Dear Friends:

It has been an exceptionally productive year at the Canavan Foundation. Recently I attended a conference, sponsored by Jacob's Cure, about advances in Canavan disease research. There, I was surprised and moved to meet a large number of non-Jewish families (or families who were unaware of any Jewish heritage), who had children with Canavan disease. Several families actually had more than one child suffering from the disease.

The experience of meeting these families reminded me how important it is to continue getting our information out, and distributing it widely. I was reminded of how vital it is that carrier couples understand that it is possible to have healthy children. The experience reinforced the importance of increasing carrier screening by working not only with rabbis but also with others who counsel individuals and couples starting families, such as gynecologists.

Mindful of these lessons, and with your generous support, we decided to develop and underwrite a provider education program in partnership with the Jewish Genetic Disease Consortium (JGDC) to highlight, for providers and their patients, the importance of pre-conception carrier screening.

With best wishes for a happy and healthy new year,

Russell Pflueger

Canavan Videos Tell Inspiring Stories

Shivani Nazareth, MS, a genetic counselor, has helped thousands of couples to understand how genetic screening can help build a healthy family. In one of five videos featured on our new website, Nazareth explains what she does. Visit our website at www.canavanfoundation.org to watch the new videos and hear firsthand from Ms. Nazareth as well as from a rabbi, parents of a child with Canavan disease, and a couple who went through genetic screening before getting pregnant. Then share the videos with your friends and social networks!

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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
- Consider writing a letter to your temple’s tzedakah fund
- Request that a donation be made to the Canavan Foundation’s training initiative to educate Westchester county.

Tzedakah Gift

Two years ago Rayna Alperstein wrote a letter to her Westchester temple’s tzedakah committee, asking if they would make a grant to the Canavan Foundation for rabbi training in Westchester county. In response, her temple donated $500. “Many temples have tzedakah funds, and this is a perfect cause for them,” Alperstein says. “It is something that can be used locally, that concerns the Jewish community and the congregation directly, and that could conceivably affect every Jewish family. No Jewish couple needs to be afflicted with the devastation of these genetic diseases.”

If every friend of the Foundation wrote a tzedakah letter, the numbers could really add up. According to Alperstein, letters should contain three key elements:

1) Your personal connection to the congregation and to the cause of Canavan disease prevention.
2) A description of why the grant is important for the Jewish community.
3) A sentence about what the money is going to be used for.

Two years later she is getting ready to submit a second request to her temple’s tzedakah fund. This time she plans to request that a donation be made to the Canavan Foundation’s initiative to educate Westchester health care providers.

Consider writing a letter to your temple’s tzedakah fund requesting that a donation be made to the Canavan Foundation. If you would like help with the text, feel free to contact us at: info@canavanfoundation.org.

New Canavan Foundation Website

Lots of information, warm colors, videos, and extensive resource links reward visitors to the Canavan Foundation’s new website. Launched in December, 2012, the site has information for everyone who can benefit from knowing more about Canavan disease.

The website development, a major initiative over the past year, was guided by the Foundation’s research about how best to prevent Canavan disease. For example, photographs of young families and just-married couples are the main images gracing the new home page because research showed these are the audience we need to reach.

“There is no better way to tell our story and convince people to take action than to show people dealing with the reality of these genetic diseases,” says Foundation president Orren Alperstein.

The foundation has produced five new videos, available on YouTube as well as on the new site. Please watch the videos, and share them with friends, at www.canavanfoundation.org.

2012 Benefit: Matilda the Musical

On April 24, 2013, Canavan Foundation supporters will be treated to a production of Matilda the Musical, the award-winning show based on a Roald Dahl children’s book. Matilda’s London production garnered seven Olivier Awards, including Best Musical, Best Director, and Best Actress. According to the U.S. producers, one of whom will join us for dinner before the show, Matilda is the story of an extraordinary little girl who proves that in spite of rotten parents and a vicious headmistress, she can still do great things.

Last May’s Death of a Salesman benefit was a sold-out success. Those who attended were treated to a talk by a producer, Stuart Thompson. Thompson talked about the highly unusual decision to recreate the set design by Jo Mielziner and to use the music by Alex North from the original production. Those who saw the current production agreed that the music and sets were extremely powerful.

Canavan Foundation, Inc.
450 West End Avenue, #6A
New York, NY 10024
Toll-free phone & fax: 866-907-1847
info@canavanfoundation.org
www.canavanfoundation.org