NTSAD Lifeline

Community and Connections for Families and Individuals

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

JULY 2020

In this Issue

NTSAD's South Florida Families Make a Difference

For more than five years **the Mathew Forbes Romer Foundation** has been educating nurses in Southern Florida twice a year about the important role they will play as part of the care team for a rare child.

On June 24th, Kevin Romer, Mathew's dad and a NTSAD Board member, along with fellow NTSAD moms and Board members, Monica Gettleman and Oralea Marquardt, shared their experiences and wisdom with more than 160 nursing students as part of their genetic pediatric nursing class from Nova Southeastern College of Nursing via a virtual live chat.

Monica participated in the trainings as a tribute to her daughter Brooke, highlighting *"nurses must be the voices for children who cannot speak."*

Remembering her own experience with her son, William, as well as in her role as a social worker specializing in palliative care, Oralea shared that at the time of diagnosis of a rare disease, families are especially fragile and vulnerable, empahsizing it's nurses who can make all the difference during this difficult time. In addition, during hospice care, nurses become an important member of the care team, and for many feel like family. *"Pediatrics is truly, family-centered care."*

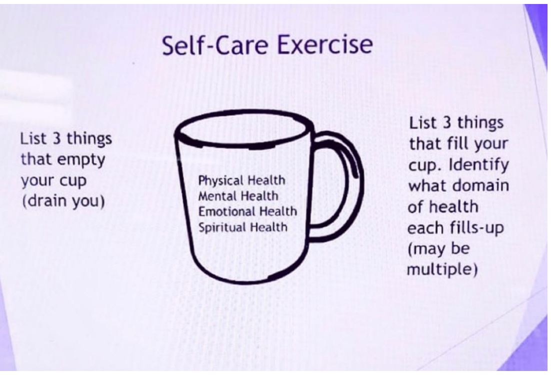
To learn more about this invaluable program, visit the Mathew Forbes Romer Foundation site **here**.

Caregiving: The Hardest Part May Be Caring For Yourself

In the last year, NTSAD has heard from **#** families seeking support and connection after receiving a diagnosis. The world has been turned upside down and you wonder, "What do we do now?" "How are we going to get through this?" We know our powerful NTSAD community offers so much-- sharing experiences about what worked, what didn't, and what things to try. A common theme for our rare families is coping with family members and friends who don't understand or know the best ways to provide support. Others struggle with caring for themselves while caring for others.

That's where Courageous Parents Network can provide additional support and resources on their website, courageousparentsnetwork.org, via curated videos, articles, and other materials to navigate topics like these. **On Coping, Family & Relationships --** Courageous Parents Network advises,

"It's natural to want to put your sick child first at all times. And then you need to care for your other children if there are any. And then there is your relationship with your spouse or parenting partner, if you have one. ***But despite what you may think, it is not selfish to also want to take care of yourself. You, too, need care.*** *When you find ways that tend to these relationships that work for you, you feel better about parenting, advocating, and keeping your relationships strong."*


Self-Care Exercise

List 3 things that empty your cup (drain you)

Physical Health
Mental Health
Emotional Health
Spiritual Health

List 3 things that fill your cup. Identify what domain of health each fills-up (may be multiple)

This spring, Oralea Marquardt, MSW, Youth and Family Grief Counselor, Treasure Coast Hospice and William's Mom, talked about self care and the importance of "refilling your cup." She encouraged families and caregivers participating in the Zoom chat to think of their individual physical, mental, emotional, and spirtual health. Then she asked families to list three things that drain their cup and three things that fill it. And she reminded all to do more things that fill the cup!

Every month, Lifeline will feature a self-care exercise. You know the saying, "put the oxygen mask on yourself first, before assisting others." Share your favorite way to take a time-out for yourself on Facebook and Instagram. #NTSADSelfCare

Late Onset in the News

A member of the NTSAD Late Onset Tay-Sachs Community, Jessica Kalnas and her mother were interviewed by *The Washington Post* for the "Medical Mysteries" column. Reporter Sandra Boodman clearly illustrated Jessica's struggle with clumsiness and journey to receive a proper diagnosis. Thank you to Jessica for sharing your story and raising awareness.

Stay Connected: Late Onset Community Zoom Chats resume in August and occur on the third Wednesday of every month at 8 p.m. (ET) / 6 p.m. (CT) / 5 p.m, (PT) - watch your inbox for the Zoom link for August 19th.

Coping with Loss

It's back-to-school season, and while many children will continue homeschooling due to Covid, the stores are still filled with notebooks, backpacks, and dorm accessories--reminders of what has been lost. Oralea Marquardt, NTSAD mom, wrote a timeless piece about navigating the grief that comes along with unmet life events. She wrote, "The beauty of William’s life, and the love I have for him will never be defined by milestones."

Read her full post **here** and find comfort knowing that you're not alone.

Jeffrey & Stanley Gottlieb Sibling Scholarships

Now accepting 2020 Sibling Scholarship applications. Deadline is August 31, 2020.

The Jeffrey Alan Gottlieb and Stanley N. Gottlieb Memorial Scholarship Funds awards monetary grants to healthy siblings in rare families attending college. Siblings of children and adults who are or were affected by Tay-Sachs, Canavan, GM1, Sandhoff, or an allied disease may apply for financial support.

Download application

After experiencing both love and loss, Judy Gottlieb has chosen to move forward in her life by demonstrating support and generosity to other rare families by investing in their bright futures. In May 2005, Judy, a mother and grandmother from Somerset, NJ, established two separate memorial college funds with NTSAD to honor her youngest son, Jeffrey Alan Gottlieb, who succumbed to Tay-Sachs in 1975, and her husband, Stanley N. Gottlieb, who passed away in 2001.

Judy's intent is that the monies be distributed for use toward college education, i.e., tuition, books, room, and board. Download the application **here**.

Let's Celebrate the Class of 2020 and all the NTSAD Family Graduates!

We know it wasn't the senior year anyone could have predicted, but you graduated. You did it! Congratulations to all of our graduates, including to the right - Jeremy Davis (Adam's brother), Katie Futterman (Billy's sister), and Kyla Marquardt (William's sister).

10th Annual Day of Hope: It's the Season of Hope

Each year, families and companies participate in the NTSAD's Day of Hope to raise awareness and critical funds for research and programs serving rare families. They create and hold events on a Day of Hope, engaging family, friends, colleagues, vendors, and their communities on or before September 12, 2020. **This year marks the 10th Anniversary of Day of Hope, and with so many clinical trials on the horizon we are truly in a Season of Hope!**

To date, more than **$500,000** has been raised since our First Annual Day of Hope on September 18, 2011. Now more than ever, we are searching for connection and community. **Day of Hope events unite people in our shared cause to find effective treatments for individuals affected by Tay-Sachs, Canavan, GM1, and Sandhoff.**

Join us by hosting an event to strengthen our rare and mighty community during our Season of Hope. Questions? Contact Becky at **becky@ntsad.org**.

Say Their Names

(April 2020 - July 2020)

Julie Cain
February 9, 1968 - June 8, 2020
Daughter of Susan Cain and Sister to David Cain

Max Randell
October 9, 1997 - April 18, 2020
Son of Ilyce and Michael
Brother to Alex

Macklen Alger
January 23, 2016 - May 26, 2020
Son of Hayes and Ryan
Brother to Findley

Lilah Yang
September 26, 2012 - July 4, 2020
Daughter of Connie Yang
Sister to Pac

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

Welcome to the World

Breeson Bryant Alexander
Born on July 8, 2020
Daughter of Caitrin and Kyle Alexander

Luke Michael Stevenson
Born on June 15, 2020
Son of Teresa and Scott Stevenson

Little sister of Embree *Little brother of Allan and Grant*

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

STAFF
Sue Kahn, Executive Director
Becky Benson, Family Services and Conference Coordinator
Sydnie Dimond, Development and Communications Associate
Susan Keliher, Director of Development and Communications
Ingrid Miller, Development and Administrative Associate
Diana Pangonis, Director of Family Services

NTSAD
2001 Beacon Street
Suite 204
Boston, MA 02135

info@ntsad.org
www.NTSAD.org