**UPDATE: Building On Success**

**21,000 brochures distributed to NY doctors:** Four years into our Ob-Gyn office education program it is clear that the program is a huge success. We are known to nearly every Ob-Gyn practice in the New York Metropolitan area, and are in touch with about 300 doctor offices twice a year. Of the offices we contact, 90 percent reorder brochures and many tell us there’s no other brochure that is as comprehensive. We regularly update our database of current practices and research new office openings.

**52,000 brochures distributed to synagogues:** This past summer we received a grant from Genzyme to expand the NY metro area database of 1,800 rabbis, cantors and synagogue lay leaders to cover the entire nation. Our current database stands at 4,495 contacts in approximately 1,800 synagogues across the country. Reaching out to these contacts through initial emails, special High Holy Days emails, as well as phone calls – we received almost a thousand orders for 52,000 of the brochures developed in conjunction with the Jewish Genetic Disease Consortium (JGDC).

**Web traffic is up.** Our website now attracts an average of 114 visits per day, 41,000 over the past year. This number is up 14% from the previous year and a 48% increase over our historical average. One reason for the rise in visitors may be that we now update a home page feature monthly, which raises our searchability on Google.

**So how are we doing?** We developed our education program four years ago. Having reached our goal of blanketing the New York area through Ob-Gyn offices and synagogues with information aimed at every woman of Jewish heritage of childbearing age, did we rest on our laurels? Not at all.

Recently we have embarked on a survey to better understand whether having all these brochures in Ob-Gyn and fertility offices has altered women’s behavior. Aimed at women who have had children in the New York Metro area in the past ten years, we query respondents about whether and when they were screened and what influenced their decision. We are pleased to report that our research is revealing progress.

Our preliminary results indicate that more couples are being screened before conception, though a sizeable chunk still wait until they are pregnant. Would a different approach to educating doctors change these numbers? Would better insurance or lower screening prices? These are some of the questions we hope to explore further. We also plan to survey New York area doctors in the near future.

**Please share this survey** with appropriate friends and family by guiding them to the homepage of our website where there is a link.

**Carrier screening landscape evolves**

Carrier screening is a rapidly evolving field, but where is it heading now? Until recently, carrier screening was based solely on a person’s family or ethnic background. For example, couples with Ashkenazi Jewish background are generally tested for a panel of 16, 19, or even 38.

But new techniques, like next generation sequencing, make it possible to test for many more recessive gene mutations at one time, at relatively low cost. A coalition of five professional organizations recently issued a joint statement that helps clarify for physicians how to use expanded carrier screening and, even more importantly, who can benefit from it. The statement advises offering the same carrier screening to ALL patients, regardless of race or ethnicity. In our increasingly multi-ethnic society ancestry is often unclear; we can’t rely exclusively on screens of specific ethnic groups.

Many screening services are now offering expanded panels of diseases. For example, the screening service JScreen now offers a test for 40 diseases for just $99 for people with insurance – with an option for an “expanded panel” that includes another 40 diseases that are fairly common in the general population. This kind of pan-ethnic, wide net carrier screening is certainly the wave of the future. Stay tuned for more information as this dynamic field continues to evolve.

**Dear Friends,**

The Board of the Canavan Foundation hopes you’ve been able to share the new brochure we distributed with last year’s newsletter with any friends or family members planning to start their families. Remember: even couples with mixed background – Jewish and non-Jewish – should receive carrier screening BEFORE CONCEPTION.

It’s been another busy year! This issue of the Canavan Foundation newsletter highlights the work we continue to do to provide that revised brochure we sent you last year to Ob-Gyn offices and synagogues for couples planning to start families. We’ve distributed close to 73,000 brochures this year!

We’ve also undertaken a survey of women with some Jewish ancestry, or with a spouse with some Jewish ancestry, in the New York Metro area who’ve had children here within the past ten years. I invite you to check out our article about the preliminary results in this issue. You can help by sending friends or family who fit the criteria to our website (www.canavanfoundation.org) to click on a link to the survey on the homepage.

I do hope you’ll join us for Shuffle Along on May 3rd. Mark your calendar now and watch for an invitation in March. At dinner beforehand we’ll hear from George Wolfe, the director and writer. It’s going to be fantastic!

Best Wishes for a happy and healthy holiday and New Year!

Orren Alperstein

**Board members (l. to r.) Ellen Metzger, Seth Gelblum, Orren Alperstein, Pat Hischhorn and Deedy Goldstick.**
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 website 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

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Research update

Dr. Paola Leone, Professor of Cell Biology & Director of the Cell and Gene Therapy Center at Rowan University - School Of Osteopathic Medicine in New Jersey, received a three-year grant from the National Institutes of Health this year to develop a human neural stem cell transplantation approach to treating Canavan Disease in collaboration with Stem Cells Inc. of California. This project supports research designed to assess the benefit of a regenerative therapy focused on the repopulation of myelinating cells in Canavan Disease.

Dr. Leone is also collaborating with Dr. Heather Lau of New York University on a natural history and registry study of patients with Canavan Disease, funded by a grant from the Canavan Foundation and the National Tay-Sachs and Allied Diseases Association.

Dr. Lau and Leone have been working together for more than a decade, providing counseling and clinical care to the families of newly diagnosed Canavan patients. They also provide diagnostic services for rare genetic mutations and prenatal screening with a grant from the Canavan Foundation.

Patrick Healy Charms All at 2015 Benefit Dinner

On April 23, 2015, 150 Canavan Foundation supporters gathered to see Helen Mirren as Queen Elizabeth II in the critically acclaimed Broadway show The Audience. The gala sold out, with proceeds going a long way toward funding the Canavan Foundation’s vital work in promoting early and complete genetic carrier screening for Canavan and other Jewish genetic diseases.

During dinner before the show at Barbetta, we were treated to a dialogue between New York Times theater critic Patrick Healy (pictured at left) and Canavan Foundation board member Seth Gelblum (r), Healy, who had been a political reporter before being named the Times’ theater critic, talked about the business of theater, and the Times’ decision-making process with respect to the paper’s theater news. He said his time as a journalist covering the theater made him appreciate how committed people in the theater are to trying to create works of quality.

SAVE THE DATE May 3, 2016 Theater Gala: Shuffle Along

The Canavan Foundation’s spring theater benefit will be Shuffle Along: Or The Making Of The Musical Sensation of 1921 And All That Followed, on Tuesday May 3rd, 2016 at 7pm. The show tells the story of a musical written by black authors that was expected to fail when it opened in 1921 with a rare all-black cast, but instead set New York on fire, attracting racially diverse audiences with its exuberant dancing and infectious jazz score. The new production is choreographed by Savion Glover. It stars Audra McDonald, Brian Stokes Mitchell and Billy Porter and is directed and written by the esteemed George C. Wolfe, who will be our speaker at dinner.

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