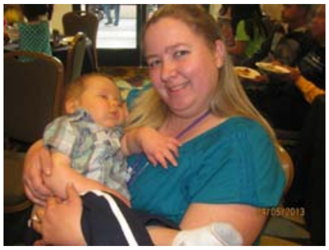
NTSAD
National Tay-Sachs & Allied
Diseases Association, Inc.

National Tay-Sachs & Allied Diseases Association

Keeping Up with NTSAD, April 2013

In This Issue



Dear Diana,

Three weeks ago NTSAD hosted its 35th Annual Family Conference in San Diego. Nearly 200 members attended for a long weekend of compassion, hope and support. It was my sixth conference and it still moves me how this incredible group of parents and individuals support one another unconditionally. It is also clear to me how important our work with research and raising awareness about these rare diseases is to all of them.

In this special e-edition of "Keeping Up with NTSAD" we share stories and highlights of the conference in words and pictures. I encourage you to click through and read more on our website about this unique and restorative weekend. Your support makes it all possible!

Most sincerely,

Sue

Sue Kahn
Executive Director

In Others' Words

Miss Elliott's Mom Becky wrote, *There's something so remarkably freeing about having the opportunity to exist, for however long, in a state of total nonjudgmental acceptance. Not merely the absence of the words of judgment but the complete absence of judgmental thoughts and feelings as well. We can cry, we can laugh, we can just be ourselves...no questions asked.* Click **here** to read more.

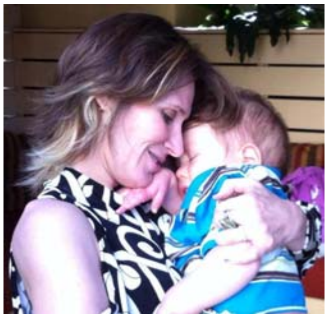
William's Mom Oralea Marquardt wrote, *This was our 6th conference and each year as I try to describe the weekend, I feel I cannot find the words that can give justice to how it feels to be* *surrounded by complete understanding and love. If you could take a small glimpse of the weekend, you would see a mom who is grieving the loss of her child comfort a new family as they cope with the knowledge that their child will slowly decline and are overwhelmed with the medical interventions that are to come. In turn, you would see a newly diagnosed mom or dad offer the best gift they can give - a moment of holding their child. The best hugs are given at conference. The best talks are had. There are tears, there is laughter.* Click **here** to read more.

Dr. Kaback with Shari Ungerleider, NTSAD President

Conference Award Honorees

It was with great pleasure that NTSAD honored Dr. Michael M. Kaback with the *Above and Beyond* Award and Cynthia Schwartz with the *Ethel Berkman Power of One* Award. Each year NTSAD recognizes the outstanding efforts of those who have demonstrated extraordinary commitment to the families and mission of NTSAD.

Click **here** to read more about the Honorees.

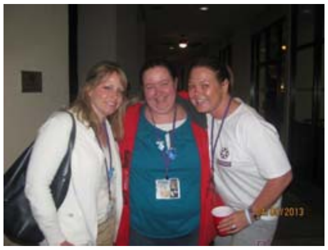


NTSAD honoree, Cynthia with Isaac.

Research Update Session

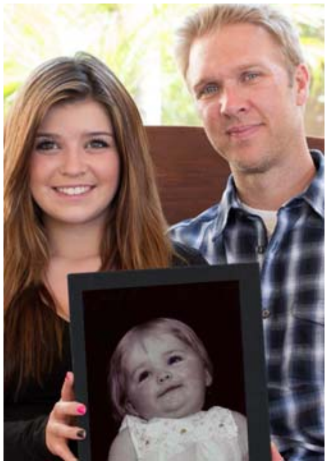
The small group discussion format gives families the opportunity to connect directly with leading researchers. Gone are the days of long lectures too technical for most to understand. Families are encouraged to ask questions and keep the lines of communication open. The scientists appreciate the chance to connect directly with those they are trying to help, as one speaker said "being able to meet the families and the people that we are trying to help was very motivating!" Click **here** to read more about this engaging session.

At the Conference, we also announced that a Research Initiative grant award was made to Alessandra d'Azzo, PhD, of St. Jude Children's Research Hospital for her proposal, "Studies of the molecular and biochemical bases of neurodegeneration in sialidosis". The researcher and her group have a reputation for delivering high quality research. They have published a lot in the field of lysosomal storage disorders (LSDs), including in GM-1. This is a basic research project studying lysosomal biology and function of lysosomes in a mouse model of sialidosis. Data gained from this could be important across many lysosomal diseases and may also apply to more common neurodegenerative diseases. Dr. d'Azzo submitted one of 16 grants that were received in NTSAD's annual Request for Proposal process.



Living with LOTS

Though the number of families coping with Late Onset Tay-Sachs (LOTS) at the Annual Family Conference was few in numbers, their



spirit and courage is beyond measure. Their small but mighty group attended the general sessions with all attendees as well as sessions specific to their unique needs and challenges that included Q & A with clinical expert Dr. Susan Perlman, 'Coping with Isolation and Finding Support,' 'How Current Research Relates to LOTS' and 'Promote Independence through Exercise.' After two days filled with informative and empowering sessions, families coping with all forms of the disease, speakers, volunteers and Board Members joined the LOTS families to light a candle, raise a glass of Bailey's and share stories and memories of friends lost to LOTS. Click **here** to read about Cary Berman's first conference experience.

3rd Annual Day of Hope Kick Off!

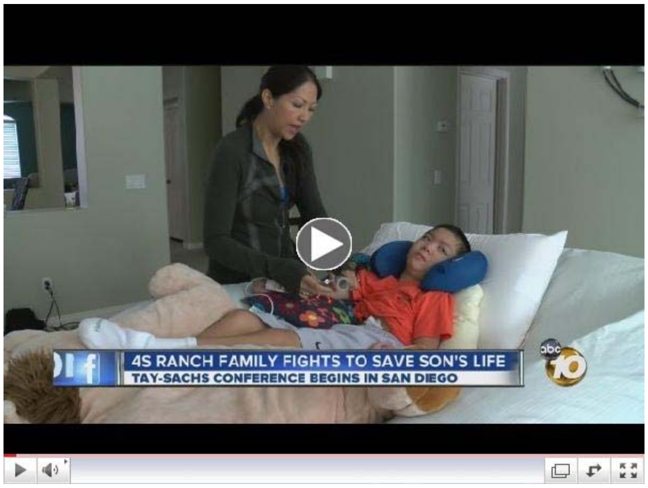
Dylan's dad Brian Manning, Jase's mom Ashley Watson and Brookie's mom Rose Urban hosted the 'Honoring Your Loved One' session under the San Diego sun with refreshing beverages and sweet tasty treats. Their passion was contagious, which is exactly their message to inspire people to get out and raise awareness and funds! ~~The goal is to raise at least $50,000 for research on our 3rd Annual Day of Hope on September 21, 2013.~~

Call NTSAD and we can help with the details! Speak with Diana, Communications Manager, and she can provide materials, help you develop a planning timeline and connect with a mentor who has done a similar event.

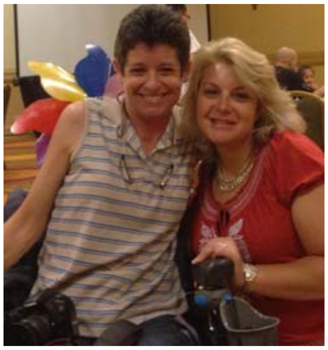
In the News

Thank you to Janelle Marquez for leveraging her media contacts to get Annual Family Conference coverage on TWO local news stations!

Click **here** to view NBC coverage. And click below to view the ABC coverage.

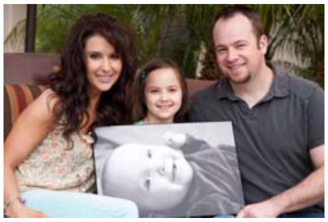


Local family battles Tay-Sachs disease, fights to save son's life

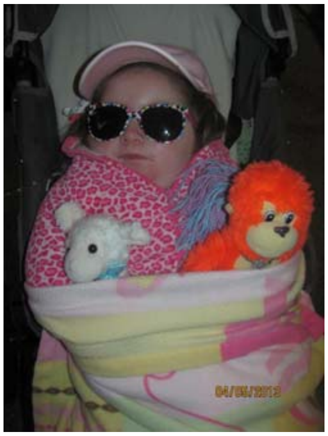


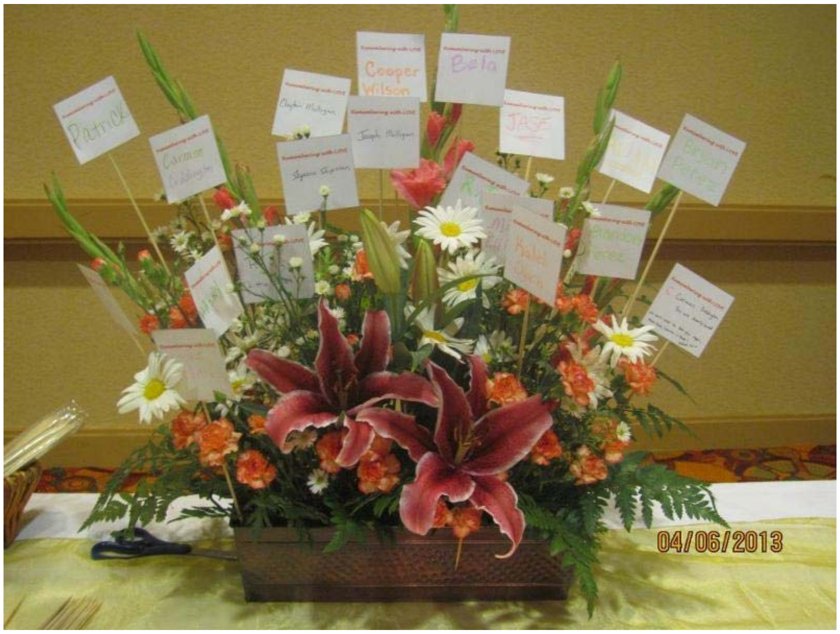
Living with Grief by Becky Benson

In attending the 35th Annual NTSAD Family conference I was so honored to have been asked to facilitate the first bereavement session of the weekend for our members. This year, as we made our way back to the west coast for the first time in sixteen years and also reached out to past attendees we were very heavy on the bereaved families. As a group with ever changing needs it's important that we do our best to make sure every member feels welcomed and supported. This year that meant making sure everyone had the opportunity to share their story and honor the memory of their loved one.



Nothing compares to being with others who truly understand your feelings, and in the absences of judgment shower you with nothing but love. When we gather together it's immediately evident how strong of a bond we all share, how present the names of our loved ones are on our hearts, and how committed we all are in the fight for the lives of those affected by these allied diseases.





Memorial Garden

A great way to get to know NTSAD and our families is to follow us on **Twitter**, subscribe to us on **YouTube** and "Like" our **Facebook** page.

The more awareness the better!

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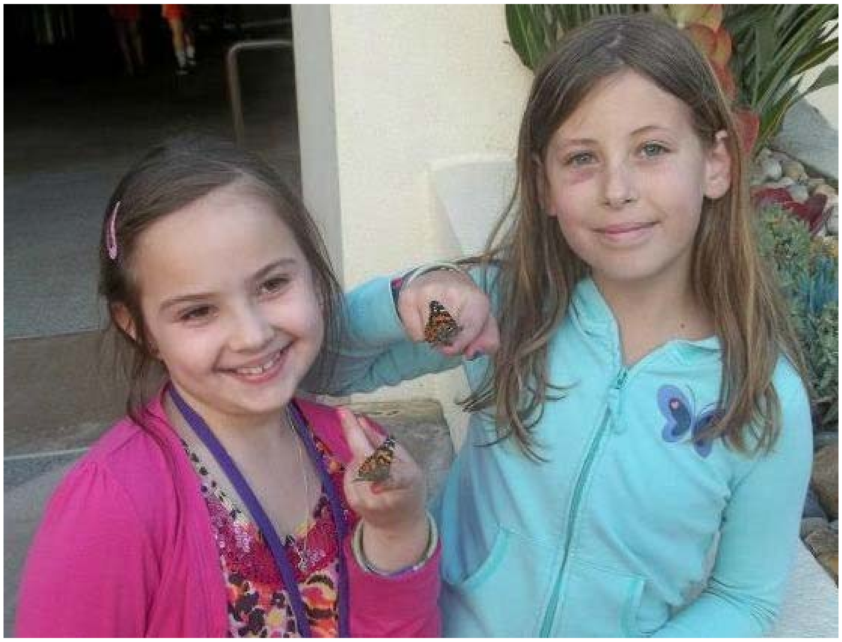
View our videos on YouTube

Like us on Facebook


Butterfly Release after Commemoration Ceremony

An Opportunity to Say Thank You

NTSAD hosted a reception for local donors, friends and supporters during the conference. It was a wonderful opportunity for donors to see first hand how their support helps families. Sienna's dad Dave Caponero shared:

Thank you so much for inviting Bonnie and I to the San Diego Reception. It gave us an opportunity to reunite with our Tay-Sachs family. Seeing the strength, love, and commitment in person was overwhelming. We are truly blessed to be associated with such wonderful people and an amazing organization.

To our generous **sponsors** for making this amazing weekend possible!

The Spring 2013 print edition of "Keeping Up with NTSAD" will be mailed and in your mailbox soon.To make a gift to support these amazing families, research and the good work of NTSAD, please **click here.**

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