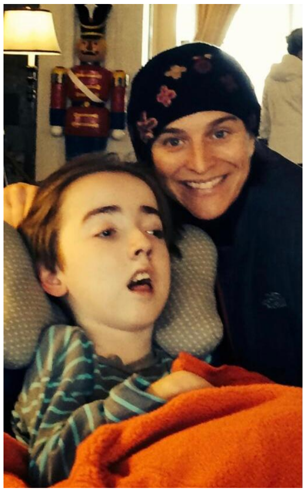
All sessions are held in English via *Zoom Webinar or Meeting, in **Eastern Daylight Time**, and links to each session will be automatically uploaded prior to the conference and housed on both the NTSAD website and on the Crowd Compass app. In planning your attendance, please make note of which sessions are open to parents, grandparents and extended family, siblings, late onset, or all attendees.

***Zoom session links also will be sent via email at time of conference.**

It's a global affair! Join in by connecting as an attendee, posting pictures, and chatting with other rare families and individuals. No matter where we are in the world, we come together: ***Heart to Heart, Home to Home!***

Register Here!

Four Easy Ways to Participate in Rare Disease Day



Rare Disease Day is February 28th

1. Visit the Rare Disease Day website, www.rarediseaseday.org, to learn about all of the events happening worldwide to raise awareness about rare diseases and their impact on people's lives.

2. Add Rare Disease Day picture frames and badges to your social media pictures by visiting **here.**

3. Share the **Official Rare Disease Day 2021 Video** with family and friends.

4. Share your own story with rare disease and submit a photo or video **here!**

Abby Rogers became involved with NTSAD when her son, Benjamin, was diagnosed with Canavan disease. Benjamin, known for his ever-present smile and hopeful heart, passed away in 2014 at 12 years of age. As a parent advocate for Ben, Abby leverages her experience and skills professionally providing advocacy on public health issues for non-profit organizations in the New Hampshire legislature. Abby, her husband Bob, and their two sons Sam and Oliver, live in New Hampshire. NTSAD is delighted to have Abby serve as an ongoing "Lifeline" contributor on advocacy.

Update for the GM2 Community:

Thanks to this community we are 88% of the way towards our research recruitment goal, in partnership with AllStripes!

This is a testament to how much we can achieve when we come together. Once 2 more patients or caregivers sign on, AllStripes can get started collecting your records, and analyzing the de-identified data for insights that can power advancements in GM2 research.

Help make research for GM2 possible. Together, we can power faster, better drug development for GM2.

AllStripes

Register Today

***For the GM1 Community** - if you haven't registered yet or completed your enrollment, click **here** to join the GM1 efforts.*

Congratulations to CPN's Blyth Taylor Lord

Today, the **American Academy of Hospice and Palliative Medicine** recognized **Courageous Parents Network's** founder, NTSAD mom, and Immediate Past President of the NTSAD Board of Directors, **Blyth Lord** with a Presidential Citation Award, specifically for Courageous Parents Network (CPN).

“CPN's efforts to provide parents and families with the information, skills, tools, and the virtual support they need during this difficult time is incredibly inspiring to the pediatric community within hospice and palliative medicine.”

Courageous Parents Network responded, *"This is really a tribute to all the families and providers who have shared their experiences and expertise with the Network. We commend the Academy for foregrounding PEDIATRIC palliative care."*

Read Our New Family Service Newsletters

The NTSAD Family Services Team is pleased to announce the launch of a new program providing ongoing support for families for one year following either the diagnosis or passing of a loved one. Families receive newsletters full of supportive information to help them along their journey at specific, monthly intervals.

These newsletters feature original pieces written by fellow parents, links to articles and online resources, and strategies and tools focused on managing care and healing from loss.

View the first installment of each newsletter below:
Newly Diagnosed
Newly Bereaved

Sowing Seeds of Support

As part of the rare community, you're invited to contribute to a new ongoing peer support effort. The purpose of the initiative is to create a safe place to share words of support with other families. Whether you're a veteran or even a newly diagnosed family or individual, the perspective that comes from a life-altering diagnosis is something that often only someone who has walked a similar path can understand. Here we offer a place to share that wisdom.

If you'd like to sow your seeds of support by sharing anonymously, visit our Google form here.

Modern Loss Hosts A Sibling Gift Swap

Here's an opportunity to connect with other bereaved siblings through the annual gift swap from our friends at **Modern Loss**.

"We are well known for the crazy experiment known as our communal gift swaps. We do them for Mother's Day, Father's Day and the winter holidays. Last year, we introduced our first-ever Modern Loss Siblings Day gift swap, which took place April 10, on Siblings Day (yeah, it's actually a thing, and no, we didn't realize it until then, either).

Why? Because over the years, we have heard from so many of you whose siblings have died. You've told us you feel marginalized; as though sibling loss weren't as important or talked about or respected as other types of relationships. You frequently feel alone in your grief and want more ways to connect with other people moving through a similar loss. And that bites. Especially in the throes of a global pandemic.

So we decided to make an event just for you. Take this day that might serve as a trigger and turn it into one where you can give and get something special from someone else who feels the same way. We've played matchmaker for nearly 1500 people over the years. Join the crowd.

Early registration is now open to our subscribers. We close the form at 250 participants, so if you're interested, get on it! **Sign up here through March 3."**

Say Their Names

Novalee Grace Zollar
March 22, 2019 - February 1, 2021
Daughter of Mindi and Kyle Zollar

Atticus Avery Gamble
May 19, 2019 - February 14, 2021
Son of Samantha and Roman Gamble

Liam Starlin Morel
February 11, 2018 - February 18, 2021
Son of Zuleyma Barbosa and Farlin Morel

**If your loved one's name is missing please accept our deepest apologies and sincere condolences, and please email Diana@ntsad.org your loved one's information and dates to be included in the next issue.*

NTSAD leads the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1, and Sandhoff diseases by driving research, forging collaboration, and fostering community. Supporting families is the center of everything we do.

Donate

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