



# NTSAD Community News

## Research, Collaboration, and Community



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

# December

December 2022

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Dear NTSAD Community,

During this season of giving, I reflect on the generosity of the NTSAD Community, particularly families, who give to one another. For the first time in three years, families were able to provide comfort and in-person support at the conference, a family "meet-up" in California, and Imagine & Believe. *This is only possible because of you and your support!*

As we look toward 2023, we are focused on planning the conference and programs for families, launching a new website, and as always driving research leading to potential treatments. We know there are challenges ahead, including a tough economic climate affecting many of our industry partners.

**Today you can support families, help advance research, and sustain NTSAD's ability to respond to challenges.**

**[Give today.](#)**

Please know how deeply we appreciate YOU and your support of families and NTSAD.

[Donate Now](#)

Wishing you and your family a peaceful holiday season,

A handwritten signature in purple ink that reads "Kathy".

## Support NTSAD through Your Holiday Shopping

**Looking for the perfect gift? Participate in NTSAD's Holiday Auction!** We have some incredible items— island vacations, fitness and wellness coaching, museum tour and dinner, and tickets to the NFL Football Hall of Fame. If you win an item, you not only have a great gift for someone, but you support NTSAD families at the same time!

**To bid on any of these auction items email Sydnie at [sdimond@ntsad.org](mailto:sdimond@ntsad.org). Deadline to submit a bid is Monday, December 19 at 5 PM ET.**

### Auction Items

#### **Elite Island Resorts Packages** *Donated by Elite Island Resorts*

Need an escape to a warm island? Purchase one of seven Elite Island Resort packages from the NTSAD auction and receive an incredible discount on your stay for up to three rooms depending on the resort!

Locations include Galley Bay Resort & Spa Antigua (seven nights, \$3,500 value), Hammock Cove Antigua (seven nights, \$3,800 value), Pineapple Beach Club Antigua (seven to nine nights, \$2,100 value), St. James Club Antigua (seven to nine nights, \$3,600 value), the Verandah Resort & Spa Antigua (seven to nine nights, \$2,700 value), The Club Barbados Resort & Spa (seven to ten nights, \$2,400 value), Los Establos Boutique Inn Panama (seven nights, \$3,750 value). It's simple, pick a location, and the cost of your trip goes to NTSAD. Daily fees per person and blackout dates apply.



Restrictions: Additional costs per day per person. Additional fees for reservations made during the busy season at some resorts. Airfare not included.

Fair Market Value and Purchase Price/Donation Range: \$2,100-\$3,800/trip

Want to know more about the packages we have available? Email NTSAD Development and Communications Manager Sydnie Dimond at [sdimond@ntsad.org](mailto:sdimond@ntsad.org) to learn more.

#### **Five Sessions with Personal Trainer and Fitness Coach** *Donated by David Piken*

Get stronger, move, and feel better in 2023 with a personal trainer. This is the perfect introduction to personal training that will focus on helping you do more of the things you love to do. This package includes five, one-hour-long sessions with Boston-area fitness trainer David Piken and includes a movement screening. Kickstart 2023 with more energy and feeling good. Questions, email [Susan Keliher](mailto:Susan.Keliher@ntsad.org), NTSAD Director of Development and Communications and fitness client!

Fair Market Value: \$625 (\$125 per session)

Starting Bid: \$400 (Subsequent bids in minimum increments of \$25 i.e., \$425.)

#### **Health and Wellness Coaching** *Donated by David Piken*

Want to make a change in your life from the comfort of your own home? Maybe you've been thinking about becoming more active, getting more sleep, or making nutritional changes? A health coach is a guide to sustainable change. No matter where you live,

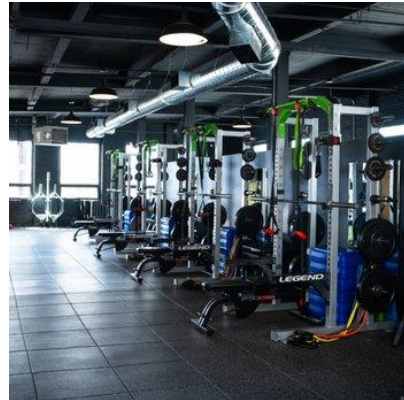
working with experienced coach David Piken will help you to assess your current skills and clarify and focus your goals and objectives to live the most meaningful life you can. This 12-week program includes a kickoff call or Zoom chat with David plus six (6) bi-weekly check-in calls/Zoom chats with additional support as needed. Invest in yourself this year! Questions, email [Susan Keliher](mailto:Susan.Keliher@ntsad.org), NTSAD Director of Development and Communications and fitness client!

Fair Market Value: \$379

Starting Bid: \$250 (Subsequent bids in minimum increments of \$25 i.e., \$275.)

**Get Fit in South Boston** *Donated by Lifted Fitness + Performance*

Get in shape before the holidays at [Lifted Fitness + Performance](#), Boston's premier strength and conditioning facility, providing a gym experience that delivers real results within a fun and welcoming environment. Their full-body workouts incorporate free weights, kettlebells, ropes, med balls, sleds, and more to increase strength, torch body fat, build muscle, and jack up your metabolism. Train at Lifted in South Boston with this \$100 gift card to try it all out!



Fair Market Value: \$100

Starting Bid: \$50 (Subsequent bids in minimum increments of \$10 i.e., \$60.)

**Isabella Stewart Gardner Museum and Dinner for 4** *Donated by Isabella Stewart Gardener Museum and Barcelona*

Bring three (3) of your friends with you on a trip to the legendary and exquisite [Isabella Stewart Gardner Museum](#) located in Boston. This beautiful museum is home to many works of master artists and is known for its history, architecture, gardens, and one of the largest art thefts in history. Discuss your visit over dinner for four (4) at [Barcelona](#), a delightful Spanish tapas restaurant located in Brookline, Mass.



Restrictions: Dinner at Barcelona excludes alcohol and gratuity. Expires 10/19/2023.

Fair Market Value: \$350

Starting Bid: \$225 (Subsequent bids in minimum increments of \$25 i.e., \$250.)

### **Pro Football Hall of Fame & Autographed Football**

*Donated by New England Patriots and Pro Football Hall of Fame*

Calling all NFL fans! Take a trip to the [Pro Football Hall of Fame](#) in Canton, Ohio, and stay overnight in a Marriott hotel with a \$200 gift certificate. Diehard Patriots fan? Add a football autographed by New England Patriots Wide Receiver Kendrick Bourne to your sports memorabilia collection. Perfect for the sports fan in your life.



Fair Market Value: \$400

Starting Bid: \$250 (Subsequent bids in minimum increments of \$25 i.e., \$275.)

### **Living-United Gloves** *Donated by Living-United*

[Living-United](#) creates soft and sleek, thoughtfully designed gloves for women that are made in the USA by craftspeople who are committed to enduring quality and unparalleled good looks. Perfect for any woman who is looking to stay healthy and fashionable. The innovative, antimicrobial fabric infused with silver ions naturally prevents bacterial growth and stays feeling fresh all day. And you can feel good knowing the fabric is made without chemicals that harm our environment. Two pairs in white and black. Size: large.



Fair Market Value: \$200

Starting Bid: \$100 (Subsequent bids in minimum increments of \$25 i.e., \$125.)

**To bid on any of these auction items or with questions, please email Sydney at [sdimond@ntsad.org](mailto:sdimond@ntsad.org) to submit a bid by Monday, December 19 at 5 PM ET!**

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### **AmazonSmile and Rare is Real Sweatshirts**

This holiday season if you shop online with Amazon, consider choosing to support NTSAD 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.](#)**

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. **[Check out the options here.](#)**

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

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.

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

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.

[Learn More.](#)

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### **Tea Party Celebration Marks Milestone in Treatment of GM1 Gangliosidosis**

Before JoJo received gene therapy for GM1 Gangliosidosis at the National Institutes of Health, she could not sit up or feed herself. Three years since she's received gene therapy, she returned to NIH for a tea party with Cyndi Tiff, M.D., Ph.D., the deputy clinical director at the National Human Genome Research Institute (NHGRI). At the tea party, Dr. Tiff noticed how Jojo's quality of life has improved—Jojo sits up, smiles, and even helps herself to a cookie!



[Read about this heartwarming event and the promising gene therapy for GM1 Gangliosidosis here.](#)

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### **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 application process.](#)

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### **Get Involved With NTSAD**

Have you ever thought about becoming more involved in NTSAD's efforts? We are always looking for community member volunteers to join us in our mission! The NTSAD Board of Directors is seeking new Board members for its 2023 slate of officers, and if you have an interest in getting more formally involved, we want to hear from you! We are in particular need of individuals with marketing and communications expertise working in industry. And if volunteering on a committee sounds like something you may enjoy, we are always looking for community and family members to join our efforts – be it helping to plan an event, supporting our research projects, or providing aid with our communication outreach.

NTSAD is here to serve YOU, and we welcome all community members who are interested in exploring ways to volunteer with us!

To express interest or find out more about ways to get involved, please contact Kathy at [kflynn@ntsad.org](mailto:kflynn@ntsad.org).

## Mathew Forbes Romer Foundation's 25th Silver Anniversary Gala



Save the Date: NTSAD's partner, the Mathew Forbes Romer Foundation, is hosting its "Sweetness and Laughter" Gala Celebration on Sunday, March 5, 2023 starting at 6 pm. This gala celebrating the Foundation's 25th anniversary will take place at the Broken Sound Country Club in Boca Raton, Florida and feature a stand-up comedy set from Bobby Collins.

[Learn more about the event.](#)

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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[Sydney](#) Dimond, Development and Communications Manager

[Valerie](#) Greger, Director of Research

[Diana](#) Jussila, (formerly Pangonis) Director of Family Services

[Susan](#) Keliher, Director of Development and Communications

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