A Message from NTSAD's Family Services

Over the last year, NTSAD went through a Strategic Planning process to evaluate our unique strengths, listen to the perspectives and needs of the NTSAD community, and update our goals as we move into the world of clinical trials.

As a result of the new 5 year strategic plan, my role as Director of Family Services now encompasses more program development as well as clinical trial advocacy and education. I will still be here for you and your family with whatever you need - that will not change one bit.

In light of our new plan and priorities, I'm thrilled to let you know that Becky Benson's role as our Conference Coordinator is now shifting to be my Family Services partner as the Family Services & Conference Coordinator.

Becky wrote, ""As a parent and member of NTSAD for the last eleven years, and after serving as NTSAD Conference Coordinator for the last six years, I am overjoyed to assume the role of Family Services & Conference Coordinator. I look forward to continuing to serve the families and individuals of NTSAD, and working with my fellow staff members, parents, friends, and supporters."

Becky and I are here for you. Please feel free to contact either one of us for whatever you need. Becky's email is becky@ntsad.org and mine is diana@ntsad.org.

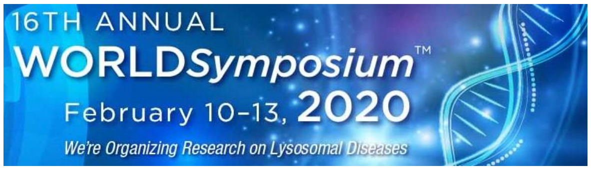
Best,

Rare Disease Day is every day for our community which means you can always take action to share your voice when it comes to the issues that impact the rare disease community. There are two issues you can bring up to your local representatives that can make a difference.

- Encourage your senators to be cosponsor for the Newborn Screening Re-authorization Act that is sitting in the Senate waiting for a vote. The goal is to have 50 bipartisan cosponsors for this bill - the Senate 2158 (but with the HR 2507 proposed amount of $60 million).(Find your elected officials **here**.)
- The need for a Center of Excellence for Rare Diseases at the FDA to ensure there are consistent policies in place that impact rare disease research and therapies. Read more about it **here**.

The Rare Disease Legislative Advocates (RDLA) has a group of advocacy tools that you can access **here** to help you advocate in your community.

WORLD Symposium | February 2020



The 16th annual WORLD symposium was held in Orlando, FL the week of February 10th where scientists, researchers, industry and patient groups came together to discuss and share information about the world of lysosomal diseases.

Sue Kahn, Executive Director, and Staci Kallish, DO, NTSAD's Board chair attended and had a busy week meeting with companies and researchers. A synopsis of what they heard will be sent out and shared with you all in a couple of weeks. Sue is in direct communication with a number of companies that have an interest in applying their technologies in developing possible treatments for one or more of our diseases including Canavan, a leukodystrophy. These companies turn to NTSAD for guidance, information and advice on best practices.

Courageous Parents Network: Clinical Trials Pathway

The complicated and sometimes convoluted world of clinical trials is at our doorstep and we're knee-deep in understanding all the nuances.

Courageous Parents Network just launched their clinical trial unit to help parents navigate the issues that may come up for their families. Diana, NTSAD's Director of Family Services, took part in one of their podcast interviews about how to offer support for families as we move through clinical trials.

Visit this important unit **here** to explore the issues that come up for you and your family. Diana, Director of Family Services, took part in a podcast interview about supporting families through clinical trials.

To watch the NTSAD Be Informed webinar about Clinical Trials, visit our page ***here****.*

NTSAD 42nd Annual Family Conference

Do you have questions about the conference?

We can help answer all your questions and help you figure out how you can be in Denver the weekend of May 28 - 31st to connect with the community, meet the people working on therapies, and share and learn about how to care for yourself and your family.

Join our weekly ZOOM call next Friday, March 6 at 10:00 am (EST) to talk with Becky, Monica and Diana about any concerns or questions you have about the conference.

JOIN the CALL

Airline Special Request Numbers

Flying can be daunting when you have to worry about more than just a suitcase. We recommend that you call the airlines ahead of time to make sure you have no surprises on the day you're traveling.

This link **here** is for a list of all the airlines and their special disability service web pages and phone numbers (in the U.S.).

NTSAD Annual Family Conference Website

To find the latest news, session descriptions and information about registration, hotel reservations and Helping Hand Grants, please visit the conference website **here**.

NTSAD Family Service Hours Online

with Becky Benson and Diana Pangonis

Every Friday from 10:00-11:00 am (EST). There is no pressure to stay for the whole hour so you can still stop by even if you have just 15 minutes. We'd love to see you.

Follow this link **here** to access the meeting every Friday.

NTSAD

Staff
Sue Kahn, Executive Director
Becky Benson, Conference Coordinator
Ingrid Miller, Development & Admin Associate
Diana Pangonis, Director, Family Services

NTSAD
2001 Beacon Street
Suite 204
Boston, MA 02135
(617) 277-4463 | www.**NTSAD**.org