

# ***NTSAD ANNUAL FAMILY CONFERENCE***



**Community - Connection - Support**





# #NTSADAFc

*From the bottom of my heart thank you for all you do and for all the support you provide.*

*-Conference Attendee*



## Who, What, Why?

The Annual Family Conference, the cornerstone of our work, is an unforgettable experience for affected children and adults and their rare families including parents, partners, grandparents, healthy siblings, and caregivers.

The Conference provides families and affected individuals coping with Tay-Sachs, Canavan, GM1, or Sandhoff the rare opportunity to connect with people that truly understand. It is a place where you receive both compassion regarding care choices and bereavement support from professionals and other families, learn about the latest research and symptom management approaches, and honor your loved one.





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# Annual Family Conference FAQs

**Who is the AFC for?** All affected individuals and their families. With a wide range of programming for the whole immediate family, the conference supports the needs of affected adults, their partners and caregivers, as well as affected children, parents, siblings, etc.

**What if I'm not a family member?** There are also separate attendance tracks for industry and medical professionals.

**What sessions are offered at the AFC?** A wide range of support groups for parents both caring for and grieving the loss of their child, Late Onset individuals, healthy siblings, and grandparents and extended family. There are also sessions focused on research, advocacy, awareness, and more. These sessions are broken into three daily themes: Support Day, Research Day, and Health and Symptom Management Day.



## Helping Hand

Helping Hand Grants exist to help affected individuals and their families greatly ease the expense of attending the Annual Family Conference. The grant may cover most of the cost of registration, meals and hotel rooms.

**We have received a grant in the past, can we apply again?** Yes, but priority is given to those living with the disease, families who recently received their diagnosis, or have lost a loved one in the past year.

**Our family needs a grant for all our expenses, is that possible?** Unfortunately, NTSAD is not able to cover travel expenses. You may apply for a grant to cover your full conference fees (registration and hotel), but please be aware, to serve as many families as possible, you might not be awarded the full amount you apply for.

**We live outside the US; are we eligible for a Helping Hand Grant?** Yes!

**Do I need to pay for my affected child?** No. We never charge for affected children.

**Are there limits to how much I can ask for?** Yes. While we ask all families to make every effort possible to seek out conference funding before applying for a Helping Hand Grant, we must also limit the amount we grant to each family to ensure we can help as many families as possible. The maximum awarded is three room nights, two adult, and two children's registrations.

**How/when will I know if I was awarded a grant?** The Family Services Team will notify you of your grant award status after the grant approval process is complete.

**What do I need to do if I am approved?** You will be sent an award letter which serves as a contract of attendance and adherence to all NTSAD attendance guidelines.



*I would not be here if it was not for my NTSAD family. The support, the love, and help we get from NTSAD and the families is immeasurable. They say our son's name without fear. They talk about him and they love him...I can't tell you how much that means. - Conference Attendee*



## Registration Requirements

All attendees of the AFC must be registered participants. Learn more about registration requirements below.

No outside participation is granted without registration.

The use of outside/personal photographers, company and group meetings, and unapproved volunteers are strictly prohibited at the AFC.



If you are a family who has already or will apply for a Helping Hand Grant, you will wait to register until after your grant is approved. Families of affected children and individuals receive a reduced registration rate (current prices for 2025 noted below). The actual cost of attendees is currently \$500/adult and \$250/child.

**Family and Affected Individual Adult Registration** (13 years old and up) \$250.00

**Child Registration** (4-12 years old) \$125.00

**Free Child Registration** (Affected Children and Children 0-3 years old) No Charge

**Healthcare Provider/Academic Partner** \$350.00

**Industry Member** \$500.00

**Day Rate Family Member** \$100, **Non-Family Member** \$150 5



## Daily Sessions

# Programming at the AFC

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## 1. Adult Programming

Multiple sessions are held each day covering support, research, care, bereavement, and more. Some sessions are open to everyone, while others are disease and onset specific, or tailored to those caring for a loved one, or those who are bereaved.

Aside from spending our days in sessions, we also enjoy all of our meals together, and offer our Family Lounge when sessions are not running.

## 2. Children's Programming

The AFC offers three levels of children's programming: Camps Snuggle and Active for affected children, Camp Sunshine for healthy siblings ages 0-9, (contracted through KiddieCorp) and the Youth Group for healthy siblings ages 10-high school senior.

Camps Snuggle and Active are open during conference sessions. They are staffed with a highly skilled team of trained nurses and dedicated volunteers, many of whom are parents of affected children, who can care for the children during conference session times allowing parents to attend sessions both hands and worry-free.

While Camps Snuggle, Active, and Sunshine are all on-site, the Youth Group has the opportunity to explore the local area on their Youth Retreats each day!

02



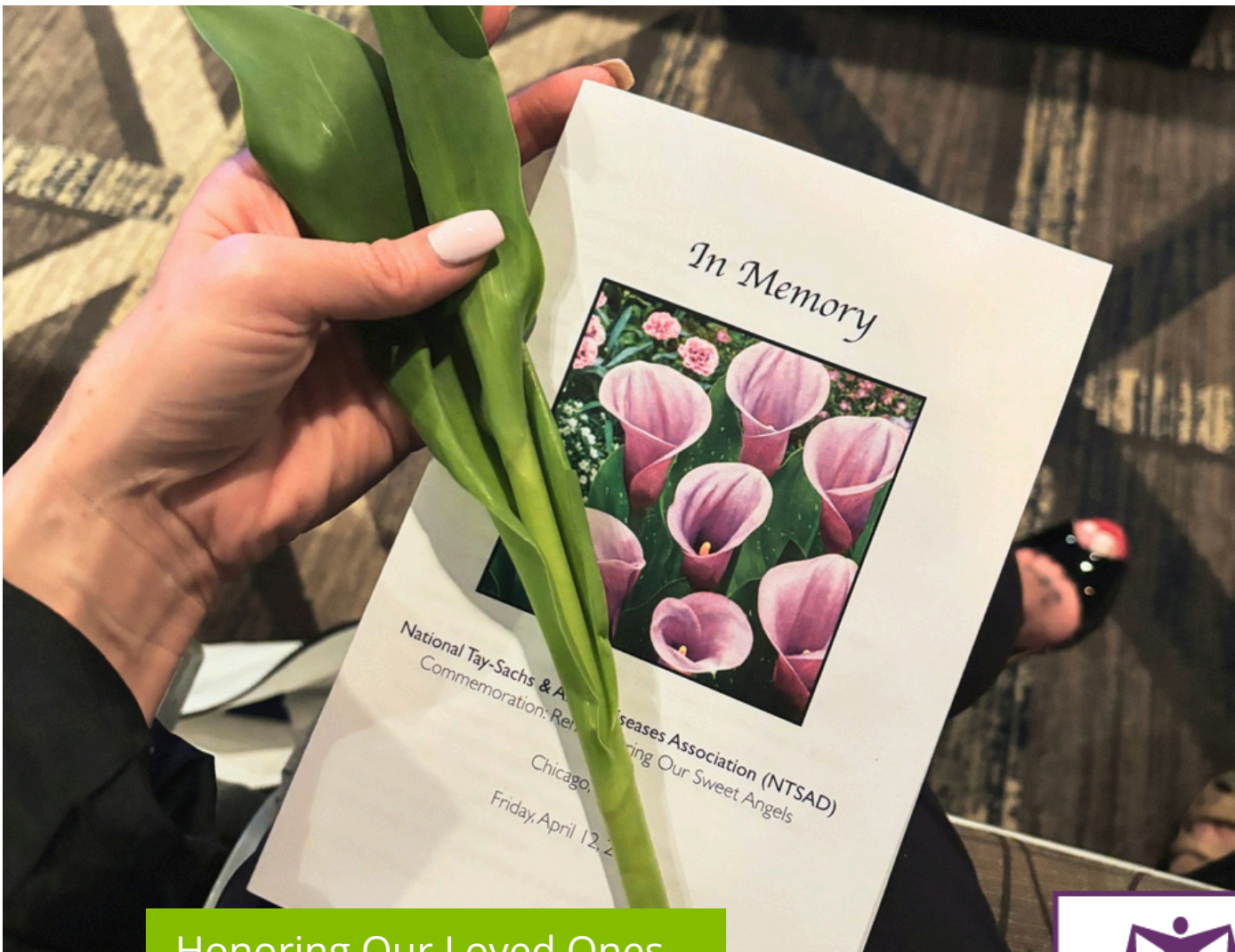


# Research Update Sessions

National Tay-Sachs & Allied Diseases Association (NTSAD) is dedicated to finding a cure for Tay-Sachs, Canavan, GM1 gangliosidosis, and Sandhoff diseases. We support researchers around the world through our Research Initiative, collaborative programs, and fundraising. The Scientific Advisory Council (SAC) supports our efforts by reviewing research proposals, monitoring the field, and sharing important developments and breakthroughs.

The research sessions at the Annual Family Conference highlight the current work being done to find effective treatments for Tay-Sachs, Canavan, GM1, and Sandhoff diseases. These sessions consist of a general update, followed by disease-specific breakouts featuring the leading companies, clinicians, and researchers in these fields.





Honoring Our Loved Ones



# Commemoration Ceremony

The Commemoration Ceremony is a special time to honor our loved ones who have left us too soon. Before the ceremony begins the Quiet Reflection period is held. During the Quiet Reflection families may choose to set out mementos of their loved one to be viewed in memoriam by those in attendance of the ceremony.

During the ceremony slides are shown as loved one's names and a selection of poems are read aloud. A single candle is lit for those not in attendance. For those who are in attendance, this is a time to also come to the front of the room and light a candle for your loved one. The Commemoration Ceremony is open to all attendees, but attendance is not required.



# Enrichment

# Opportunities

## The Family Lounge and Photography Sessions



The Family Lounge is a quiet place to rest, relax, and take a break. Open at various times when sessions are not running, its a great place get to know your fellow attendees.

Due to most hotels' strict no alcohol policy in meeting rooms, we must ask that you please respectfully observe this policy when in the Family Lounge.

**Children are not permitted in the Family Lounge without parental supervision.**

## Free Family Photography Sessions

All families and affected individuals are welcome to schedule a free family photography session with our dedicated professional photographers. Some bereaved families choose to bring a framed picture of your loved one to hold in your photos.



# Conference Awards — #NTSAD AFC

Each year at the Annual Family Conference, NTSAD presents two awards to individuals who have shown tremendous efforts in support of affected families and individuals to further the mission of NTSAD through advocacy, awareness, fundraising, research, and promoting community and connection.

The **Power of One** award is given to someone within NTSAD, such as an affected family member or other person closely affiliated with our organization, who exemplifies the impact one person (or family) can make.

The **Above and Beyond** award is given to someone outside of this purview who has championed these causes for affected families and individuals out of the goodness of their heart and strong feelings of connection to our community.



## Sponsorship Opportunities

You can support families by sponsoring the Annual Family Conference.

For questions about sponsoring the conference, please email [development@ntsad.org](mailto:development@ntsad.org) or reach out by phone (617) 277-4463.

You can also make a gift by donating here:

<https://interland3.donorperfect.net/weblink/WebLink.aspx?name=E94381&id=55>

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.

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