

# NTSAD Community News

## Research, Collaboration, and Community



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

September

September 2022

#### In this Issue

[Imagine & Believe 2022](#)

[Thank You Sponsors](#)

[Day of Hope 2022](#)

[Myra Sack Shares Lessons from Daughter Havi](#)

[Brady Manning Honors Brother Dylan with Beyond Birdies](#)

[College Scholarships for Healthy Siblings](#)

### ***Imagine & Believe– Marking Our 65<sup>th</sup> Anniversary***

Join us on Thursday, November 10, for NTSAD's *Imagine & Believe and 65th Anniversary* where we envision a world with effective treatments for Tay-Sachs, Canavan, GM1, and Sandhoff diseases. For the first time in three years, we will gather in-person for the event, returning to the Royal Sonesta Boston.

***At Imagine & Believe, we will honor research pioneer Guangping Gao, PhD, for his life's work in identifying the Canavan gene, revitalizing gene therapy, and his many accomplishments leading to potential treatments for Canavan disease and many rare diseases.***

*Imagine & Believe* includes a reception, silent auction, and speaking program, and each year the NTSAD Community supports families by raising funds for programs and services and research. Admission begins at \$200 per person, and sponsorships range from \$750 to \$25,000.

**[Learn more about Imagine & Believe sponsorship opportunities or purchases your ticket here.](#)**

**[Can't attend? Make a Donation to Support Imagine & Believe here!](#)**

We have some exciting auction items, but we are seeking more great items, such as donations of items such as wine, golf outings, signed sports memorabilia, restaurant gift certificates, stays at vacation homes, and tickets to shows and sporting events are needed and appreciated. If you would like to donate an auction item, email Development and Communications Manager Sydnie Dimond at [sdimond@ntsad.org](mailto:sdimond@ntsad.org).

Thank you to sponsors of *Imagine & Believe 2022*! To become a sponsor or learn more about *Imagine & Believe*, contact Director of Development and Communications Susan Keliher at [skeliher@ntsad.org](mailto:skeliher@ntsad.org).

#### **Believe Sponsor**

[Aspa, a BridgeBio Company](#)

#### **Hope Sponsor**

[Gerald Cox MD, PhD\\*](#)

[Passage Bio](#)

#### **Inspiration Sponsor**

#### **Determination Sponsor**

[Acom Healthcare\\*](#)

[Adelman Associates](#)

[Lori and Lee Greenwood](#)

[Blyth and Charlie Lord\\*](#)

[Myrtelle](#)

[NTSAD New York Area Fund\\*](#)

Amicus Therapeutics  
Azafaros  
CANBridge  
Robin Lynn and Lawrence Blumberg  
Mathew Forbes Romer Foundation\*

\*NTSAD Board Member

(Sponsor listing as of September 26, 2022.)

---

## Day of Hope 2022

During the 12th Annual Day of Hope, the NTSAD Community came together as one -- Walking Miles for Hope in honor of loved ones and connecting at the Day of Hope Afterparty. Thank you to everyone who Walked a Mile for Hope, joined the Afterparty, and spread Rare awareness on September 17th.

GIVE to DAY OF HOPE



**We remain grateful to all the families who held their own special Day of Hope events this summer including the Cornett/Watson Family, Gropp Family, Jackson Family, and Stidham Family** and to others who participated in Day of Hope by hosting t-shirt campaigns, asking friends to donate via online fundraisers, and share Rare information to spread awareness. **Shout out to Becky Benson, Al Croft, Sydnie Dimond, Kate Gomez, Yasmina Halim, Stephanie Hough, Susan Keliher, Myrtelle, Mandy Ronaldson, Gloria Rocha, Lorelei Sandoval, Jen Salazar, Zach and Kaitlyn Silva, and Crystal Villalobos** for their online fundraising and awareness efforts!

**Together we have raised more than \$34,000 for research for Tay-Sachs, Canavan, GM1, and Sandhoff diseases.** If you wish to host a Day of Hope event – you can do so at any time, and we are glad to assist. Please contact Sydnie at [sdimond@ntsad.org](mailto:sdimond@ntsad.org) to get started.

**You can be a part of Day of Hope and give now.**



Becky Benson and her family on a Hike for Hope in honor of Becky and Loren's daughter Miss Elliott.



NTSAD CEO Kathy Flynn, NTSAD Scientific Advisory Council member Cynthia Tifft, MD Ph.D., Merlie and Jessie Jackson at Jessie's Rally for Hope.



Stephanie Hough with her son Aidan, sporting a Team Felix t-shirt created by Kate Gomez in honor of her son.

The Season of Hope continues with more Day of Hope events in October!

**[The Karp Family is hosting Jaxson's Train of Hope Annual Poker Run on October 8 in San Diego, California.](#)**

**Kyla Marquardt**, President of The University of Florida Kickboxing Club, and its members are hosting a UFC Fight Night Watch Party and Raffle, in honor of Kyla's **brother William, who had GM1 gangliosidosis.**

It's not too late to participate in Day of Hope! Host an event, create a t-shirt campaign, or launch an online giving campaign via your own personalized fundraising page. We can help!

**[Learn how YOU can participate in a Day of Hope.](#)**

---

## Rare Mom Myra Sack Shares Havi's Story

In honor of her daughter Havi and Tay-Sachs Awareness Month, Myra Sack reflects on loss, strength, and the importance of genetic screening in a recent interview.

After Havi's Tay-Sachs diagnosis and her passing in January 2021, Myra shares her newfound perspective.

***"We laugh a lot. And I think that's something that Havi taught us: What seems to be a big stressor is actually, maybe trivial. Find moments to laugh and experience joy more often."***

**[Read the article.](#)**

---



## Brady Manning Honors Brother Dylan with Beyond Birdies Fundraiser

Brady Manning has taken on a special project for his senior year golf season—raising awareness and funds

in memory of his brother, Dylan, who had Tay-Sachs disease. This season, Brady will be golfing with a purpose—his personal fundraiser “Beyond Birdies” fueling his swing. Brady intends the proceeds from Beyond Birdies to go toward healthy sibling programming at NTSAD’s Annual Family Conference, as it has made a significant impact on his life. Brady also plans on volunteering as a counselor at **NTSAD's 45th Annual Family Conference to be held June 1-4, 2023 in Reston, Virginia.**

If you'd like to support Brady, you can make a one-time donation or pledge an amount to donate for every birdie this season. Brady is aiming to shoot at least one birdie (1 under par) every round this season, and hopes for more!

### Support Brady and Give to Beyond Birdies for Dylan



[www.bradymanning.com](http://www.bradymanning.com)

11/22/01-08/02/06  
Dylan James Manning

## BEYOND BIRDIES

BRADY DYLAN MANNING GOLFS FOR A PURPOSE...  
A SENIOR TRIBUTE PROJECT TO REMEMBER HIS BROTHER DYLAN.

**HOW IT WORKS...** Donate a LUMP SUM at **ANY TIME** –OR- PLEDGE a DONATION in any denomination  
For each **BIRDIE** Brady shoots during the 2022 golf season to be collected in October '22.  
Online donations <http://weblink.donorperfect.com/BEYONDBIRDIES> or visit [www.ntsad.org](http://www.ntsad.org)  
**VENUE** Brady-Manning-10. All TAX DEDUCTIBLE donations benefit NTSAD youth programs.  
E-mail [bradymanning12@icloud.com](mailto:bradymanning12@icloud.com) for more details on how your donation helps to fight Tay-Sachs Disease.

If you would like to raise awareness for our rare diseases by hosting a fundraiser in honor or memory of a loved one, contact Sydnie at [sdiamond@ntsad.org](mailto:sdiamond@ntsad.org) for assistance.

---

## College Scholarships Available for Healthy Siblings

Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarship Funds provide financial support for college to healthy siblings of children and adults affected by Tay-Sachs, Canavan, GM1, Sandhoff or an allied disease. In May 2005, Judy Gottlieb established two separate memorial college funds at NTSAD to honor her youngest son, Jeffrey, who succumbed to Tay-Sachs in 1975, and her husband, Stanley, who passed away in 2001.

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

Siblings who are entering college or are currently in college may apply for financial support for college education, tuition, books, or room and board. *If you are a healthy sibling who previously received a Gottlieb scholarship, and you are still in college, you may apply again!*

[Apply here. The deadline is October 14, 2022.](#)

**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

**Sydney** 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](mailto:info@ntsad.org)

[www.NTSAD.org](http://www.NTSAD.org)