NTSAD Lifeline

Community and Connection for Families and Individuals

January 2021

In this Issue

A Message of Hope and Peace for 2021

As we turn the calendar to 2021, we are here to meet and support you on your rare disease journey. Throughout the coming year and beyond--we promise to walk along side of you. We hope 2021 is filled with clinical advancements in treatments, increased connection, greater support, and a brighter tomorrow for each and every rare family.

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.

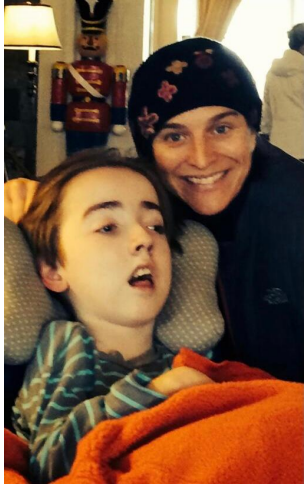
Please reach out to us if you need extra support and be sure to check in on our **Family Support Group page** to connect with other families like yours. In addition, the CDC offers some proactive ways to cope **here**.

43rd Annual Family Conference "Heart to Heart, Home to Home"

Building on the success of last year's virtual Family Conference, we are developing an online program that's bigger, better, and even more interactive for all attendees including new sessions focused on addressing current and upcoming clinical trials, family planning and carrier screening, and advocacy. **Please save the dates of April 22 - 25, 2021 for our second, virtual Family Conference.** We look forward to sharing the schedule of events and opening registration by mid-February.

In addition, if it is safe and permitable to gather, we hope to host mini-meetups across the country for our families and affected individuals ideally early this fall as vaccinations become more available and accessible.

The Importance of Advocacy in the Rare Disease Community by Abigail Rogers



Advocacy on issues affecting children and adults with rare diseases and complex medical needs is important as health care, community inclusion, education, and basic human rights. By advocating on issues at the local, state, and federal level, you can help shape policy and discuss ideas that can make lasting, beneficial change.

By increasing awareness, telling your story, and educating decision makers on what is important for you or your child is essential to increase access and coverage for essential medical therapies and to advance medical research. Often families living with rare diseases have to do a lot of educating – including family, friends, and other individuals. Your experience of educating others can be readily transferred to advocacy on issues affecting the rare disease community with lawmakers, with other patient advocacy groups, and in your own community.

In order to make changes and provide the most support possible for people with rare diseases, it is important to get your message out there and to be heard, This can be done through all forms of communication– through emails, phone calls, letters, in-person meetings, and by using social media platforms such as Twitter, Facebook, or Instagram. Maybe you already have. Perhaps you have joined a social media campaign, contacted members of Congress to support or to oppose a piece of legislation that would affect your family, or given an interview to a local news outlet or newspaper. These are just some examples of advocacy.

Every person whose life is affected by a rare disease advocates every day for themselves or their child during physician visits, while working with your child's early intervention team and with other professionals who are part of your child's world. If you would like to learn more about advocacy and how you can help, please visit the links below.

For more information:
Rare Disease Day at the NIH
Rare on the Road, with Global genes

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 the age of 12. 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 lives in New Hampshire with her husband Bob and two sons, Sam and Oliver. NTSAD is delighted to have Abby contributing to "Lifeline" in an ongoing column on advocacy.

RARE ACROSS AMERICA
EVERY VOICE, IN EVERY DISTRICT, MATTERS

Join Rare Across America

February 22 - March 5, 2021 Rare Advocacy
(Virtual Congressional meetings on March 3rd and 4th)

- Make an impact on federal policy.
- Share your rare disease story.
- Meet other rare disease advocates.

Rare Disease Legislative Advocates (RDLA) organizes virtual advocacy events and virtual meetings for rare disease advocates (like you) with your local Senators and members of Congress and/or their staff. The RDLA team also helps to prepare advocates for legislative meetings, provides resource materials, and hosts advocacy training webinars. Advocacy meetings with legislators are held virtually on March 3rd and 4th.

Learn more about Rare Across America, and register, **here**.

Rare Disease Day is Coming! February 28, 2021

There are many ways to get involved, share your story, and be a rare disease hero including wearing that you

care!

In advance of Rare Disease Day, get your special **NTSAD Rare Disease Day t-shirts**! Whether you're a rare mama bear, rare papa bear, grand, bro, sis, the rare bear yourself, or a rare support bear, we have a special t-shirt for every member of the family in multiple colors and sizes from which to choose!

Learn more about **Rare Disease Day**, **here**, and visit the Bonfire store to purchase your family's rare bear shirts **here**. A portion of proceeds support NTSAD.

New Resource for Newly Diagnosed and Newly Bereaved Families

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 will 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

Siblings With A Mission

"Siblings with a Mission strives to provide support to siblings of individuals with special needs and developmental delays. We aim to provide platforms that serve both siblings and sibling supporters of all ages and all backgrounds. Through our platforms and services, we encourage siblings and families to:

- *Share their story with others*
- *Express any concerns and challenges as well as any insights and joy*
- *Empower others to use their unique experiences to raise awareness and make a difference*
- *Have fun and make the best of every moment*

In addition to offering support, Siblings with a Mission will connect siblings and families to resources located near them.

Siblings with a Mission strives to inspire siblings of all ages and backgrounds to spread awareness of their brother or sister's differences and teach the world that people can have fun and enjoy life regardless of their health challenges or developmental delays."

Learn more about Siblings With A Mission, **here**.

A Congratulations to the Happy Couple!

Sending our best wishes to NTSAD sibling Cailee Watkins on her recent

engagement to Reece Countryman!

Sharing Our Grief - You Are Not Alone

"Grief is the last act of love we can give. Where there is grief there was great love." - Unknown

We know the beginning of a new calendar year can be daunting for those who are grieving the loss of a loved one. You are not alone. Recently, we reached out to bereaved members of our community to express and share their thoughts and feelings on the loss and grief they're experiencing. Below are some of the responses we received.

My grief feels like _____.
"An unexpected explosion. It sneaks up out of the blue sometimes."
"Everlasting pressure on my heart."

I wish my friends and family knew _____.
"That even though I always smile and seem fine it's bubbling just under the surface like a duck frantically paddling its feet under the water while remaining calm above."
"We can have normal conversations."

I wish someone would _____.
"Not try and make it better or 'fix' things but just sit with me and let me be. No hugs, no 'I understand how you feel', no 'I'm sorry'."
"Take the pain away."

If you'd like to view more responses or share anoymously, visit our Google form **here**.

Say Their Names

Shoshanna Drinks
December 21, 2018 - January 8, 2021
Daughter of Renny and Eric Drinks

Havi Goldstein
September 4, 2018 - January 20, 2021
Daughter of Matthew Goldstein and Myra Sack

Mark Hyman
June 28, 1948 - January 4, 2021

**If your loved one's name is missing please accept our deepest apologies, 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

STAFF
Sue Kahn, Executive Director
Becky Benson, Family Services and Conference Coordinator
Sydnie Dimond, Development and Communications Associate
Susan Keliher, Director of Development and Communications
Diana Pangonis, Director of Family Services

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