NTSAD Lifeline

Community and Connections for Families and Individuals

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

SEPTEMBER 2020

In this Issue

NTSAD Partners with AllStripes to Accelerate Research

NTSAD is excited to partner with AllStripes Research to drive **new GM2 research**!

AllStripes offers a platform to makes it easy for rare disease patients and caregivers to contribute to drug development research from home and free of charge.

How AllStripes Accelerates Research

Patients and their families living in the U.S. and Canada can contribute valuable data to be used in drug research from their homes by allowing AllStripes to collect medical records at no cost to patients or to NTSAD. AllStripes does all work, so there is no need to worry about scanning and uploading documents.

AllStripes improves the speed and design of trials by extracting and compiling research-grade data from patients' medical records. The company uses a unique mix of technology and medical expertise, creating a pool of previously untapped knowledge about each rare condition that can be leveraged for multiple research studies.

How It Works

1. Sign up: Create a private account at **https://www.allstripes.com/gm2**; review the research consent information; and identify the hospitals and other institutions from where health care services have been received.
2. AllStripes gets to work: The company retrieves and processes a patient's records. Once records are uploaded, records are accessible and available for download for the patient as well.
3. Empower research: Each individual's contribution to research projects are tracked, and AllStripes notifies patients if qualified for new clinical trials.

Benefits to Patients and Families

1. Increases the speed for GM2 drug development
2. Easily access a patient's medical records in one secure platform
3. Follow new clinical trials
4. Make de-identified health information available for multiple research projects

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Preparing for the Flu Season during COVID

As we enter October, "flu season" looms on the horizon.

Recently, we had a conversation with our friends at Sanofi Genzyme about how this flu season is different due to the pandemic. The company shared information about their **The Race to 200M** initiative with the American Nursing Association. Here's the key takeaways:

TOP 5 TIPS FOR STAYING SAFE

- Schedule a visit with your doctor between September and October
- Wear a mask when attending your appointment for your shot
- Wash your hands before and after your shot
- Abide by your local vaccination site's protocols
- Speak with your healthcare provider about quiet or special hours

Remember...

- COVID-19 and the flu have similar symptoms
- It's possible to get the flu and COVID-19 at the same time

Rare Artist Deadline: Thursday, October 1, 2020

The **Rare Artist Program** raises awareness about rare diseases by amplifying people's stories through art. Participating in the Rare Artist Contest is a way of getting your voice heard. Anyone connected to the rare disease community can submit artwork, including caregivers, patients, physicians, siblings, and friends. Children ages 4 years and up can enter as well. Amateur artists are welcome and encouraged to enter the contest.

Submit artwork **here**.

If you do not have a Facebook account, or do not wish to participate in the public voting in the Facebook category, you may enter by emailing **lcundiff@everylifefoundation.org**

Stay Informed for the 2020 Elections

EveryLife Foundation has created a resource to help you and rare families as you make your decisions for the U.S. elections on Tuesday, November 3rd. It is so important to make sure the rare voice is heard on the local, state, and federal levels.

Visit **here** to view a list of resources compiled for the rare disease community.

Understanding the Sibling Perspective

October Family Connections Zoom Chat

Stay tuned for the next installment of our monthly Zoom Family Connections series, coming to your inbox soon. October's topic focuses on the sibling perspective.

Save the Date: Tuesday, October 20, 2020
7 p.m. (ET) / 6 p.m. (CT) / 4 p.m. (PT)

Please join us for an in-depth conversation featuring parents and siblings. Paritipants are invited to join in the discussion of life in a rare family while siblings share their unique perspective.

Kyla and Jessie - Rare Siblings Featured in Courageous Parents Network Short Film for The Disorder Channel

Global Genes hosted their annual Patient Advocacy Summit virtually this year. They opened the summit with several watch parties including one focused on the sibling experience. Kyla, whose brother William had GM1 Gangliosidosis, joined CPN founder and rare parent, Blyth Lord, for a live chat following the film. She candidly and eloquently shared her perspective as she reflected on how being a rare sibling has impacted her.

We invite you to watch the film **here** and then join us on the October 20th Zoom Family Connections Chat to talk more about this topic!

Orphanet Journal of Rare Diseases

RESEARCH Open Access

Patient and caregiver perspectives on burden of disease manifestations in late-onset Tay-Sachs and Sandhoff diseases

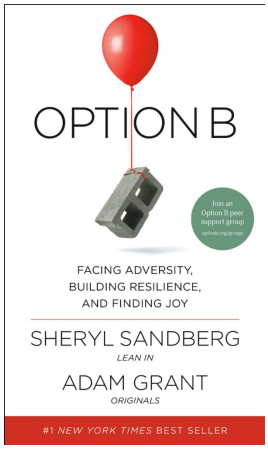
The Impact of the Late Onset Assessments at the Annual Family Conferences from 2015-2019

A paper was published earlier this year about what investigators learned from five consecutive years of assessments with Late Onset GM2 adults at the NTSAD Annual Family Conferences. The information learned helped launch the Sanofi Genzyme clinical trial along with some of the trial design.

Read the full paper **here**.

Thank you to all who participated!

Coping with Loss: Book Reviews



Option B: Facing Adversity, Building Resilience, and Finding Joy by Sheryl Sandberg and Andy Grant

A Review by Becky Benson

In *Option B*, Sheryl Sandberg discusses her deeply personal journey through grief following the sudden and unexpected loss of her husband. Part memoir, and part self-help, *Option B* motivates readers to find both meaning purpose in their grief as they continue to live on past the death of a loved one. Sheryl shares her intimate journey through the highs and lows of mourning and perseverance as a family. She humbly encourages those living with loss to continue to navigate their journey despite the pain, and to realize that even in the midst of such trauma, life can still be beautiful.

Say Their Names

Isabelle Vieira
September 16, 2018 - September 21, 2020
Daughter to Cibelle Vieira and Alexandre Candido Dos Santos
Little sister to Thiago

**If your loved one's name is missing, our most deepest apologies.*
Please send Diana the right information and dates to make those corrections.

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

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