



# NTSAD Community News

Research, Collaboration, and Community



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

September

September 2023

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## Spreading Awareness and Hope

September is an important month for our community. NTSAD was founded 66 years ago, and September also marks Tay-Sachs, Leukodystrophy, and Newborn Screening Awareness months. We sincerely thank everyone for sharing their stories and educating others about rare, neurodegenerative disorders that affect the lives of people you love.

On September 9, the NTSAD community came together for Day of Hope. Yet, in our close-knit community, every day is a Day of Hope – filled with connection and collaboration as we raise awareness and funds for research.

Since the first Day of Hope was held in September 2011, NTSAD families, friends, and rare allies have raised more than \$710,000 for research.

Because of you, NTSAD can fund more research through our Research Initiative. Please help us spread the news about our next round of funding as we launch our 2024 request for proposals; details are below.

Thanks again to all those who supported NTSAD's efforts this month as together we unite to support families, accelerate research, and advocate for our loved ones with Tay-Sachs, GM1, Canavan, and Sandhoff diseases.

Sincerely,

Kathleen Flynn, CEO

## NTSAD Launches Next Round of Research Funding: Seeking Proposals

**NTSAD has begun the next round of research funding via the Research Initiative Program, inviting proposals from academics and researchers.**

NTSAD's Research Initiative Program is soliciting proposals for innovative research projects studying the following diseases: Tay-Sachs, Canavan, GM1, and Sandhoff. We are interested in all aspects of therapeutic discovery. Basic research and translational studies are strongly encouraged

to generate strong preliminary data to enable major funding by other third parties in the future.

Grants of up to \$50,000 will be awarded over one or two years.

In addition to funds from NTSAD, [Blu Genes Foundation \(BGF\)](#), [Canavan Foundation](#), and [Cure Tay-Sachs Foundation \(CTSF\)](#) are partnering with NTSAD in this funding round and may support selected projects that align with the foundations' missions and grant-making priorities.\*

Since its inception in 2002, NTSAD's Research Initiative has awarded more than 69 grants and provided more than \$4.1 million in funding. The data generated in some of these projects funded by NTSAD grant opportunities were leveraged to obtain later funding from larger National Institutes of Health (NIH) grants, resulting in more than \$10 million to further these research efforts.

For more information, interested applicants should review the current [Request for Proposal \(RFP\)](#), which outlines 2024 funding priorities and the application process.

**Pre-applications must be submitted as a PDF document to NTSAD Research Director Valerie Greger, PhD, at [vgreger@ntsad.org](mailto:vgreger@ntsad.org) by 5 p.m. EST December 1, 2023. Please direct any questions to Valerie.**

*\*Please note CTSF and Blu Genes' funding priorities are limited to research relating to Tay-Sachs and Sandhoff diseases and gene therapy research for rare disease, with a priority for Tay-Sachs, respectively. The Canavan Foundation priorities are limited to research relating to Canavan disease.*

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## Hope Continues

**Through the Day of Hope, we showed the world that while we are rare, together we are mighty.**



The Cornett/Watson Family hosted their silent auction in Texas, known as the **12th Annual Jace Benefit!**



The NTSAD Community sported their Miles for Hope laces all over the USA as they Moved for Hope on Sept. 9th!



The Jackson Family held their annual two-day event in North Carolina, **Jessie's Rally of Hope!** The event included a ride, concerts, an auction, and more.



In Canada, the Gropp Family hosted **Brodryck's Bean Bag Tournament**, with a Christmas in August theme this year.

Rare families raised more than \$18,000 via Facebook fundraisers and through customized t-shirt campaigns.



In Connecticut, the Negrón Family gathered friends and family for a **Day of Hope celebration** in honor of Chloe, which included a sing-a-long of Chloe's favorite songs.



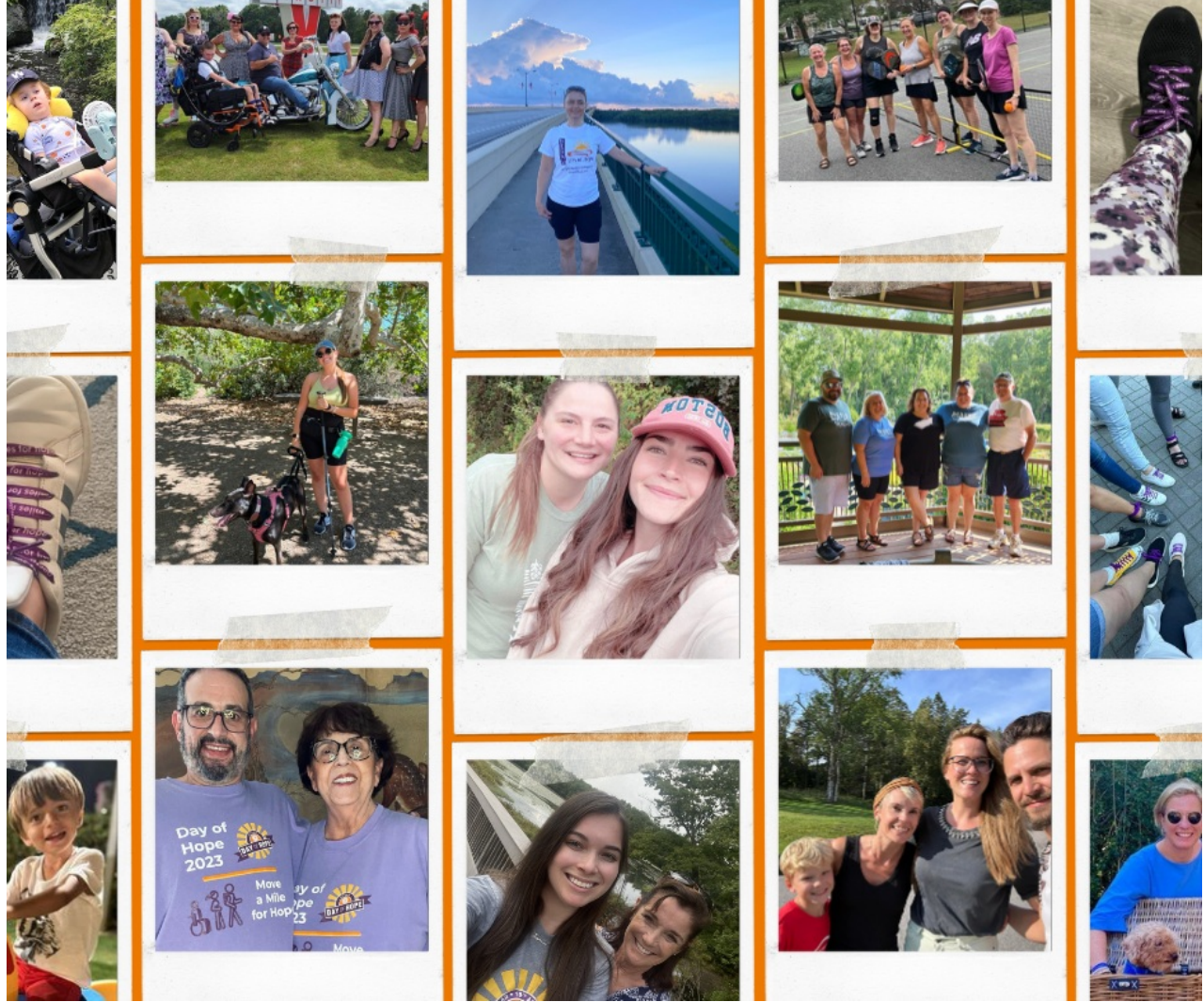
Members of the Azafaros team showed that they care for rare by Moving for Hope across Europe!



NTSAD hosted a family meetup in Bellevue, Washington, and families moved a Mile for Hope together in honor of their loved ones.



The Stidham Family hosted their annual event, Eli's Cruise for a Cure in Georgia!



Thank you to all those who have participated so far. There are several families and individuals still planning Day of Hope events, and we continue to raise rare awareness! Your support makes a real difference. [Give today!](#)

[Make a Donation to the Day of Hope](#)

## ***Imagine & Believe 2023 – November 9***

Join us on Thursday, November 9, at the Royal Sonesta Boston for NTSAD's signature fundraising event, [Imagine & Believe](#). Your support helps families by raising money for programs, research, and advocacy.



At the event, a rare family will share their inspiring story. We also will honor Jayne Gershkowitz, Chief Patient Advocate at Amicus Therapeutics and former NTSAD Executive Director, for her trailblazing leadership in patient advocacy and championing children, adults, and families living with rare diseases.

It's not too late to sponsor the event. [Learn more.](#)

[Tickets are \\$200. RSVP by October 13.](#)

[Purchase a tribute ad for our digital program.](#)

[Donations welcome.](#)

Thank you to our 2023 *Imagine & Believe* Sponsors!

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Questions? Contact Development and Communications Manager Sydnie Dimond at [sdimond@ntsad.org](mailto:sdimond@ntsad.org) or at 617-277-4463.

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## Ask Me about Vayle

*“When your time with your child is limited, you really have to value the time you have,” Dawn shares about her daughter, Vayle Rose, who has Canavan disease, “I just want to be together, to be happy.”*

When Vayle Rose was first diagnosed with Canavan disease, Dawn thought about if, and how, she wanted to share the news. She reflected on the diagnosis she'd received from the healthcare team, which was bleak.

***“They focused on all the things Vayle won't be able to do, but failed to convey how beautiful her life would be, and the joy she would experience,”*** says Dawn.

Today, Dawn and her family mark every milestone, and celebrate birthdays and half-birthdays with Vayle.

*“My story isn't what people expect when they ask,”* says Dawn. *“But I want to talk about my child, too. Please ask me about her, just like you would anyone else.”*

Earlier this month, Vayle turned five years old. Read her full story -- [\*\*“Living with Canavan Disease: Sharing the Little Moments that Mean So Much.”\*\*](#)



[You can also support the Vayle Rose Fund by making a gift today.](#)

## NTSAD Thanks Research Associate, Caroline Aragón, MS, CGC

NTSAD is grateful for the seven months of service provided by Research Associate, Caroline Aragón, MS, CGC.

*“While Caroline was with NTSAD, she created valuable resources including the virtual biorepository and the mutation data base, initiated an internship program guiding an intern and a volunteer through projects – all while supporting the Research Initiative in numerous ways. And she is a fabulous colleague! We will miss her.”* -NTSAD Research Director, Valerie Greger, PhD



We wish Caroline the best as she cares for her family and wherever her career takes her next!

## Honoring Loved Ones and Spreading Awareness

As part of Tay-Sachs Awareness Month, NTSAD Board member Bonnie Davis, former Board President Kevin Romer, and Molly Meyers, along with Mom to Miss Elliott and NTSAD Family Services Manager, Becky Benson, shared their rare experience to help other families in a recent interview in the *Hollywood Times*.

[Read the article.](#)

**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

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