National Tay-Sachs & Allied Diseases Association, Inc.

NTSAD

Working toward solving the puzzle of these devastating genetic diseases.

National Tay-Sachs & Allied Diseases Association, Inc.

About NTSAD

More than 50 years ago, a group of concerned parents *came together to discuss how to cope with their children's diagnoses and other related genetic diseases. National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD) was the outcome of their discussion. In 1957, NTSAD was the first of its kind to deal with rare and devastating genetic disorders. It was this pioneering group of parents who dedicated their time and energy to raising the money that ultimately lead to identifying the Tay-Sachs gene and consequently, the first of numerous community carrier screenings. Almost immediately, the scope of the organization grew beyond education and prevention to include support services for families through the early days of diagnosis, to caring for their children, and sadly, beyond their children's short lives.*

Half a century later, the range of NTSAD has broadened and includes not only the family of more than 40 lysosomal storage disorders including Tay-Sachs, Late Onset Tay-Sachs and Sandhoff Disease, but also includes the different forms of the leukodystrophies, such as Canavan Disease and Pelizaeus-Merzbacher. The NTSAD staff works diligently to address the issues in each of these groups from member support and advocacy to ground-breaking research as well as educating higher risk populations. In addition, collaborations with groups such as the Lysosomal Storage Disease Research Consortium and the National Institutes of Health bridge the gap between the rarity of these diseases to other more "common" neurodegenerative disorders such as Parkinson's Disease and Multiple Sclerosis.

Today, NTSAD continues to provide compassion and hope by offering programs and services to individuals and families dealing with the cruelty of these neurodegenerative diseases and letting them know they are not alone.

NTSAD's Programs and Services

Research

NTSAD supported the advent of carrier screening. Since the 1970s, more than two million individuals have been tested for the Tay-Sachs gene. That breakthrough alone led to the development of many other carrier tests including those for breast cancer. Current research is promising and NTSAD continues its leadership role with its Research Initiative, remaining dedicated to funding cutting-edge research into neurodegenerative genetic diseases.

Member Support Services

NTSAD links more than 400 parents, grandparents, extended family, affected adults and their families and caregivers to each other via a confidential network. Staff manages a mentoring system, matching families and individuals with a buddy to ease them into the harsh reality of these genetic diseases. New members find unequaled support and understanding from those facing similar challenges, and share symptom management tips, resources and home care options.

Public and Professional Education

Education is at the core of NTSAD's mission, and coupled with carrier testing, has proven to be the most effective weapon in the campaign against Tay-Sachs, Canavan and the allied diseases. NTSAD has a library of information ready to share with the public. Inquiries come from a range of backgrounds — from students studying this particular group of disorders, to home care nurses newly assigned to a family struggling with the 24-hour care of an affected child, to a physician becoming more familiar with their patient's diagnosis.

Carrier Screening

The only known cure for diseases such as Tay-Sachs, Canavan and the allied diseases is prevention. Therefore, it is vital NTSAD continues its mission to educate the public about the importance of carrier screenings and the risks of being a carrier. NTSAD carries out this aspect of the

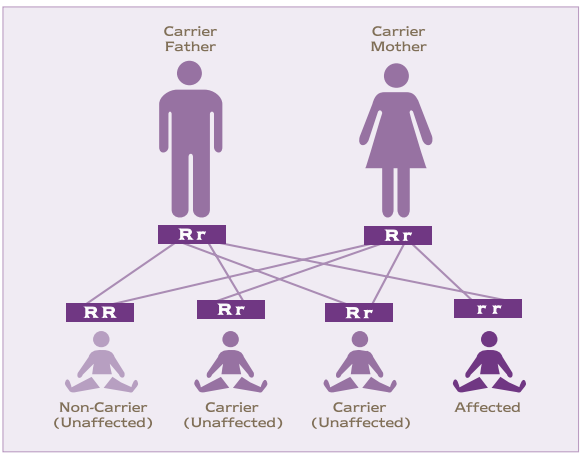
mission by providing public and professional education, organizing carrier screening programs for at-risk communities as well as funding the International Quality Control Tay-Sachs Carrier Testing Program.

Advocacy

The complicated issues of genetic privacy legislation, health insurance coverage, entitlements and government funding affect us all. It is important for NTSAD to continue to advocate for families and persons of all ages with disabilities and the public on an individual, state and national level.

Genetics "101"

Most of the lysosomal storage diseases and leukodystrophies are autosomal recessive diseases, which mean these particular genes are passed down from the parents.



With each pregnancy, a carrier couple has a:

- 25% chance of having an affected child.
- 50% chance of having a child who is a carrier.
- 25% chance of having a child not affected and not a carrier.

NTSAD highly recommends carrier testing *before* pregnancy to avoid further complications.

Make a difference by making a gift to NTSAD

Imagine receiving the heartbreaking news that your child has an extremely rare and incurable neurodegenerative disease – one that you, your friends and even your physician hasn't heard of before – where do you turn?

Or imagine you're an adult in your 30's and you begin experiencing slurred speech, muscle weakness and memory loss. You suddenly find that you can no longer take care of yourself. It takes you years to be diagnosed with Late Onset Tay-Sachs Disease (LOTS). Where do you turn?

For more than 50 years, National Tay-Sachs and Allied Diseases Association (NTSAD) has been the place for families and individuals to turn when faced with the unimaginable.

Your support helps make this possible.

In addition to member support, advocacy and education, gifts also fund innovative research programs. Much has been accomplished, but there's so much more that needs to be done. The world of genetics is fast-paced and constantly changing and in order to stay on top we need your help.

Keep in mind — Tay-Sachs, Canavan, Sandhoff and the other allied diseases don't affect thousands each year. However, the number of children and adults affected doesn't change the pain and heartache that these families feel. So, please, give today. *Your gift makes a difference*.

There are several ways you can make a contribution:

- Monetary gift
- Gift of stock
- Bequests
- In-kind gifts
- Volunteer to help

NTSAD is a registered 501(c)(3) nonprofit voluntary health organization.

National Tay-Sachs & Allied Diseases Association, Inc. (NTSAD) is a 501(c)(3) nonprofit health organization dedicated to the treatment and prevention of Tay-Sachs, Canavan and related genetic diseases. NTSAD is committed to providing information and support services to individuals and families affected by these disorders, as well as the public at large. The strategies for achieving these goals include family support services, research, public and professional education, carrier screening and advocacy.

This brochure was generously underwritten by
the Benjamin Baker Fund of NTSAD

In loving memory of Benjamin Baker (2001-2004)

NTSAD

**National Tay-Sachs &
Allied Diseases Association, Inc.**

2001 Beacon Street, Suite 204
Boston, Massachusetts 02135
617.277.4463 • 1.800.90.NTSAD
www.ntsad.org