Dear Friends:

It’s been a year of surprises and excitement at the Canavan Foundation. We have been collaborating with several other organizations in the development and launch of COUPLES AWARE, a major new rabbi training program informed by our own market research data. In addition, we helped to fund screening programs and clinical practice in genetic diseases.

Thanks to your past support, we continue to make progress toward the reduction of cases of Canavan Disease and other Jewish genetic diseases. I hope you will continue to support us as we roll out this wonderful training program in the New York area and nationally. We want all rabbis to hear the message of parent Steve Hoffman, quoted in a recent Jewish Week article about our launch: “Please, when you sit down with couples, speak with them about genetic testing. I wish our rabbi did.”

Regards,

president

With the help of the Canavan Foundation, a new training program is informing and empowering rabbis to make discussion of genetic disease screening a staple of their standard premarital counseling sessions.

During the training, rabbis meet parents of children with genetic diseases, learn from a genetic counselor about the science behind screening, and discuss the critical role rabbis play in premarital counseling.

The COUPLES AWARE training program was launched in October 2010. COUPLES AWARE is a program of the Jewish Genetic Diseases Consortium developed in collaboration with the New York Board of Rabbis, with major funding from the UJA Federation NY. Find out more about the training on the “In the News” section of the Canavan Foundation website.

In last year’s newsletter, we described how research funded by the Canavan Foundation revealed that couples who are planning families are the prime audience for testing and education about genetic screening. Rabbis who counsel such couples before marriage were also identified as an ideal group to deliver education and screening information.

This year, working closely with the New York Board of Rabbis, we sent surveys to 725 New York metro area rabbis. The survey results showed that rabbis needed and wanted more and better information for themselves, as well as material to hand out to young couples.

President Orren Alperstein has taken a leadership role in the development of COUPLES AWARE training, one rabbi joked “It looks like a plate of latkes!” eliciting a roar of laughter from the assembled rabbis.

In this photo from Obgyn.net, one cell of a seven-cell embryo created in vitro is siphoned off for genetic testing. Through a process called Pre-implantation Genetic Diagnosis, or PGD, couples at high risk for passing on genetic diseases can ensure that only unaffected embryos are implanted in the woman’s uterus. Seeing this image at a COUPLES AWARE training, one rabbi joked “It looks like a plate of latkes!” eliciting a roar of laughter from the assembled rabbis.

Canavan Foundation research on rabbis’ experiences with counseling about screening for Jewish genetic diseases provided valuable information for the development of COUPLES AWARE, now being rolled out in the New York area. “I am delighted that the JGDC has taken the lead in formalizing this educational outreach to Rabbis,” said JGDC rabbinic advisor Rabbi Peter Kasdan.

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Save the Date for War Horse!

Thanks to all who attended last year’s show, The Addams Family, and had the opportunity to hear producer Stewart Oken speak at the dinner beforehand. Oken described the inside story of how the creators’ morale was affected by early, poor reviews of The Addams Family, but how pleased they felt when it turned out the public liked the show and it generated good business.

"Now and then the theatre throws up a piece of work so exhilarating that it makes you rejoice to be alive."
- The Times of London

On May 5th, 2011 Canavan supporters will be treated to the show War Horse at the Canavan Foundation’s spring 2011 theater benefit. War Horse is the story of a boy seeking his beloved horse, sold to the cavalry at the start of World War I. War Horse, which has been critically acclaimed in London, has been called “a sweeping drama of extraordinary power.” Looking forward to seeing you all on May 5th!

Canavan Foundation Funds Screening Program in Omaha

Far from New York and other centers of Jewish-American life, Jean Duitch created a screening program for Jewish Genetic Disease in the Ashkenazi community of Omaha, Nebraska. Mrs. Duitch, whose daughter wasn’t screened before giving birth to a child with Canavan disease, worked tirelessly to organize a free screening. She enlisted the help of local medical professionals, congregations, and the local Jewish paper. This year the Canavan Foundation supported Mrs. Duitch with a grant to fund an upcoming Spring 2011 screening and education program in Omaha.

Foundation Supports Professorship

In June 2010 the Canavan Foundation contributed to the Darryl C. De Vivo, MD Fund. This new endowment, established at the Columbia University Medical Center, will support the work of a pediatric neurologist to carry on Dr. De Vivo’s “legacy as a clinician and researcher in the devastating neurological conditions of children.” Dr. De Vivo has served as the Canavan Foundation’s scientific/medical committee chairman for many years.

About the Canavan Foundation

The Canavan Foundation is a non-profit organization dedicated to educating at-risk populations about Canavan disease, encouraging carrier testing, and supporting 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

Education leads to screening, the first line in prevention of genetic diseases. Inform your rabbi about the new COUPLES AWARE training program, which arms rabbis with information and materials to play this pivotal educator’s role. Spread the word to couples who are planning, or have started a family, to make sure they understand their options.