Dear Friends:

I am pleased to announce the publication of an updated version of the brochure we provide to rabbis and Ob-Gyn offices all over metropolitan New York. We hope you will share the brochure included in this mailing with anyone you know who may be starting — or expanding — a family.

The brochure highlights that there are now more diseases for which people of Ashkenazi ancestry can be screened — up from 19 to as many as 38. It also emphasizes that interfaith and Jewish couples, as well as those who may not self-identify as Jewish, should consider carrier screening before they start a family. By emphasizing that genetic heritage is separate from religious identity, we hope to encourage even more couples to seek timely and complete carrier screening.

Because the field of genetic testing is changing so rapidly, the new brochure has a free-standing list of diseases for which tests are available, which can be changed as test offerings expand without needing to revise the brochure.

New Brochure Keeps Up With the Times

Early this fall, with our input, the Jewish Genetic Disease Consortium (JGDC), of which the Canavan Foundation is a founding member, produced an updated version of our educational brochure. The brochure will be given to doctors at Grand Rounds — presentations at hospitals — placed in Ob-Gyn offices, and distributed to rabbis and cantors.

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Renewed outreach to Jewish clergy and lay leaders

Several years ago the Canavan Foundation, in partnership with the JGDC, embarked on a program to educate rabbis in the New York area about Jewish genetic diseases and encourage them to recommend preconception screening to couples during premarital counseling.

In expectation of the new updated brochure, we spent several months updating and expanding our database to make sure the new materials get into the right hands. We visited the website of every synagogue in the New York metropolitan area and captured data on all clergy and lay leadership, tripling our list. We plan to offer the new materials to nearly 1,500 contacts and inform them of the updated screening options.

We are actively seeking funding to expand this effort nationwide. We estimate there are at least 3,500 Jewish clergy and lay leaders outside of the New York area. If you are interested in funding a program to identify and contact them, please let us know.

New service offers low-cost saliva-based carrier screening

J Screen is a new, affordable service offering an at-home saliva test for a panel of 40 genetic diseases that are common among Sephardic, Ashkenazi or Mizrahi Jewish populations. Launched in 2013, the service also offers an option to test for 40 additional genetic diseases that are common in the general population.

While the Canavan Foundation does not recommend one screening program over another, we applaud J Screen for providing a program that fills a niche in the market: individuals all over the country who have no local access to affordable screening. See jscreen.org for more information.

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We are still eager to take our Provider and Patient program national. If you have contacts in cities around the country who might be able to help, please let us know. It’s not very expensive to launch a program in another city, and with your help we hope to be able to do so.

I do hope you will be able to join us for our annual theater benefit at “The Audience” in April. Look for details in this newsletter and online.

All the best for a happy and healthy holiday season and New Year!
Seeking to expand education program

Couples in the New York area are now highly likely to receive advice on genetic carrier screening when talking about family planning with their doctors, thanks to our ongoing Provider and Patient Program for New York area Ob-Gyns.

Three years ago the Canavan Foundation launched a program to identify all the Ob-Gyn offices in the New York metropolitan area and to distribute educational materials for providers and brochures for patients to them. We now have a list of over 300 practices, representing nearly 800 doctors, to whom we have distributed over 40,000 brochures. The practices routinely tell us they have come to rely on these materials.

The Canavan Foundation has been applying for grants to expand this program to other cities with major Jewish populations. The program is highly cost-effective: for under $10,000 we can reach all Ob-Gyn offices that serve Jewish couples in a smaller city like Baltimore or Boston; $40,000 would bring the program to a larger market like Los Angeles.

If you know of an individual or foundation who might help fund us to reach new cities, please let us know.

Theater Gala: Raisin in the Sun

On April 29, 2014, 150 supporters and friends of the Canavan Foundation gathered in New York City for our annual theater gala. The sold-out event provided much needed support for the Foundation’s work advocating for early and complete genetic carrier screening for Canavan and other Jewish genetic diseases.

Before seeing mesmerizing performances by Denzel Washington and LaTanya Richardson Jackson, we were treated to a lively discussion between Canavan Foundation founding board member Seth Gelblum (above l.), and the show’s Executive Producer, Joey Parnes (above r.), about the challenges of mounting a revival of a beloved classic, having a 59-year-old Denzel Washington take on the role of a 35-year-old man, and the ways in which the world has — and hasn’t — changed in the half century since Raisin in the Sun premiered on Broadway.

Research update

The Canavan Foundation has long supported research on gene and stem cell therapy. Two researchers we have funded continue to explore therapies for treatment and cure:

Dr. Paola Leone, at Rowan University in New Jersey, explores rare mutations of Canavan disease and refers patients for follow-up and off-label drug therapies. Her human stem cell project for Canavan disease, carried out in collaboration with Stem Cells Inc., has been resubmitted to the NIH and is currently under review.

Dr. Guangping Gao, of the University of Massachusetts Medical School, has been working to develop intravenously delivered gene therapy for Canavan disease. His lab has undertaken several studies; researchers are intrigued that for early time points, treated mice now perform even better than healthy (wild-type) mice on some behavioral tests, prompting them to look into the cause of this “super-mouse.”

For Canavan disease, gene therapy is still a tantalizing promise, but for one boy the therapy provided a cure for another disease. That boy’s story is told in The Forever Fix, a new book by Ricki Lewis, a geneticist, journalist and genetic counselor. The Forever Fix chronicles the fascinating history of gene therapy, a story in which the Canavan Foundation played an important part with respect to the controversy over patenting the gene. Check out Chapter 14 for details.

SAVE THE DATE 2015 theater gala: The Audience

We are excited to announce that the Canavan Foundation’s spring 2015 theater benefit will be Peter Morgan’s play The Audience on Thursday, April 23rd at 7pm. Please note the early start time.

The Audience stars Oscar-winning actress Helen Mirren as Queen Elizabeth. Mirren created the role in the play’s original London production, and is now bringing it to New York. The play breaks the silence on 50 years of Queen Elizabeth’s weekly secret meetings with Britain’s Prime Ministers.

The Canavan Foundation Board is Expanding

We’re actively recruiting new board members, particularly individuals of child-bearing age who would be committed to reaching out to their friends and family about the importance of carrier screening. If you or anyone you know would be interested in joining our board, please contact us.

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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

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