

FUNDRAISING TOOLKIT

.....

YOUR GUIDE TO FUNDRAISING WITH NTSAD

GET IN TOUCH



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**National Tay-Sachs &
Allied Diseases Association**

Supporting families is the center of everything we do

OUR MISSION

National Tay-Sachs & Allied Diseases Association (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.



OUR VISION

We envision a world in which Tay-Sachs, Canvan, GM1, and Sandhoff diseases are no longer fatal or debilitating. To uphold our vision, NTSAD will:

- Provide compassionate support, advocate for affected individuals and their families, and promote early diagnosis and prevention
- Empower, educate, and connected affected individuals and families
- Be a key resource for individuals, families, clinicians, researchers, and industry members
- Direct, promote, and invest in research to accelerate the development of treatments, therapies, and cures
- Serve as a leader within the rare disease community

YOUR FUNDRAISING, OUR SHARED MISSION



Dear NTSAD family, friend, and supporter,

On behalf of the National Tay-Sachs & Allied Diseases Association (NTSAD), thank you for joining us in raising critical funds and awareness in your community. Your collaboration truly means the world as we work together to lead global efforts to discover treatments, therapies, and ultimately a cure for Tay-Sachs, Canavan, GM1, and Sandhoff diseases. Your support fuels NTSAD's mission - driving research, building connections, fostering collaboration, and nurturing community.

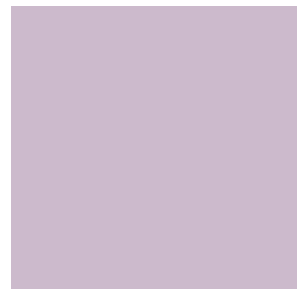
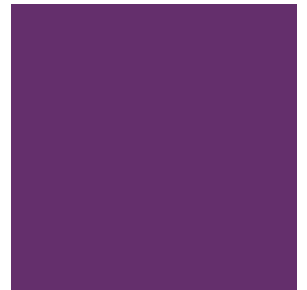
At NTSAD, supporting families is at the heart of everything we do. Fundraising is never an expectation - this toolkit is simply here if and when you feel ready. It's designed to help you honor your loved one through meaningful action, and we'll be here to support you every step of the way.

Fundraising can feel daunting, but you are not alone. Inside this toolkit, you'll find Fundraising 101, examples of different types of fundraisers, ways to give, templated tools and resources, and guidance to help you identify your fundraising fit. And beyond this toolkit, you have the strength of the entire NTSAD community to lean on.

Together, we'll continue to fuel relentless advocacy, advance research, and provide critical family services. Thank you for being part of this journey of hope and action.

Erin K. Demers

Development Manager





OUR SHARED COMMITMENTS

We are so grateful for your commitment to raising funds and awareness for NTSAD. To ensure that all fundraising activities are safe, transparent, and aligned with our mission, we asked families and friends to keep the following guidelines in mind:

Before You Begin:

- Please contact NTSAD before planning any event using our name or logo.
- Share your idea with us so we can support you and ensure compliance with state laws, insurance, and nonprofit regulations.

Materials & Promotion:

- NTSAD can provide brochures, fact sheets, and templates to help promote your fundraiser.
- Always use our full name - National Tay-Sachs & Allied Diseases Association (NTSAD) - and include our website (www.NTSAD.org) in printed materials.
- Send draft copies of invitations, flyers, or press releases to NTSAD for approval before printing.

Handling Donations:

- All checks should be made payable to NTSAD, with your event name noted.
- If you collect cash, convert it to a money order or bank check payable to NTSAD, with donor names and addresses recorded.
- Do not deposit checks made out to NTSAD into personal accounts - this is considered “co-mingling” and is not allowed.
- Please mail all donations and donor information to NTSAD within 30 days of your event.

Tax Receipts and Acknowledgements:

To comply with nonprofit IRS regulations, NTSAD can only issue tax receipts to individuals or organizations who make their donations directly to NTSAD. To ensure your supporters receive tax receipts, please encourage them to make their donations directly to NTSAD (online, by check payable to NTSAD, or through approved fundraising platforms). Lump-sum checks from events cannot be receipted to individual donors.

Fundraising Related Expenses:

NTSAD is deeply grateful for the time, creativity, and resources families invest in fundraising. Please note:

NTSAD does not reimburse expenses related to third-party fundraising events.

- Any costs for venue rental, supplies, food, entertainment, or other event-related expenses are the responsibility of the organizer.
- We encourage you to keep expenses modest so that the maximum amount raised can go directly toward advancing research, fueling advocacy, and providing family services.

KEY CONTACT INFORMATION

NTSAD Mailing Address

2001 Beacon Street

Suite 204

Boston, MA 02135

Erin Demers Development Manager

edemers@ntsad.org



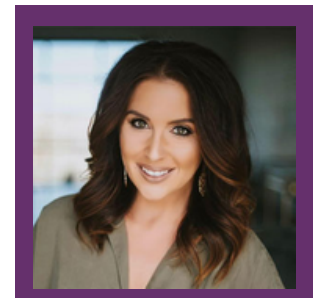
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National Tay-Sachs &
Allied Diseases Association

Supporting families is the center of everything we do

TABLE OF CONTENTS

| | |
|--------------------------------------------------|--------------|
| FUNDRAISING 101 | 06 |
| WAYS TO GIVE | 07 |
| FIND YOUR FUNDRAISING FIT | 08 |
| ONLINE FUNDRAISERS | 09 |
| HYBRID FUNDRAISERS | 10 |
| IN-PERSON FUNDRAISERS | 11 |
| PLANNING YOUR FUNDRAISER | 12 |
| KEY FUNDRAISING DATES | 13 |
| SHARING YOUR STORY | 14 |
| RESOURCES & INSPIRATION FROM FAMILIES | 15-16 |



**National Tay-Sachs &
Allied Diseases Association**

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FUNDRAISING 101:

THE BASICS YOU NEED TO KNOW



WHY FUNDRAISING MATTERS

- Every dollar supports families affected by Tay-Sachs, Canavan, GM1, and Sandhoff diseases.
- Your story inspires others to give and builds awareness.

SET YOUR GOAL

- Pick a fundraising target (e.g., \$250, \$500, \$1,000, \$5,000).
- Decide if you want to raise awareness, funds, or both.

SHARE YOUR STORY

- Tell people why NTSAD matters to you and your family.
- Keep it short, heartfelt, and personal.
- Use photos or videos if you're comfortable.

SPREAD THE WORD

- Post on social media (Facebook, Instagram, LinkedIn).
- Send personal emails or texts to friends and family.
- Ask supporters to share your page.

ENGAGE & THANK

- Celebrate milestones (halfway to your goal, final push).
- Thank donors promptly - a quick message goes a long way.
- Share updates on how their gift makes an impact.



QUICK TIPS

- Start small and build momentum.
- Ask directly - people give when asked.
- Don't be afraid to remind people (they appreciate it!).
- Keep it fun and authentic.



WAYS TO GIVE



1

WITH A CHECK

*Checks made payable to NTSAD can be mailed to:
201 Beacon Street, Suite 204, Boston, MA 02135.*

2

WITH A CREDIT CARD

Make a one-time donation or set up a monthly recurring donation online by visiting ntsad.org/donate-to-ntsad/.

3

THROUGH A FAMILY FUND OR EVENT

Search our list of family funds and events that are in honor of loved ones, research for specific diseases, and provide assistance for families in need.

4

WITH A COMPANY MATCH

Double your impact! If your employer has a matching gift program, submit a request.

5

WITH AN ESTATE GIFT

Make a lasting impact by adding NTSAD to your will.

6

WITH A GIFT OF STOCK

A gift of stock or securities can be coordinated through an electronic transfer. Your broker can advise on initiating the process.



FIND YOUR FUNDRAISING FIT

There are a number of fundraiser ideas available to you. Below are three types of fundraisers you may consider. The following pages provide further details on activating the fundraiser.

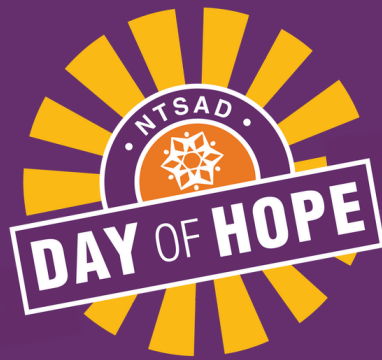
Actively caring for loved ones? Fundraising may not be possible right now - and that's okay. This resource is here if and when you're ready.

Online Fundraiser



- **Bandwidth:** Low
- **Great for:** Birthdays, sharing on social media, reaching a larger audience
- **Estimated Cost:** \$0
- **Example:** Facebook Birthday Fundraiser

Hybrid Fundraiser



- **Bandwidth:** Low to Medium
- **Great for:** Local and larger audience, one-day or multi-day event
- **Estimated Cost:** \$0-\$500
- **Example:** NTSAD Day of Hope

In-Person Fundraiser



- **Bandwidth:** Medium to High
- **Great for:** Building local awareness, community, and support
- **Estimated Cost:** \$0-\$2,500+
- **Example:** Golf Outing, House Party, Community Walk, Partner with a Local Business, Concert Benefit, Silent Auction

ONLINE FUNDRAISERS

Online fundraisers provide the widest reach and are most cost-effective. Often, all that is needed is a Facebook/Instagram page or a simple donation link (which NTSAD can provide).



EASY AND ACCESSIBLE

- Online fundraisers provide flexibility on start and stop dates
- No need to reserve a venue!
- NTSAD can provide a dedicated link for your fundraiser so you can easily share it across all your social media platforms

WHAT YOU'LL NEED

- A quick email or phone call to NTSAD to set up your link
- Social media account (e.g. Facebook, Instagram)
- Persistence, keeping your posts top of mind takes time and dedication!

DOS

- Tell NTSAD when you're planning on sharing posts
- Use #hashtags to increase engagement online
- Leverage special dates (like birthdays!)

DON'TS

- Forget to set a fundraising goal
- Forget to use the NTSAD or NTSAD Day of Hope logo - just ask our team!
- Forget to thank everyone who has supported your fundraising

CONSIDERATIONS

- Once a fundraising link is made, you can use it multiple times a year
- Ask your HR department at work if they will match gifts
- Online fundraisers do not require a lot of bandwidth



Tip: Keep it simple and personal.

People are more likely to give when they feel emotionally connected to your cause. If supporters have to click through multiple pages or create accounts, they're less likely to donate.



HYBRID FUNDRAISERS

Hybrid fundraisers involve virtual (online) and in-person components.



ACCESS AND FLEXIBILITY

- Hybrid events give you both an online and in-person community to engage
- Offer a built-in alternative if weather hinders the in-person component

WHAT YOU'LL NEED

- A quick email or phone call to NTSAD to set up your link
- Social media account (e.g. Facebook, Instagram)
- A venue for the in-person component

DOS

- Tell NTSAD when you're planning on sharing posts
- Use #hashtags to increase engagement online
- Ask NTSAD about event materials - we may have some items on-hand for your event (e.g. pamphlets, swag)

DON'TS

- Forget to set a fundraising goal
- Forget to use the NTSAD or NTSAD Day of Hope logo - just ask our team!
- Forget to thank everyone who has supported your fundraising
- Forget to secure any necessary permits for the in-person component

CONSIDERATIONS

- Ask your HR department at work if they will match gifts
- The in-person component may require sponsors to minimize costs



Tip: Consider joining other rare families and allies in NTSAD's Day of Hope.

Each year families, friends, neighbors, and colleagues come together for a "Day of Hope" and host an event to raise awareness and critical funds for research. All summer long and into the fall, families hosted walks, runs, dance parties, pancake breakfasts, trivia nights, cornhole tournaments, Facebook fundraisers, t-shirt campaigns, and more in support of NTSAD.



IN-PERSON FUNDRAISING



In-person events provide a great opportunity for both fundraising and 'friendraising' - building relationships between NTSAD and your community. In-person events require a larger investment of time, treasure, and dedication.

COMMUNITY IMPACT

- In-person events have a significant impact - gathering the community builds camaraderie and increases awareness of ...
- Local businesses may sponsor the event and those relationships can develop into transformative gifts in the future

WHAT YOU'LL NEED

- A quick email or phone call to NTSAD to set up your link
- Social media account (e.g. Facebook, Instagram)
- A planning committee
- A venue

DOS

- Tell NTSAD when you're planning on sharing posts
- Use #hashtags to increase engagement online
- Ask NTSAD about event materials - we may have some items on-hand for your event (e.g. pamphlets, swag)

DON'TS

- Forget to set a fundraising goal
- Forget to use the NTSAD or NTSAD Day of Hope logo - just ask our team!
- Forget to thank everyone who has supported your fundraising
- Forget to secure any necessary permits

CONSIDERATIONS

- Ask your HR department at work if they will match gifts
- The in-person component may require sponsors to minimize costs



Tip: Create a welcoming atmosphere.

Small touches like signage, decorations, or music make guests feel engaged and connected.



PLANNING YOUR FUNDRAISER



One checklist, every fundraiser.



1. Set Your Goal

- Define a clear target - whether it's dollars raised, awareness built, or new supporters engaged.
- Share why the cause matters to you or your family - make it personal and heartfelt.
- Break the goal into smaller milestones (e.g., \$100, \$500), so you can celebrate progress along the way.

2. Budget & Resources

- Identify any costs you might have (venue, tech, t-shirts, signage, decorations, swag).
- Consider sponsorships or partnerships to offset expenses.
- Keep it simple - many fundraisers thrive with minimal costs.

3. Choose Your Format

- Decide if your fundraiser will be in-person, hybrid, or virtual.
- Think about your audience reach, budget, bandwidth, and comfort level.
- Prioritize accessibility and inclusivity (physical access, digital access, language, time zones).

4. Technology & Tools

- Select a donation platform that's easy for supporters to use (NTSAD can provide this for you!).
- Ensure reliable internet if you're streaming or hosting online.
- Test any audio/visual equipment ahead of time.

5. Engagement & Programming

- Plan activities that fit your format: speakers, entertainment, games, or family-friendly challenges.
- Use storytelling to connect donors emotionally to the NTSAD community.
- Add interactive elements like raffles, silent auctions, or milestone celebrations.

6. Promotion & Outreach

- Spread the word through social media, email, local press, and personal networks.
- Tailor your message to your format (e.g., "Join us from anywhere" vs. "See you at the park").
- Encourage early sign-ups or donations to build momentum.

7. Logistics & Operations

- In-person: venue, catering, permits, accessibility.
- Hybrid: balance onsite and online audiences.
- Virtual: choose your platform(s).

8. Day of Execution:

- Assign roles (host, tech support, donor relations).
- Run a rehearsal or dry run.
- Have a troubleshooting plan for tech issues, weather, or cancellations.

9. Follow-Up:

- Thank donors and participants promptly - a personal note goes a long way.
- Share impact stories and results (how funds will help individuals and families affected by rare diseases).
- Reflect on what worked well and consider making it an annual tradition!

Remember, you're never fundraising alone. NTSAD is here to support you every step of the way - whether you have questions about planning, need ideas for activities, or just want encouragement along the journey. Reach out to us anytime, and we'll help make sure your fundraiser feels manageable, meaningful, and connected to NTSAD's mission.

KEY FUNDRAISING DATES

You're not alone in planning. NTSAD is here to help with resources, ideas, and encouragement. If you have questions or need support, reach out - we'll work with you to make your fundraiser meaningful and successful.



NTSAD Day of Hope

- **When: Annually in September**
- Why: A community-wide day dedicated to hope, remembrance, and action
- How: Host a walk, organize a family gathering, launch a fundraising campaign, or share your story online



Rare Disease Month

- **When: February (entire month)**
- Why: An extended opportunity to spotlight rare disease communities and build momentum
- How: Run a month-long fundraiser, set weekly fundraising challenges, or organize themed events in your community



Rare Disease Day

- **When: February 28 (or February 29 in leap years)**
- Why: A global day to raise awareness for the 300 million people worldwide living with rare diseases
- How: Share your journey on social media, host a fundraiser, or encourage friends to donate in honor of rare diseases



National Tay-Sachs Awareness Day

- **When: May 15**
- Why: A day to honor families affected by Tay-Sachs and raise awareness about the disease
- How: Share educational resources, host a family-friendly event, or create a tribute fundraiser in honor of loved ones



Personal Milestones

- **When: Any meaningful date in your life - birthdays, anniversaries, memorials, holidays.**
- Why: Personal milestones make fundraising authentic and emotionally powerful, connecting your story to the cause.
- How: Invite friends and family to donate in lieu of gifts, host a small gathering, or share your milestone online with a fundraising link.



Tip: Choose the date that feels most meaningful to you.

Whether it's a community awareness day or personal milestone, tying your fundraiser to a special occasion makes it easier to rally support and share your story.

SHARING YOUR STORY:

HOW TO INSPIRE OTHERS THROUGH YOUR CONNECTION



Sharing your personal story is one of the most powerful ways to inspire support. Your words connect people to NTSAD's mission and help them understand why their gift matters. Here are some steps to guide you:

Start with a Personal Moment

- Many families honor their loved one's birthday by writing to friends and relatives.
- Siblings also have used their birthdays to recognize and honor their brothers or sisters.
- Choose a moment that feels meaningful to you!

Speak from the Heart!

- Don't worry about the structure or details in your first draft.
- Let your emotions guide you - share what your loved one means to you and why you're fundraising.

Add the Facts Later

- Once you've captured your feelings, step away and return to add context.
- Include a simple explanation of the disease (resources are available on the NTSAD website, and NTSAD staff can also help simplify).
- Share carrier statistics to show how widespread the impact can be - many supporters are surprised by these numbers.

Explain Where Support Goes

- Tell your audience why you're asking for their help.
- Share how donations to NTSAD fuel research, advocacy, and family services, and how that connects back to your story.

Express Gratitude

- Thank your community for considering a gift and let them know how much their support means.
- Invite them to visit NTSAD's Facebook, Instagram, or website to learn more.



RESOURCES & INSPIRATION FROM FAMILIES

Families across the NTSAD community have found creative and heartfelt ways to honor their loved ones through fundraising. From celebrating birthdays and milestones to organizing community events, each story reflects the power of love transformed into action. These examples are meant to inspire you as you consider how to share your own journey and invite others to join in making a difference.

Create Your Own Custom T-Shirt Fundraiser

Get an NTSAD Branded T-Shirt

Browse Family Funds and Events

Eli's Cruise for a Cure

All Money Raised Goes to Research

ELI'S CRUISE FOR A CURE Car Show

10am-2pm

September 28, 2024

ELI THE COURAGEOUS

you not love his little face? Meet Eli The Courageous, a determined and young superhero on a mission to raise awareness of Tay-Sachs and other diseases, and to share love and strength with everyone he meets. He and the world in his classic Ford Faircar, with music blasting that brings people together. After all, life is a highway and he's hitting the road with the best of buddies: his happy Biggles and his best buddy and his best friend. Eli's outlook, his happy Biggles and his best buddy and his best friend: his happy Biggles and his best buddy and his best friend. Eli's outlook, his happy Biggles and his best buddy and his best friend. Eli's outlook, his happy Biggles and his best buddy and his best friend.

DOWNTOWN AUBURN
1369 4TH AVE.
AUBURN, GA
30011

Handmade Trophies:

- Best in Show
- People's Choice
- Eli's Award
- Angel Awards

WOW! \$20

CTSF NTSAD Seaside CLASSIC

Jaxson's Train of Hope

Jaxson

JAXSON'S TRAIN OF HOPE
CONNECT FOR A CURE

6th Annual

POKER RUN

Saturday
September 27, 2025
Starts at 9:00 am

- * The event Starts and Ends at Indian Motorcycle of El Cajon.
- * Poker Run Registration starts at 9am ~ Bikes out by 10am. (Complimentary coffee from Motorcycle Monkey & Complimentary Donuts)
- * Poker Run - \$20 registration fee includes Poker Card & Lunch. \$10 each additional card or riders.
- * End of day Celebration is at 1pm including results from the Winning Poker Hand, 50/50 drawing, plus participation in our Raffle Drawings, AND Unique Auction Items!

Please check with Jaxson's Train of Hope web page for any updates or ride changes <https://www.jaxsonstrainofhope.net>

If you would like to be involved with drawing prizes, sponsorship, volunteering, or assisting with our ride, please reach out to thekarp@jaxsonstrainofhope.net or call 619 916-9226

SPECIAL THANKS TO
Indian MOTORCYCLE El Cajon

ALL PROCEEDS BENEFIT
National Tay-Sachs & Allied Diseases
501c (3)

Jaxson Karp has a rare disease called Tay-Sachs. It is a genetic neurological disorder that is fatal and there is no cure yet. It would be an honor if you would join us to help raise money towards a cure and celebrate his 12th birthday in the meantime!

INSPIRATION FROM FAMILIES

Jessie's Rally of Hope



Live Music
Both Days !!!

All Proceeds
go to
National Tay Sachs &
Allied Diseases
(NTSAD)



NTSAD/GM1 Awareness Event

Saturday Oct 4th-Sunday Oct. 5th
12:00 PM - 6:00 PM

Vendors &
Silent Auction

Call Family Distillery
1611 Industrial Drive
Wilkesboro, NC 28697



Where Friends Gather, So Does Hope®

This is a Biker/Family-Friendly Event

To learn more about Jessie's journey and NTSAD, please visit
NTSAD.org and Jessie's Facebook page: Trucking For Jessie

For Questions, email: simply4thekids@aol.com

Jase's Benefit



Cayden's Day of Hope



Brodryck's Beanbag Tournament





Honoring loved ones. Inspiring action. Building community.



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www.ntsad.org
Development@ntsad.org
(617)277-4463