



National Tay-Sachs & Allied  
Diseases Association, Inc.



Topic of the Week

Friday, August 2, 2013

*Part of the healing process is sharing with others who care.*

*~ Jerry Cantrell*



Stew & Lorrie

## Families...In the News



Miss Brielle and her family had a big bash on July 27th in Beloit, Wisconsin as they held the Third Annual Battle for Brielle. Their benefit was held at the Rock Bar

& Grill from 11am to 11pm with live entertainment, games, face painting, raffles and refreshments throughout the day.

Local reporter, Hillary Gavan, wrote a nice article leading up to the event in the Beloit Daily News. [Click here to visit their website and read the article.](#)



Becky with Miss Elliott



Our handsome friend, Dylan, and his parents were featured in an article on



Shelly with precious Kaleb



Julie at the beach

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help find a cure and  
care for families**

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*We are here to help!*

Sue Kahn  
Executive Director  
[skahn@ntsad.org](mailto:skahn@ntsad.org)

myCentralJersey.com on July 24th. The article reflects a common theme of embracing each moment in itself and not focusing on what won't be. [To read more about Noreen and Cliff's outlook, visit myCentralJersey.com.](#)

### **Editor's Note:**

Contacting local media and sharing your story can have an amazing impact and a terrific way to raise awareness in your community. If you need help contacting local media, email Diana at [diana@ntsad.org](mailto:diana@ntsad.org).

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## **Screening...In the News**

A couple of articles published online this week featured news related to testing and screening.

News from [www.oregonlive.com](http://www.oregonlive.com) shared news that Kaiser Permanente Center for Health Research will receive an \$8 million grant to look for recessive mutations in parents who could be carriers of genetic disorders such as Tay-Sachs or Canavan diseases.

Dan Goldberg from the [Star Ledger](#) in New Jersey wrote an article regarding NJ Governor Christie's commitment of \$1.6 million to fund Emma's Law which would require newborns in New Jersey to be screened for lysosomal storage disorders.

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## **Upcoming Events**

**Wednesday, August 14th**  
**[5th Annual 'Fore' Jack Memorial](#)**  
Golf & Tennis Outing  
Piping Rock Club, Locust Valley, NY

Kim Kubilus  
Family Services Director  
[kim@ntsad.org](mailto:kim@ntsad.org)

Joan Lawrence  
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Diana Pangonis  
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**Saturday, September 14th**  
14th Annual Eagle for Emily  
Indianapolis, IN

**Saturday, September 21st**  
**Third Annual Day of Hope**  
*Rally & Raise Funds for Research*

For information about these and any other  
events, contact NTSAD at (617) 277-  
4463.

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