NTSAD Community News

Research, Collaboration, and Community

Supporting families is the center of everything we do…

November

November 2022

In this Issue

Dear Friends,

At NTSAD, we know the holidays can be a challenging time for the families and individuals in our rare community. We simply want to say we see you. We hope knowing the NTSAD family is there for you brings a bit of comfort this season.

Wishing you and your family a peaceful Thanksgiving,

Imagine & Believe 2022 – Our 65th Anniversary

On November 10th, the NTSAD Community gathered in-person for *Imagine & Believe.* Thanks to all our attendees, sponsors, and donors for your support of NTSAD and *Imagine & Believe* 2022. Together, we raised $115,000 this year! Your generosity supports family services and programming, and research for Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

At *Imagine & Believe,* we commemorated NTSAD's 65th Anniversary and how far we have come as a Community in supporting families and advancing research.

Watch our 65th Anniversary video here.

It's not too late to support families and research and make a gift to *Imagine & Believe.*

At the event and on behalf of patients and families, we recognized research pioneer Guangping Gao, PhD, not only for his astounding life's work in identifying the Canavan gene, revitalizing gene therapy, and his many accomplishments leading to potential treatments for Canavan disease and other

rare diseases, but for his true and sincere dedication and connection to families.

Watch NTSAD families pay tribute to Dr. Gao.

Make a gift in honor of Dr. Gao and to support families.

DONATE

Save the Date for Imagine & Believe 2023 on November 9 at the Royal Sonesta Boston.

NTSAD Launches Next Round of Research Funding: Seeking Proposals

Pre-application (Letter of Intent) Deadline: January 8, 2023

NTSAD, along with partners Cure Tay-Sachs Foundation (CTSF) and Blu Genes Foundation, is soliciting grant proposals that align with their missions and grant-making priorities. *

Grants will be awarded to novel research projects that involve translational studies or clinical studies that focus on Tay-Sachs, Canavan, GM1, and Sandhoff diseases and generate strong preliminary data that will attract significant funding from other sources.

NTSAD's 2023 Research Initiative Program awards one-year grants of up to $70,000 or two-year grants of up to $140,000 for two years, inclusive of indirect costs not to exceed 5%. Funding for the second year of a two-year grant is contingent upon adequate progress made in the first year.

Requests for funding from NTSAD's Research Initiative Program will adhere to a two-step application process: a one-page pre-application letter of intent, followed by a full application.

The deadline to submit a one-page pre-application (letter of intent) is January 8, 2023. After review of the pre-applications by members of NTSAD's Scientific Advisory Council and Research Committee, a select group of applicants will be invited to submit a full proposal for further peer review and funding consideration.

Since 2002, NTSAD's Research Initiative has awarded more than $4 million in seed grants that have been leveraged to more than $30 million of additional investments leading to potential new therapies for Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

Learn more about the Request for Proposal.

Any questions related to the Research Initiative Program and application process may be directed to Valerie Greger, Ph.D., NTSAD's Research Director. **Email Valerie.**

** Please note CTSF and Blu Genes' funding priorities are limited to research relating to Tay-Sachs disease.*

NTSAD to Hire Research Associate

NTSAD is seeking a part-time Research Associate to play an important role in coordinating NTSAD's Research Initiative and to aid Research Director, Valerie Greger, Ph.D. The ideal candidate will support scientific work groups and manage an international network of researchers, clinicians, and industry partners.

Learn more about responsibilities, qualifications, and how to apply.

NTSAD Launching New Website

As one of the oldest patient advocacy organizations in the country, NTSAD is a trusted expert with decades of expertise. And to better meet the needs of Our Community, we are redesigning our website to provide the most up-to-date information for every family, caregiver, and clinician. The new website will launch soon.

Take a sneak peek at NTSAD's new website.

Does your company need a new website? Here's an opportunity to build a new website and support NTSAD Families at the same time. Michael Foley, the incredibly talented founder of eLearnza, NTSAD's web developer is generously donating design of a new website via a special online auction, which includes new website design of 15 pages, one year of maintenance, year of hosting, and transfer of past website content, if necessary. Michael brings his 25+ years of web design expertise including partnerships with other rare disease groups. The value is $5,000. For more information or to make a bid, contact Susan Keliher, Director of Development and Communications.

Learn more about Michael Foley and eLearnza here.

Giving Tuesday: November 29, 2022

November 29 marks Giving Tuesday, a worldwide effort to inspire philanthropy. November is also Family Caregiver Month. Show you care for Rare and consider making a gift to NTSAD in honor of all the families caring for Rare loved ones or the caregiver in your life. **Donate today!**

Rare is Real – Holiday Gifts

Need a gift for your Rare loved one or maybe one for yourself? **Purchase NTSAD's Rare is Real hoodie or sweatshirt and support families, too.**

"When you hear the sound of hooves, think horses, not zebras." The phrase is taught to medical students throughout their training. In medicine, the term "zebra" is used in reference to a rare disease or condition. Doctors are taught to assume that the simplest explanation is usually correct to avoid patients being misdiagnosed with rare illnesses. Doctors learn to expect common conditions. But at NTSAD, we know Rare is Real!

Show your support, spread awareness, and stay warm throughout the winter all at the same time! A portion of each purchase goes toward NTSAD's programs and services.

You will find a wide variety of hoodies in an assortment of colors and styles for the whole family. Tell the world that Rare is Real!

Shirts ordered during this first batch will arrive by December 22nd. **Buy a sweatshirt now!**

Crewneck Sweatshirt

Tie Dye Pull Over Hoodie

Women's Lightweight Cropped Hoodie

Amazon Smile

This holiday season if you are shopping online with Amazon, consider choosing to support NTSAD (National Tay Sachs & Allied Diseases) as part of Amazon's charitable program, AmazonSmile.

It's super easy-- whenever you shop **use this link to AmazonSmile,** and Amazon will donate to NTSAD.

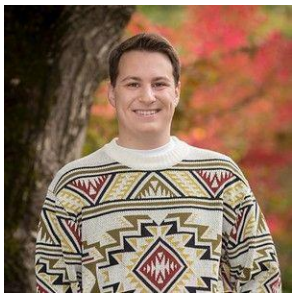
2022 Gottlieb Scholarship Recipients

During the last 17 years, Judy Gottlieb has generously awarded scholarships to 56 siblings, some of whom have received multiple awards!

Judy Gottlieb has been supporting NTSAD families via the Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarships since the funds were established in May 2005. The funds are in honor of her youngest son, Jeffrey Alan Gottlieb, who succumbed to Tay-Sachs in 1975, and her husband, Stanley N. Gottlieb, who passed away in 2001. The Scholarships provide funds for college to healthy siblings in families affected by Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

The 2022 Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarship recipients are:

Skylar Benson began her education at Columbia Basin College in 2020, and received her Associates of Applied Sciences degree in June of 2022, while also graduating from high school. She is now pursuing her bachelors at Washington State University. Skylar is majoring in biology, with intent to continue into the field of medical genetics and research. Skylar's experience with her little sister Miss Elliott has inspired her dream to be a geneticist. ***"I believe that one of the best ways I can honor my sister's life and memory is to use my career to be of service to families of children with genetic disorders, families like my own."***



Jeremy Davis is a junior at the University of California Santa Cruz studying ecology and evolutionary biology. He honors his brother Adam, who passed before Jeremy was born, by continuing to spread joy and inform others about genetic diseases. ***"My brother's memory may be made up of stories and photographs, but it is real to me. The influence he has had in my life makes his memory real, and something that I honor through my attitude towards life as well the action I take to inform my peers about Tay-Sachs and genetic diseases."***

Gavin Levine is a sophomore at Ohio State University, majoring in environmental engineering and Chinese. Although he never got to meet his older sister Lila, Gavin expresses gratitude to her for showing him how precious life is and what a miracle it is to be alive. ***"In my career as an engineer, I want to solve problems that affect people's health: water quality and scarcity, soil toxicity, and air pollution. I will honor Lila's life by allowing more people to live as healthy and lucky of a life as I live."***

Kyla Marquardt is a junior at University of Florida, majoring in chemical engineering. Her little brother William taught her about resilience, compassion, and the value of life. ***"I aim to honor William's life in college by volunteering with organizations that aid those with special needs, by planning and executing fundraising events to give back to NTSAD, and by continuing to spread awareness about GM1."***

Aaron Ronaldson is a sophomore at Liberty University studying mechanical engineering. Aaron plans to honor his sisters, Mollie and Madelyn, by using his engineering knowledge to improve the lives of special needs individuals. "***As an engineer, my job is to design and create in a way that improves the world. Why not start with using that for my sisters and others like them? I would like to design a contraption that eases the constant lifting involved in everyday life for parents of children like my sisters."***

Rebecca Wells is a freshman at Michigan State University, studying animal science on a pre-vet track. Although Rebecca never got to meet her older sister Emily, her parents honored Emily by teaching Rebecca to always show compassion and support others. ***"I will continue to share my family's story about my older sister with anyone who will listen. I have begun to educate my friends and peers in college on Tay-Sachs and the impact it has on families."***

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
Kathleen M. Flynn, CEO
Becky Benson, Family Services Manager
Sydnie Dimond, Development and Communications Manager
Valerie Greger, Director of Research
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