**New Technique Creates Hope**

**Saliva test is accurate & easy**

At a hospital in Englewood, New Jersey one day in September, Orren Alperstein found herself standing in the corner of a room, spitting into a small test tube. “It was so easy!” she said of the first public carrier screening using a brand new saliva test for Jewish genetic diseases, including Canavan Disease.

Since increasing awareness and testing are the front lines in preventing genetic diseases like Canavan, the new and more convenient saliva testing technology represents a major opportunity for the Foundation.

Research has shown that saliva is as accurate as blood when used as a source of DNA for genetic testing. DNA from saliva is even being used in police work: saliva on an envelope or cigarette can now be used to identify a criminal as surely as a fingerprint.

Since collecting saliva is less expensive, less invasive, and less unpleasant than collecting blood, the new test may encourage more people to decide on testing. When Lois Neufeld took saliva collection kits to a meeting with the young staff of Birthright Israel, she reported that “the kids were talking on the phone, laughing while they spit into the collection tubes. It was all out in the open, absolutely no shame.”

The saliva carrier test for genetic diseases (often reimbursable by insurance) seems to be a winner. For more information see the Canavan Foundation Web site at www.canavanfoundation.org and click on “Screening and Testing Centers.”

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**Canavan Foundation to World: Get Tested**

The Canavan Foundation is undertaking an exciting new venture this fall: the development of a professional marketing plan to help every at-risk person become aware of genetic diseases and get tested.

In Stage One of the plan, the Canavan Foundation will fund research on screening program effectiveness, organizations and thought leaders working on this issue, and the epidemiology of genetic diseases.

In Stage Two of the plan, creative professionals guided by research will create a marketing campaign to raise awareness of and participation in carrier testing.
Lois Neufeld Talks

During her 5 years as President of the Canavan Foundation, Lois Neufeld says, “One of the most satisfying developments has been the Grand Rounds program.”

Grand Rounds is a presentation made to medical professionals, covering 11 genetic diseases. The discussion covers benefits and limitations of genetic testing, as well as ethical issues.

Following the presentation, a family member stands up to talk about what it is like to live with and care for a person suffering from one of these diseases. This personal commentary is “so searing,” says Lois, that “medical professionals are never going to forget about these diseases.”

The foundation has given a $72,000.00 grant so that the Grand Rounds Program can continue to be rolled out nationwide.

The Grand Rounds program, the brainchild of genetic counselor Elson Langfelder-Schwind when she was a member of the Foundation Board, has already educated 700 medical professionals. The goal is first to reach all obstetricians and gynecologists in the country. That number currently stands at about 45,000.

Neufeld also hails the selection of Rabbi Peter Kasdan to the Rabbinic Advisory Committee as “one of the smartest moves the Canavan Foundation made.”

Neufeld says Rabbi Kasdan has led the way to educating several thousand rabbis about the existence of Jewish genetic diseases and the opportunity to educate young adults who are members of their synagogues, as well as those they see for pre-marital conversations.

Neufeld will stay on as Vice President of the Canavan Foundation, and will also keep her post at the helm of the Jewish Genetic Disease Consortium.

GINA Protects Against Genetic Discrimination

The Genetic Information Nondiscrimination Act (known as GINA) will be a comfort to families who know they are genetic disease carriers, and to people interested in finding out. GINA will make it illegal for insurers, employers and others to discriminate based on a person’s genetic data.

Before, some avoided tests that could result in genetic bad news, since that information could potentially raise insurance rates or harm job prospects. The GINA legislation will remove that barrier to testing.

New board member Ellen Metzger notes the legal protection is well-timed, coming just when new opportunities and techniques for testing are becoming available.

GINA was signed into law in May 2008 and is scheduled to go into effect in the spring of 2009. In the meantime, regulations are being developed to guide the law’s implementation.

For more information about the GINA legislation, see www.genome.gov/10002328

Three Talented Women Join Foundation Board

Sara Edlin
Sara Edlin was born in New York but raised in Houston and Austin, Texas. She has a degree in Library Science from the U. of Wisconsin, and has worked for the National Hemophilia Foundation and the National AIDS Clearinghouse.

Edlin met Orren when looking for an alumni parent to serve on the board of her daughter’s preschool. She appreciated Orren’s kindness and ability to make difficult, pragmatic decisions using limited resources.

Last spring, Orren returned the compliment by recruiting Edlin to the Canavan Foundation board. Edlin accepted because of her interest in public health, and because she admired the vision and insight of the experienced and dynamic women on the Canavan board. “With Canavan right now, something big is going to happen,” Edlin says. “It would be so exciting to develop and fund a national campaign with an impact on public health.”

Ellen Metzger
Raised in the Bronx, Ellen Metzger went to Hunter high school, then the U. of Pennsylvania. For 21 years she has been practicing corporate and securities law as an in-house attorney for investment management firms.

Metzger loves piano. She has played since age seven. Metzger and her husband have been Canavan Foundation supporters for many years, attending all Foundation fundraisers.

The request to join the Board came “just absolutely at the right time for me,” she explains. “I had been thinking about giving back more. I have more time as my daughter is getting older, and I have always had the greatest admiration for the Foundation.”

Metzger felt instantly compatible with the other board members. “It’s not all the time you can walk into a room and find people who all share the same level of interest and commitment.”

Beth Zuriff
One of Beth Zuriff’s earliest New York memories is a Canavan screening at Mount Sinai hospital in 1995, soon after she and husband Laurence moved from Washington, D.C.

That 20 years later many of the same people still devote their energy to the Foundation is impressive, says Zuriff.

Zuriff is completing a degree in sign language interpretation, a future career. Her children are ages 8 and 11.

“We’re entering a new era of testing combined with genetic technology,” Zuriff says, “which presents the chance to reach a generation just entering their reproductive years.”

“These days,” Zuriff adds, “it’s becoming much more mainstream to think about genetics. Every woman about to get pregnant buys, ‘What to Expect When You’re Expecting’ and starts taking vitamins. Genetic testing lets her cross one more thing off her list of worries.”

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