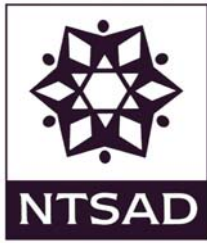


Having trouble viewing this email? [Click here](#)



National Tay-Sachs &
Allied Diseases Association, Inc.

Keeping Up with NTSAD
a monthly e-newsletter

December 2014 - In This Issue:

Thank you!

Research Rewind

Family Support

The Tale of Two Screenings

Path to Advocacy & Awareness

Plans for 2015



TOGETHER.
We can make a difference.

LOOKING BACK...2014 REWIND

Dear Diana,

I want to personally tell you that your support, on all levels, made the it possible for NTSAD to achieve a successful year in 2014. I extend my thanks to you for believing in our mission as we seek out and fund innovative research while caring and connecting families.

I hope you received the year-end appeal that highlights our global family - it is a

Families, their children and individuals affected by Tay-Sachs, Sandhoff, GM1 and Canavan diseases in all its forms are at the core of NTSAD's mission. They are why NTSAD advocates, raises awareness and funds research.

It is NTSAD's goal to work toward a future where these diseases do not rob families of bright and healthy futures for their loved ones.



The NTSAD Family

We hope you take a moment to watch this short film and consider making a gift [here](#) in support of our families this holiday season.

EDUCATION & AWARENESS

Screenings from East to West

There were two screenings held this year in Portland, Oregon and Pearl River, New York, thanks to the hard work of two NTSAD families. The Davis Family coordinated an educational program and a screening at their local synagogue in October in Portland. This type of program could easily be duplicated in any community - please contact NTSAD at (617) 277-4463 if you're interested in doing something similar. On the other side of the country in New York, the Kenny/Whitney family worked with the Einstein Medical Center in Philadelphia and coordinated their walk fundraiser with a carrier screening. The center is currently conducting a study on Irish American carrier rates. For more information visit www.tay-sachs.org to learn how you can participate in the study.



To read about the Portland, Oregon screening in the October issue of "Keeping Up with NTSAD," [click here](#).

For more about the Pearl River screening in the December 5th issue of "Topic of the Week," [visit here](#).

ADVOCACY...A PATH TO CHANGE

Advocacy Opportunities to Make Change

NTSAD's partnerships with organizations such as the **EveryLife Foundation**, **Global Genes**, **National Organization for Rare Disorders** and the **Rare Disease Legislative Advocates** are invaluable. They keep us informed of legislation that has an impact on the rare diseases community such as the Newborn Screening Act and Accelerating the Biomedical Research Act. They also encourage patient groups like NTSAD to participate in workshops that can improve the development process for rare disease treatments.

As an example of the power of advocacy, three NTSAD moms joined 60 advocates on Capitol Hill for the Palliative Care Lobby Day. They had the opportunity to educate lawmakers about the two bills that would impact how palliative care benefits families.



To read a past "Topic of the Week" about their experience and other advocacy, [visit here](#).

LOOKING AHEAD TO 2015

NTSAD has a busy year ahead starting in **January** with the Research Initiative *Request for Proposals' pre-application deadline* on January 9th and a Board of Directors Meeting toward the end of the month. A progress report from the *Tay-Sachs Gene Therapy Consortium* is also expected in early January. The month of **February** leads up to *World Rare Disease Day on February 28th* and many advocacy events happening, some which offer travel scholarships for patient advocacy group families ([learn more here](#)) so their voices are heard. **April** brings the *37th Annual Family Conference* and a *Science Symposium and Workshop* at the Hyatt Regency Reston on April 16th. Plans for the *Fifth Annual Day of Hope* begin in **June**. The goal is to double the events and double the funds raised for research for next **September**. The year will end with several meetings within our rare disease community in September and **October**, and our annual Boston "Imagine & Believe" benefit in **November**. Watch your emails for more updates and family stories as NTSAD continues its work to care for families and find a cure.



Thank you again for making 2014 a productive and incredible year.



I want to give NTSAD
my support today.

Give a gift here.

Sue Kahn, Executive Director (skahn@ntsad.org)
Joan Lawrence, Development Director (joan@ntsad.org)
Ingrid Miller, Office Manager (ingrid@ntsad.org)
Diana Pangonis, Communications Manager (diana@ntsad.org)

NATIONAL TAY-SACHS
& Allied Diseases Association, Inc.
2001 Beacon St - #204
Boston, MA 02135
(617) 277-4463 * www.NTSAD.org

STAY CONNECTED



[Forward this email](#)

 SafeUnsubscribe™

This email was sent to diana@ntsad.org by joan@ntsad.org |
[Update Profile/Email Address](#) | Rapid removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).



National Tay-Sachs & Allied Diseases Association | 2001 Beacon Street, #204 | Boston | MA | 02135