



## Lifeline Online A Family Newsletter

FEBRUARY 2019

# RARE DISEASE DAY 2.28.19



Rare Disease Day is on February 28, 2019.

It's a day where we recognize that we are part of a global community of rare faces, rare stories and rare families.

Let's make some noise and spread awareness about who we are, what we do and who we do it all for every day!

Ways to participate:

Show you're rare by sharing! Send us your rare picture, what makes them happy and content, and we'll share it the week of Rare Disease Day!

Tell your story! Upload your story [here](#) to the Rare Disease Day website and represent GM1, Tay-Sachs, Sandhoff and Canavan diseases.

### A RARE PROFILE FRAME

Show you are rare this month with this profile frame [here](#).



### THE 2019 RARE VIDEO



### THE RARE FACTS

1 in 10 people have a rare disease.

350 million people worldwide have a rare disease.

95% of rare diseases lack an FDA approved treatment.

## Attend Rare Disease Week on Capitol Hill!

This is an unique opportunity to share your story with members of Congress and meet other advocates to learn more about legislation and policy that affect our rare community. Learn more about how you can attend January 24-28, 2019 [here](#).

Rare Diseases impact more people than HIV and cancer combined.

Get more facts from Global Genes [here](#) and share them.

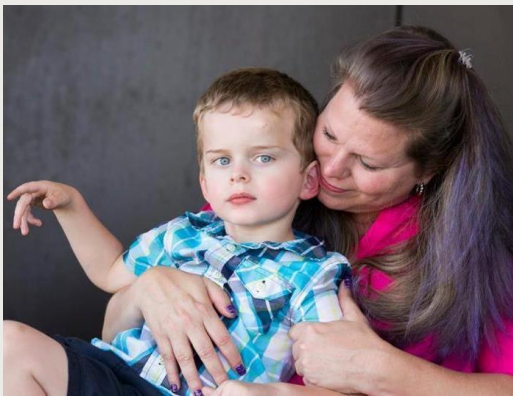
## **Congratulations!**

It is our privilege and honor to recognize two very special members of the NTSAD community, Brian and Sherri Manning, as recipients of one of the Sanofi Genzyme 2019 TORCH Awards! TORCH Awards put a spotlight on "the inspiring patient advocacy efforts of individuals, families and friends in the rare disease community."



## **IT'S ALMOST CONFERENCE TIME!**

April 11-April 14, 2019, Raleigh, NC | Marriott Crabtree Valley



We hope you consider coming to the conference this year so you can **meet and interact with the companies, scientists and doctors** who are developing therapies for GM1, GM2 Tay-Sachs and Sandhoff, and Canavan diseases. *(Read the last issue of NTSAD's Research Review [here](#).)*

They WANT to meet you, your children, and hear about your experiences!



We have a **Helping Hand Grant Fund** to help with the costs of registration and hotel nights.

Visit the conference website [here](#) for more information.

Email **Becky**, NTSAD's Conference Coordinator if you have questions or want more information about the conference.

# Siblings, Moments, PINs and Connections



NTSAD can customize brochures and fliers with your pictures and specific to any form of Tay-Sachs, Sandhoff, GM1 and Canavan to help you raise funds, awareness and educate people you meet in your community.

Send two-three of your favorite photographs as JPGs or PNGs to Diana here and we can print them out and mail them to you.

Give us at least two weeks to get them produced and printed.



Emma's Fund for Families was created by Becca and Gary in memory of their daughter Emma to give families the opportunity to create special memories and moments.

Some ideas are photography sessions, a membership to a favorite museum or local pool, or a weekend trip for the family.

Apply [here](#) for an opportunity to be in the moment with your family and post what you've done with your Emma's Fund grant!

## Have You PINNED GM1, GM2 or CANAVAN?

Thank you to those of you who have registered with your PINs. It is exceptionally helpful!

For anyone who has not taken a few minutes to register, we ask you to please take a moment and sign up. It is an easy way for us to share a clear picture of the impact of the diseases to researchers and companies looking to develop therapies for GM1, GM2 and Canavan diseases.

Visit [here](#) to find your PIN.



Would you be interested in a virtual video chat to meet other parents before the conference?

Yes

Select

No

Select

## Please welcome...

(Since April 2018)

Caitrin and Kyle  
Parents of Embree  
(Sandhoff)

*6/11/2017 - 9/17/2018*  
TEXAS

Franz and Nathalie  
Parents of Wrantzly  
and Nayalie (Tay-Sachs)  
Ages 5 and 3 ½ months  
MASSACHUSETTS

Deanna  
Late Onset Tay-Sachs  
ONTARIO, CANADA

Tom  
Late Onset Tay-Sachs  
WISCONSIN

Lorraine  
Sister of Keith (Late Onset  
Tay-Sachs)  
ENGLAND

Marie  
Parent of T-Jay (GM1)  
Just turned 2 years old  
ENGLAND

Amanda and Manuel  
Parents of Andrea (GM1)  
14 months old  
MALTA

Toni and Cameron  
Parents of Islah (Tay-  
Sachs)  
*3/3/2014 - 8/13/2018*  
AUSTRALIA

Alejandra and Luis  
Parents of Guiliana and  
Facundo (Juvenile Tay-  
Sachs)  
Ages 13 and 8  
ARGENTINA

Kristen and Dan  
Parents of Ava Rose (Tay-

Gina  
Parent of Frank (Juvenile  
GM1/Morquio)  
CALIFORNIA

Alecia and Zach  
Parents of Brayden  
(GM1)  
*11/17/2017 - 2/2/2019*  
MONTANA

Milagros and Oscar  
Parents of Victoria (Tay-  
Sachs)  
She will be 2 years old in  
July  
ARGENTINA

Brianna and Gabriel  
Parents of Maximus  
(GM1)  
He turned 2 years old in  
January  
ARIZONA

Beatrice  
Parents of Emy  
(Sandhoff)  
She is 2 years old  
FRANCE

Ghilary  
Parents of Arí Gustav  
(Tay-Sachs)  
He will be 2 years old in  
May  
PERU

Hannah  
Parent of Natalie  
(Sandhoff)  
She is one year old  
IOWA

Judith  
Parent of Emely Camila  
(Tay-Sachs)  
She turned 3 years old in  
December  
WISCONSIN



Robert  
Parents of Malgorzata  
(Canavan)  
She is one year old  
POLAND

Vidya  
Parent of Divyansh  
(GM1)  
Just turned 3 years old  
INDIA

Manj  
Parents of Anshdeep  
(Sandhoff)  
One year old  
INDIA

Brittany  
Grandmother of Naleiha  
(Tay-Sachs)  
She will be 2 years old in  
April  
HAWAII

Prabin  
Parents of Priyan  
(Sandhoff)  
*8/5/2015 - 3/28/2018*  
NEPAL

YunYun  
Parent of Shenghe (Tay-  
Sachs)  
One year old  
CHINA

Daniel  
Parent of Kinsley (Tay-  
Sachs)  
She will be 2 years old in  
April  
INDIANA

Katrina  
Parent of Daisy (GM1)  
She turned one year old

Sachs)  
She will be 2 in May  
ALASKA

Kelsey and Zachary  
Parents of Kaydence  
(Canavan)  
She turned one year old  
in January  
TEXAS

Sandra  
Late Onset Tay-Sachs  
MISSOURI

Shannon and Ryan  
Parents of James Ryan  
(Tay-Sachs)  
He turned two years old  
in December  
OHIO

Jalisa  
Parent of Miya  
(Canavan)  
She will be three in June  
KANSAS

in December  
ILLINOIS

Shelly and Patrick  
Parents of Elliot Brian  
(Sandhoff)  
One and half years old  
KENTUCKY

Connie  
Parent of Lilah (Tay-  
Sachs AB)  
Six years old  
MINNESOTA

## ***Forever remembered...***

*Since April 2018*

Luke Ackerman (Juvenile GM1)  
Son of Deborah and Casey  
*12/8/07 - 8/19/18*

Isaiah Ackerman (Juvenile GM1)  
Son of Deborah and Casey  
*9/4/10 - 12/15/18*

Embree Alexander (Sandhoff)  
Daughter of Caitrin and Kyle  
*6/11/17 - 9/17/18*

Fernando Arcanjo (Juvenile Tay-Sachs)  
Son of Cintia  
*1/7/19*

Haylie May Binder (Tay-Sachs)  
Daughter of Eva  
*5/13/10 - 4/1/18*

Ariel Coover (Canavan)  
Daughter of Peggy and Walter  
*5/17/05 - 5/31/18*

Islah Faint (Tay-Sachs)  
Daughter of Toni Cameron Hill  
*3/3/14 - 8/13/18*

Brayden Gloege (GM1)  
Son of Alecia and Zach  
*11/17/17 - 2/2/19*

Daniel Hernandez (Tay-Sachs)



David Klauber (Late Onset Tay-  
Sachs)  
*8/31/1952 - 10/12/2018*

Ross Nash (Late Onset Tay-Sachs)  
*1/29/1955 - 4/28/2018*

Jacob Schwartz (Canavan)  
Son of Ellen and Jeff  
*5/17/97 - 1/28/19*

Chaya Tova Schwartzman (Tay-  
Sachs)  
Daughter of Nechama  
*7/3/08 - 10/31/18*

Richard Strauss (Late Onset Tay-  
Sachs)  
Son of Iris  
Brother of David, Robert, and Eric  
*4/1/65 - 7/25/18*

Kaiden Sturgeon (Sandhoff)  
Son of Kristen Brad Harper  
*5/26/15 - 1/6/19*

Carson Witte (Tay-Sachs)  
Samantha and Aaron

Son of Kareen  
11/13/2013 - 4/9/2018

11/4/15 - 10/18/18

*If we're missing anyone, we send our  
apologies and deepest condolences.  
Please let Diana know and email her  
here.*

**We need your input to help us develop a solid bereavement program.**  
Please send what you think would have helped you in the weeks, months and year  
that followed. Email Monica, Oralea or Diana with your thoughts. Thank you!!!

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### NTSAD Family Support Services

Diana Pangonis  
Director of Family Services  
Email [here](#)

### Family Services Committee

Monica Gettleman (email [here](#))  
Oralea Marquardt, MSW (email [here](#))

### NTSAD

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### Connect with us

