COUPLES AWARE Training Expands

During the past year, the Canavan Foundation has worked closely with the Jewish Genetic Disease Consortium (JGDC) training rabbis and cantors in the New York metropolitan area to counsel engaged couples about the need for genetic screening.

The JGDC, of which the Canavan Foundation is a member, produced a learning guide, a brochure, and curriculum materials for both group and web-based training seminars. This year the material adds three additional Ashkenazi diseases, and addresses Sephardic/Mizrahi diseases as well.

The content was informed by research supported by the Canavan Foundation. Our research helped identify how and when young people typically do genetic planning, what influences their decisions, and how rabbis can best convince couples of the importance of screening.

In the past year, the program has trained over 150 rabbis and cantors. We plan to train another 150 in the New York metropolitan area next year, and are fielding requests from all over the country.

Dear Friends,

It's certainly been a productive year!

We are pleased to announce the publication of a fully revised brochure, “Building a Healthy Family,” that includes information about additional diseases, both Ashkenazi and Sephardic/Mizrahi.

We are proud of this brochure—the only one of its kind—and have included it in this mailing. Take it to your rabbi and cantor; we’d be happy to provide them with training in its use—either online or in person—as well as additional copies of the brochure for free.

This year, UJA New York renewed funding to expand our clergy education program in the NY metro area. Word of our success has spread; we are also receiving requests from rabbis all over the country. With your continued support we will be able to extend our impact.

This year we have also co-funded some very promising research into Canavan disease. You can read more about that in this newsletter.

One request: please send us your current email address. We are trying to be as green as possible, and will keep the information completely confidential.

Happy New Year!

Orren Alperstein

News for 2011/2012:

Building a Healthy Family: OB/GYN Office Brochures

When Canavan Foundation research showed the importance of educating doctors and patients about genetic diseases on an ongoing basis, we moved quickly to develop a brochure for doctors’ offices. OB/GYNs and pediatricians are a trusted source of genetic family planning information, and are often the person who most influences a woman to seek genetic screening.

We plan to start placing the new brochures—the first to include a list of all the diseases affecting Jews of all backgrounds—in OB/GYN offices in the New York area this winter.

Grant for Gene Therapy Research

The Canavan Foundation has co-funded a grant with National Tay Sachs and Allied Diseases (NTSAD) to Dr. Guangping Gao of the University of Massachusetts Medical School. Dr. Gao is researching models of Canavan disease and building on previous understanding of how Canavan Disease works at a molecular level. Tests have shown that gene therapy, delivered early, can keep central nervous system function from getting worse and alleviate molecular symptoms of the disease.

Consulting With Geneticists

The Canavan Foundation is helping to bring together geneticists from around the country who make recommendations on screening to people of Jewish ancestry. The goal is to create a comprehensive consensus list of diseases for which screening is available.

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In Memoriam: Sylvia Gelblum

Sylvia Gelblum, a Canavan Foundation supporter from the start, passed away on October 24, 2011 at her home in North Carolina at the age of 85. A woman of strong beliefs, she was a fighter for democracy and social justice who was politically engaged even on the last day of her life.

Sylvia was a stalwart supporter of the Canavan Foundation ever since it was founded by Orren Alperstein, her son Seth Gelblum, and others in 1992 after her granddaughter, Morgan, was diagnosed with Canavan disease. She was always ready to lend a helping hand: she was there the night her grandson Aidan was brought home so that Orren and Seth could host the first international Canavan Disease Symposium that same evening. Sylvia attended every single Canavan Foundation theater benefit for nearly 20 years and was tremendously energetic in her support of the Foundation’s mission.

Even at 85 she persevered. The photo above shows her at last year’s War Horse benefit with her granddaughter, Madeleine Gelblum. “Grandma said she could still do anything if she could do it slowly,” says Madeleine. Sylvia will be sorely missed by the extended Canavan Foundation Family.

Save the Date for 2012 Benefit
Death of a Salesman April 25

On April 25, 2012 Canavan supporters will have the privilege of seeing Philip Seymour Hoffman directed by Mike Nichols in Death of a Salesman at our 2012 Spring Benefit. As Canavan board member and theater lawyer Seth Gelblum describes it, Death of a Salesman is “a powerful statement of the cost of economic failure to an American family that has believed in the capitalist system.”

Playwright Arthur Miller’s genius, Gelblum adds, “is to show the impact of major political and social issues on a personal level. People have great expectations for this production.”

War Horse Benefit a Success

Thanks to all who participated in last year’s Canavan Foundation benefit dinner, where producer Bob Boyette, pictured at right with Seth Gelblum, spoke about the challenges of bringing War Horse from London to New York. Training American puppeteers was a huge task, and many were curious to see whether the story would resonate with American audiences as much as it had in England, where WWI was such a catastrophic event. As it turned out, the play was so compelling that it overrode cultural differences and became a smash hit, still running nearly a year later.