You Don’t Need to Be Jewish to Have Canavan disease

Think Canavan disease is only for Jews? It’s not! Mistakes (mutations) in the Canavan gene can be found anywhere. Most children born with the gene for Canavan disease in recent years had no Jewish ancestry.

If two people, whether Jewish or not, both have a mutation for Canavan disease or any of scores of other genetic diseases, there is a 25 percent chance with each pregnancy that they will have an affected child.

If you remember just one thing: Every couple should be screened before starting a family. Even those with mixed ancestry.

Foundation Outreach Grows

With generous support from our donors, the Canavan Foundation this year nearly doubled the number of Ob-Gyns in the New York area who carry our brochure, poster or training materials. 375 area doctors’ offices said yes to Canavan outreach this year.

We also extended our reach beyond New York, to hundreds of new Ob-Gyn practices in cities with large Jewish populations. We also reach about 1,700 synagogues nationwide, restocking them with materials before the High Holy Days. Our outreach remains popular—both doctors and synagogues use and re-order Canavan patient education materials regularly.

Canavan Patient Registry Aims to Improve Treatment and Find a Cure

If you know of a family that has lost a child to Canavan disease in the recent past, or has a child currently living with it, please urge them to enter the recently-launched Canavan patient registry.

Patient registries bring together standardized data on a group of patients who share a condition or disease. As a registry gathers information, researchers can use it to look for better treatments, and may even discover a route to a cure.

You can find the Canavan patient registry that is funded by the Canavan Foundation and National Tay-Sachs and Allied Diseases at clinicaltrials.gov. Search for “A natural history study of Canavan disease.” For more information, contact Camille Corre at Massachusetts General Hospital (ccorre@partners.org, 617-724-6374).
It’s hard to believe that we have been fighting Canavan disease for a quarter of a century! On May 24, 2017 the Canavan Foundation celebrated its 25th year, with our annual theater benefit featuring *Hello, Dolly!* starring the unforgettable Bette Midler. More than 170 guests attended. At Sardi’s before the show we were treated to a fascinating dialogue between noted entertainment lawyer Stephan Schick and executive producer Joey Parnes, about differences between mounting a new production and a revival, the current economics of Broadway, and the challenges of changing casts on a long-running show.

If you joined us at *Hello Dolly!, Shuffle Along, The Audience, A Raisin in the Sun, The Addams Family, Death of a Salesman, Matilda,* or any previous Canavan Foundation theater benefit, you know what a wonderful evening this is. If not, we invite you to find out this year.

**SAVE THE DATE: 2018 Theater Gala Matinee: Carousel**

The Canavan Foundation’s 26th annual theater benefit on **Sunday April 29, 2018** will feature lunch and a 3pm matinee of Rodgers and Hammerstein’s *Carousel*. The show follows the tragic romance of carousel Barker Billy Bigelow and mill worker Julie Jordan, and features standards including “If I Loved You” and “June Is Bustin’ Out All Over.” Justin Peck of the New York City Ballet is the show’s choreographer. Originally performed on Broadway in 1945, *Carousel’s* most recent revival won a Tony in 1995. You are invited to lunch beforehand at Sardi’s at 12:30pm, where producer Joey Parnes will treat us to an interview with a senior production team member before we head to the Imperial Theater a block away.

**About the Canavan Foundation**

The Canavan Foundation is a non-profit organization dedicated to educating at-risk populations about Canavan disease and other Jewish genetic diseases. We encourage carrier screening and support research that will lead to treatment and a cure for Canavan disease. Your tax-deductible contributions help fund education, outreach, and research programs important to our mission.

**How You Can Help**

- Encourage children and grandchildren to be tested
- Share Canavan website with friends and networks
- Tell your rabbi about our training program
- Ask your OB/GYN to display our brochures
- Write a letter to your temple’s tzedakah fund
- Support the Canavan Foundation by donating

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