Two Canavan patient registries under development

There are now two efforts underway to develop registries of Canavan disease patients around the world, which help to identify research subjects and facilitate research about the disease.

One is the natural history registry and biorepository the Canavan Foundation co-funded with the National Tay-Sachs and Allied Diseases Association last year, under the leadership of Dr. Heather Lau at NYU. This effort is a collaboration with Mass General and clinicians in Germany to create a unified database that reduces redundancy by providing a unique global identifier and standardized language for data collection.

The other new registry, initiated by Canavan Research Illinois, is the patient-driven Canavan Patient Insight Network, developed by AltaVoice, a company based in Silicon Valley that aims to “optimize the search for better treatments for multiple diseases.”

If you or anyone you know has received a diagnosis of Canavan disease, you can join the AltaVoice registry through a link provided on the Canavan Foundation website.
**In Memoriam, Seth Gelblum**

It is with deepest sadness that the Canavan Foundation mourns the death of board member and co-founder Seth Gelblum, who passed away on August 8th, 2016 after a long illness.

Seth and his wife, Orren Alperstein, founded the Canavan Foundation in 1992 after their 15 month-old daughter, Morgan Gelblum, was diagnosed with Canavan Disease. Seth’s energy and wise counsel were instrumental in the growth and success of the Canavan Foundation. As one of the nation’s foremost entertainment lawyers, he was the force behind the Canavan Foundation’s annual theater benefit. His Q&A sessions with noted theater personalities were a highlight of the dinner before each year’s production.

Seth graduated from Wesleyan University and Georgetown University Law School. A partner at Loeb & Loeb LLP, Seth chaired the firm’s theater department, representing writers, producers, directors, performers and others involved in theater, television and film. Seth received numerous professional accolades throughout his life. Just this year, he was a recipient of a Tony Honors for Excellence in Theater.

In a rare honor, the marquee lights of the Broadhurst, Gershwin and New Amsterdam theaters were simultaneously dimmed in Seth’s memory after a celebration of his life at the Broadhurst Theatre in September.

Alongside his work, Seth was a loving and devoted husband, father and friend. In addition to the Canavan Foundation, he was deeply involved with Lawyers for Children and New Dramatists.

**Theater Gala crowd enjoys “Shuffle Along” on Broadway**

150 Canavan Foundation supporters gathered on May 3 to see *Shuffle Along—Or the Making of the Musical Sensation of 1921—And All that Followed*—the same day the show was nominated for 10 Tony awards. The gala sold out, with proceeds going to support the Foundation’s work in promoting early and complete genetic carrier screening for Canavan and other Jewish genetic diseases.

During dinner before the show we heard a fascinating dialogue between Canavan Foundation board member Seth Gelblum and writer/director George C. Wolfe, about the challenges of taking music from a 1921 musical and writing a brand new book that traced the making of that musical and its cultural context.

**SAVE THE DATE: 2017 Theater Gala: Hello, Dolly!**

The next Canavan Foundation Theater Gala will be *Hello, Dolly!* on **Wednesday, May 24, 2017**. The highly anticipated revival of the classic Jerry Herman musical stars the incomparable Bette Midler, joined by a talented cast of Broadway veterans including David Hyde Pierce. *Hello, Dolly!*—winner of the 1964 Best Musical—is based on Thornton Wilder’s 1955 play *The Matchmaker*. Four-time Tony Award winner Jerry Zaks will direct. In September this production broke the record for the highest first-day ticket sales in Broadway history.