



NTSAD Community News

Research, Collaboration, and Community



*Supporting families
is the center of
everything we do...*

February

February 2023

In this Issue

Rare Disease Day

Austin Meet Up

Annual Family Conference

NTSAD's New Website

Annual Report 2022

We Care for Rare Every Day

All month long, the NTSAD Community is spreading awareness about what it means to be Rare in advance of **Rare Disease Day on February 28**. Here's an example from two Rare parents:

*"For most individuals, they never experience Rare, and the concept is foreign to them. The sleepless nights, weeks-long stays in the pediatric intensive care unit (PICU), and the cancelling of plans in an instant – are just cutting the surface. Beyond all of that, **families like ours learn that being Rare just means you love and support differently.**"*

As we care for our son, simple things like watching him opening his eyes bring us so much joy. A giggle or a "coo" can change our mood. Caring for this little one is cherishing life down to the seconds. Taking everything day by day. Through the highs and the lows, never missing a beat."

-Kaitlyn and Zach, Mom and Dad of Phillip

RARE IS REAL

What do you want
the world to know
about Rare?



Show Your Care for Rare and Be an Advocate on Rare Disease Day!

Here are several ways you can participate:

- Attend the National Institute of Health's Rare Disease Day virtual event. Register [here](#) or find a local event happening near you [here](#).
- **Add NTSAD's "Rare is Real" frame to your profile picture on your social media.**
- Wear that you care! **Purchase a "Rare is Real" sweatshirt, mug, hat, or decal.** A portion of the proceeds goes towards NTSAD's Research Initiative.
- Raise funds in honor or in memory of a Rare loved one through [Facebook fundraiser](#) or [make a personal gift](#).
- Help elevate Rare voices by liking and sharing NTSAD's "Rare is Real" posts, infographics, and more on [Facebook](#), [LinkedIn](#), [Twitter](#), and [Instagram](#).
- Not on social media? Share Rare parents Kaitlyn and Zach's "Rare is Real" quote and photo (see above) via email or in-person.
- Find your representative and let them know #RareIsReal! You can share your story with them [here](#).



Rare Families Meet Up in Austin

NTSAD Family Services Team of Diana Jussila and Becky Benson recently broadened programming for affected individuals and families through the creation of regional Meet Ups which bring a weekend of community, connection, and support to all attendees. Earlier this month, eight Rare Families gathered in Austin, Texas for the second NTSAD Meet Up. In addition to parents, grandparents, uncles, and even godmothers were in attendance.

Meet Ups allow families coping with a diagnosis, caregiving, loss, and grief, to gather and find support in between Annual Family Conferences, particularly for families who may have difficulty traveling far from home. Last September, the first Meet Up in Irvine, California welcomed 22 individuals from 10 families.

No one chooses to belong to this group, but every single person there expressed their gratitude for each other, and not having to walk this path alone. Thank you to everyone who traveled to Austin and Irvine for these special and memorable events.

NTSAD will announce a fall Meet Up location later this year. If you want to sponsor or support Family programs and Meet Ups, contact Susan Keliher, Director of Development and Communications at skeliher@ntsad.org. Have a location suggestion for a future Meet Up? Contact Becky Benson, Family Services Manager, at becky@ntsad.org.



September 2022 Meet Up in Irvine, California.



February 2023 Meet Up in Austin, Texas.

Annual Family Conference 2023

The 45th Annual Family Conference is June 1 to 4, 2023, in Reston, Virginia. The Conference is open to the entire NTSAD Community, including families who are currently caregiving or bereaved, affected individuals and their loved ones, researchers, clinicians, and industry members. The Conference includes both support and informational sessions, and a whole day focused on research updates.

At the last Annual Family Conference, Rare mom Yasmina shared how the Conference had positively impacted her family and her daughter Lily.



“You'll come out of [the Conference] feeling more empowered and energized to keep on keeping on. We got new wheels coming here today from another family. I would've had to wait another three years to get her a chair and another family was like, 'I've got one she can have' and here we are. So, she's even more comfortable.

We're all leaning on each other. We're all supporting each other, and there's no wrong emotion to have when you're here. You can be angry; you can be sad. You can be happy; you can be numb. And we're all going to tell you that's normal. You're not going to feel out of place.

Seeing Lily making friends and bonding with Maddie...It's a bond that we're going to carry with us forever. And it's something that can't be replaced.”



Lily (left) and Maddie (right) play together in Camp Active.

Join us in Reston! [Register now for the conference.](#)

NTSAD offers financial assistance for families who need it. [Apply now for a Helping Hand Grant.](#)

Sponsors make these four days of connection, support, and community possible. [Learn more about this year's sponsorship levels.](#)

NTSAD's New Website

At NTSAD, supporting families is the center of everything we do, and families are the focus of our [brand new website](#). Take a moment and see photos of beautiful, rare families, read their stories, and more. Our new website also features care tips and videos, disease information, the latest in research, and news and events.

We at NTSAD cannot thank or recommend highly enough our web developer and designer Michael Foley, founder of e-Learnza. Michael brings more than 25 years of experience and the true spirit of collaboration – not to mention generosity. As Michael has done before for other non-profit organizations, he will donate his design fee to NTSAD, should you or your company wish to work with him on a new website and support NTSAD families at the same time. Michael will design you a new website including 15 new pages, and provide one year of maintenance, year of hosting, and transfer of past website content, if necessary. Michael has worked with a vast array of companies, including healthcare and other patient advocacy organizations.

[Learn more about Michael Foley and eLearnza.](#)

If you would like to share your feedback on our new website or are interested in connecting with eLearnza, please contact Susan Keliher, Director of Development and Communications, at skeliher@ntsad.org.

NTSAD 2022 Impact Report: Moving Forward Together

You and your generosity make it possible for NTSAD to provide services and programming to for individuals and families and fund critical research for Tay-Sachs, Canavan, GM1, and Sandhoff diseases. Since 1957, donors like you help NTSAD support rare families and our important mission.

[Read the 2022 report and learn about the impact of your gift.](#)

Thank you to NTSAD Board Member Jonathan Katz, and the entire team at ACOM Healthcare for their help creating this annual report.

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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