

Canavan Foundation Reaches Out To Rabbis Across The Country

Thanks to the hard work by the Canavan Foundation's Rabbinic Advisory Committee—and especially by its chairman, Rabbi Peter E. Kasdan, Rabbi Emeritus of Temple Emanu-El of West Essex, New Jersey—rabbis across the nation are joining the effort to educate young couples and spread awareness about Canavan and other genetically transmitted Jewish diseases. Created in

2002, the Rabbinic Advisory Committee initiated two major programs in 2003 designed to help rabbis with this effort.

The first order of business in this far-reaching project involved the mailing of packets of information to the 1,800 members of the Central Conference of American Rabbis, the parent organization for all Reform rabbis in the United States. The goal

of this mailing was to urge all rabbis to talk with every couple with whom they are meeting in pre-marital counseling about testing for Canavan disease as well as for Tay-Sachs and other Jewish Genetic Diseases where carrier testing is now available (See www.canavanfoundation.org for a complete list). A cover letter from Rabbi Kasdan introduced the project to the rabbis

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Lois Neufeld Assumes Presidency

Lois Neufeld, who joined the Canavan board in January 2000 at the invitation of board member Deedy Goldstick, became the Foundation's third president in July 2003. An experienced public relations executive, Lois served fifteen years as president of Media Access, Inc., a boutique agency she founded in 1987 that specialized in broadcast communications.

Since disbanding her company in 2001, Lois has divided her time between Canavan

Foundation activities and work with refugees at the Marymount Manhattan College Institute for Immigrant Concerns.

A long-time member of Congregation B'nai Jeshurun on Manhattan's Upper West Side, Lois worked as a volunteer in the synagogue's community programs for public school children with reading and writing problems. She also served as president of the board of the co-op in which she and her husband Victor live. •

Lois Neufeld, the Canavan Foundation's third President >



New Fellowship Announced

Canavan Foundation and the American Academy of Neurology Foundation Join Together to Sponsor a New Research Fellowship

In a far reaching effort to support research towards the cause, treatment or cure of Canavan disease, the Canavan Foundation has established a \$100,000 Clinical Research Training Fellowship offered this year to applicants worldwide. Administered in conjunction with the American Academy of Neurology Foundation, the two-year fellowship provides \$50,000 a year (plus another \$7,000 the AANF will pay in tuition

reimbursement) to a young investigator working in a mentored environment on the subject of Canavan disease.

Established in 1948, the American Academy of Neurology is the world's largest neurology membership organization with more than 18,000 neurologists and neuroscience professionals around the world. The AANF's mission is to increase support for public education and research in neurology

towards the ultimate goal of improving care and quality of life for people with neurological disorders, making it a perfect companion for the Canavan Foundation's ongoing program to fund research relating to Canavan disease. In support of the Canavan Foundation grant, the AANF advertised its availability in Neurology and other relevant journals and sent information about the award to AANF members, healthcare writers and heads

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Giving a Voice to My Sisters..?

Rabbi B. Elka Abrahamson, a Force for Progress

Rabbi B. Elka Abrahamson, a new member of the Canavan Foundation's Rabbinic Advisory Committee, is one of the leading figures in the U.S. Jewish community. She is currently Director of the Wexner Foundation's Graduate Fellowship Program, which identifies, supports and trains outstanding graduate students who are preparing for careers in the rabbinate, cantorate, Jewish Education and Jewish community leadership.

Rabbi Abrahamson has taught, lectured, and published widely on issues of career and parenting for Jewish professionals. She played a key leadership role in the Women's Rabbinic Network and was selected to serve on the Hadassah-sponsored Commission for American Jewish Women.

She also served on the CCAR's Executive Board and Contracts Committee and is currently a member of its Ethics Committee as well as a member of the HUC-JIR's clinical faculty.

Rabbi Abrahamson lost three sisters to Canavan disease. In a recent conversation,

Because of my family's experience with Canavan and the remarkable way my parents were able to deal with it, I have always felt a responsibility to be particularly joyful in the world. By becoming a rabbi, I am able to bring a sense of faith, joy, and bring to life what it means to choose and embrace life in a meaningful way.

CF: When you had a pulpit, did you share your experience with Canavan disease with your congregants?

RA: I feel that a lot of what I do in this area is really done to give a voice to my sisters, a voice they never were really able to use.

CF: What made you decide to work with the Canavan Foundation?

RA: When I received the mailing of educational materials that Rabbi Kasdan sent out about the Foundation, I was blown away when I learned the group had a rabbinic advisory. I felt it was the right thing for me to be doing.

I also have always been supportive of a

had not heard of Canavan disease.

All rabbis and cantors need to become aware of and educated about Canavan, to find out about testing options in their communities and to counsel couples in their congregations to get tested for it.

CF: What do you see as your role with the Canavan Foundation?

RA: Having had direct experience with Canavan instead of just knowing about it in theory makes a difference.

Mine is a dramatic story. To me, Canavan is more than just another disease or medical syndrome. It's a life-shattering disease. The birth of a child is a tremendous joy, the death of children a tragedy beyond our ability to comprehend it.

During my childhood, during the years when my parents were lovingly creating a family, these two contrasting emotions were ever-present, side by side inside. But through tremendous love, faith and a tremendous appreciation for the gift of life, we certainly prevailed.

I feel by relaying my family's experience with Canavan, I may be able to make a contribution towards helping other families, especially younger couples as they contemplate starting a family.

CF: What, in your view, is the best way to get out the message about Canavan—through doctors, clergy, others?

RA: All of the above, plus through synagogues, Jewish community centers and definitely through Hillel on campuses and wherever young Jewish adults who are starting to think about their lives and futures tend to congregate.

It was at a Hillel chapter in college when I first learned about and was tested for Tay Sachs. I'd like young people to be as aware of Canavan as a disease as they are of Tay Sachs, to start saying it in the same breath as Tay Sachs.

CF: How do you counsel young couples

I have always felt a responsibility to be particularly joyful in the world.

she shared her thoughts about this tragedy and other matters relating to the Canavan Foundation.

CANAVAN FOUNDATION: Did your family's experience with Canavan disease influence your decision to become a rabbi?

RABBI ABRAHAMSON: Yes, in the sense that I believe our history shapes us no matter what journey we are on.

I was especially influenced by the example of my parents, whose courage and resilience never cease to amaze me. They embraced their faith and constantly showed us light in the midst of darkness and death.

fund established in memory of my three sisters at the JCC in St. Paul, where I grew up and where my parents still live. The Susan, Sally and Jane Abrahamson Fund is used to support programs for special needs children at the center.

CF: What would you like to see accomplished regarding Canavan disease in the Jewish community at large?

RA: Most Jews have heard of Tay Sachs but not of Canavan disease. I'd really like to see Canavan disease get the same "airtime" that Tay Sachs does. Perhaps because it was 18 years ago, but my oldest child's pediatrician

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2003 Canavan Foundation Theater Benefit a Hit

In spite of battling a cold and cough, Bernadette Peters belted them out and made *Gypsy*, our 2003 theater benefit event, a night to remember. Over 100 family and friends of the Canavan Foundation joined together at Restaurant Charlotte on May 27 for a delightful dinner, after which



▲ Co-Chairs of the theater event, Deedy Goldstick and Pat Hirschhorn in front of Restaurant Charlotte

Seth Gelblum led a question and answer session with Ron Kastner, *Gypsy*'s producer. Kastner, whose credits include such prize winning shows as *The Real Thing* (Tony Award, Best Revival), *True West* and *Side Man* (Tony Award, Best Play) and *Angels in America, Parts I and II* (Tony Awards, Best Play), provided fascinating insights into what's involved in mounting and running shows in the fast-paced world of Broadway. Then over to the Shubert Theatre, where the group was joined by an additional 78 supporters for what turned out to be a great evening with Bernadette and Company. •

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Genetic Counseling Can Make a Difference

According to Elinor Langfelder-Schwind, Senior Genetic Counselor at St. Vincent's Hospital in New York City, people seek genetic counseling for a variety of reasons, most often because a woman is over 35 and pregnant or planning to become pregnant. In other cases a couple that is planning a pregnancy, comes to see a genetic counselor because the couple has a family or personal history of a genetic condition.

But today, seeking advice about diseases specific to a particular religious or ethnic group is becoming more and more common. Couples who suspect they may be carriers of a disease often express concerns about the health of their baby. They want to be sure they are doing everything they can to have a healthy child, and a genetic counselor can tell them what testing is available and discuss with them the risks, benefits and limitations of each test.

Approximately 2-3% of all babies will be born with some type of physical problem or birth defect that most often isn't discov-

ered during the pregnancy. Ms. Langfelder-Schwind also points out, "Many couples seek prenatal diagnosis (amniocentesis or CVS) to reassure themselves that their baby is healthy but most people are not aware that a normal result from amniocentesis (or CVS) does not guarantee a healthy baby. Amniocentesis simply provides information about certain specific conditions, such as Down syndrome, unless tests for other conditions have been specifically ordered."

The good news is that carriers of Canavan disease and several other conditions common in the Jewish population (Tay-Sachs, Niemann-Pick, Gaucher, Cystic Fibrosis, Fanconi Anemia, Bloom Syndrome, Familial Dysautonomia, Mucopolysaccharidosis IV (ML4) can usually be identified through a blood test, which ideally should be done before the woman becomes pregnant or very early in the pregnancy. While not all carriers of all diseases can be easily identified, Canavan testing will identify approximately 98% of carriers. With the facts in hand, genetic

counselors can then help couples to make decisions about becoming pregnant, and testing the pregnancy if they do become pregnant. They also counsel and support couples whose pregnancies are affected. Couples need to know that without the initial carrier testing, Canavan disease and other Jewish genetic conditions will not automatically be included in amniocentesis, according to Ms. Langfelder-Schwind.

Today, genetic counseling can provide information and reassurance for couples who have concerns about a pregnancy and the health of their baby. When a woman or man is found to be a carrier of the gene for Canavan disease or other genetic conditions, genetic counselors are there to provide guidance, support and help with the difficult decisions that must be made. For more information contact the National Society of Genetic Counselors website at www.nsgc.org. •

› Rabbi Outreach CONTINUED FROM PAGE 1

receiving the information. The packets also included the following:

- “Thinking About Having a Family?”, a brochure about Canavan disease and a list of labs that test for it;
- a message for young couples, telling them about Canavan disease and the reasons for being tested;
- a fact sheet on nine Jewish genetic diseases; and
- copies of several past issues of *Update*, the Canavan Foundation newsletter.

The rabbis were encouraged to e-mail requests for additional free packets—for themselves or in quantity to share with couples—at the Canavan Foundation website at www.canavanfoundation.org.

The response to this outreach has been very positive, with a number of rabbis

requesting materials and some sharing personal accounts of the impact Canavan disease has had on their own lives (see *Rabbis’ Corner* at the Canavan website).

Phase two of this project will include a similar outreach to Conservative, Reconstructionist and Orthodox rabbis. Our efforts here will be guided by Conservative Rabbi Morris Allen and Orthodox Rabbi Howard Zack, the two newest members of the Rabbinic Advisory Committee.

The Canavan Foundation is also planning to sponsor a second project involving the education of new rabbis. The Foundation’s Rabbinic Advisory Committee, working in conjunction with the Hebrew Union College, the Reform movement’s rabbinic seminary, is in the process of creating a mini-course in Jewish genetic diseases to all

fourth or fifth year rabbinic students. Rabbi Kasdan and fellow Advisory Committee members Rabbi Richard F. Address, Director of the Department of Jewish Family Concerns, Union of American Hebrew Congregations, and Rabbi David H. Ellenson, president of the Hebrew Union College, have joined forces to create and implement the project. By making this course an integral part of their training, the hope is that graduating rabbis will start out with an awareness of the issues concerning Jewish genetic diseases and testing and be prepared to counsel young couples as these new rabbis become leaders in congregations all over the country. The ultimate goal is to implement similar courses in rabbinic seminaries in other branches of Judaism as well. •

› New Fellowship CONTINUED FROM PAGE 1

of pediatric and neurology departments.

In previous years the Canavan Foundation has awarded research grants independently. Past recipients of Canavan fellowships include K. Michael Gibson, Ph.D.; George Hoganson, M.D.; Paola Leone, Ph.D.; Esther Leshinsky, Ph.D.; and Reuben Matalon, M.D..

In speaking about the award, AANF Chair Kenneth Viste, M.D., stated, “We hope this fellowship makes a significant contribution to our understanding of Canavan disease and at the same time, supports and nurtures

a promising young investigator who will continue to work in this area for years to come.”

Four applications for the Canavan fellowship were received by the October 1, 2003 deadline. Advisory boards comprised of equal representation from both foundations will determine the recipient of the award, whose name will be announced in early 2004. For more information, visit the websites of the Canavan Foundation www.canavanfoundation.org or the AANF www.neurofoundation.org. •



↗ Lois Neufeld presents a research grant check to Dr. Darryl C. De Vivo of the American Academy of Neurology Foundation

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planning to get married about Canavan?

RA: I always advise them to get tested. I encourage couples to be tested before they get married. I explain why I think it’s important to do so, and I also try to include this message in sermons and articles.

CF: Is the audience generally receptive to your urgings?

RA: Somewhat, yes. Everyone appreciates that testing is a wise idea, but most of us are at least a little frightened about the unknown, what genes we do or do not carry. We tend not to like voluntary medical test-

ing of any kind, right? This is no different. Many of us prefer to go with the odds rather than the facts.

CF: What impact do you think that the work that the Canavan Foundation has done

For an updated list of laboratories that perform prenatal, carrier and diagnostic testing for Canavan disease, please visit our website:
www.canavanfoundation.org

and is continuing to do is having in the Jewish community?

RA: I think the impact is obvious. The Canavan Foundation assists in educating men and women about a particular and serious disease that could be passed on through an unusual combination of genes.

Though rare, it is real and those couples that test positive can receive the counseling and assistance such information requires. •

Canavan Foundation Joins Forces in Two New Jewish Genetic Disease Coalitions

In a move designed to raise awareness of the different Jewish genetic diseases that can be passed on to children of Ashkenazi Jews and their descendants, five major organizations joined forces this summer in the creation of a new body known as the Jewish Genetic Disease Coalition.

The announcement of the move was made in July at a meeting at the Victor Center for Ashkenazi Jewish Genetic Diseases in the Albert Einstein Medical Center in Philadelphia.

To help launch the Coalition, the Canavan Foundation has donated funds to underwrite the activities of an outreach coordinator who will work within Jewish communities in the Philadelphia area, helping to increase the number of individuals who will be screened for all Jewish genetic diseases.

The meeting was attended by Lois Neufeld, president of the Canavan Foundation, the Victor Center and support groups for Familial Dysautonomia, Gaucher and Tay-Sachs diseases, all of which will be part of the new organization. Coalition members plan to disseminate information nationwide, when appropriate, about all Jewish genetic diseases at meetings and community events.

According to Adele Schneider, M.D., Director of Clinical Genetics at the Albert Einstein Medical Center, "The formation of the Coalition will help educate a greater number of people about the importance of genetic screening and about the different Ashkenazi Jewish genetic diseases that exist." The hope is that the work of the new Coalition will also serve as a model for other communities. •



Lois Neufeld also represented the Canavan Foundation at a conference called "You Could Be My Cousin—Our Jewish Genetic Heritage" on November 13, 2003 at Fordham University in New York City. Organized by the Familial Dysautonomia Hope Foundation with a grant from the Jewish Women's Foundation of New York, the day-long meeting was designed to bring together representatives of a number of organizations involved in the education, prevention and cure of Jewish genetic diseases.

Canavan Website Introduces Rabbis' Corner

CONGRATULATIONS

Two members of the Canavan Foundation's Medical Advisory Board—Dr. Darryl C. De Vivo, professor of neurology and pediatrics at New York City's Columbia Presbyterian Medical Center, and Dr. Edwin Kolodny, professor and chairman of the neurology department at New York University School of Medicine—were included in the New York Magazine 2003 listing of best doctors in New York. Our congratulations to both.

In addition to regular updates—including the posting of details concerning the 2003 research grant offered by the Canavan Foundation—our website www.canavanfoundation.org introduced a new section this year. Titled *Rabbis' Corner*, it was created to complement the Foundation's outreach to rabbis



across the country. The section is designed to give rabbis the opportunity to share information about Canavan disease with their colleagues, request materials to use with congregants or couples they are counseling, and/or contribute sermons, letters or essays they have written relating to Jewish genetic diseases. The goal of the new website section is to provide the first online center where both rabbis and others can read what rabbis are doing to inform their congregations about their personal or professional connections to Jewish genetic diseases in general and Canavan disease in particular. The first contribution, a sermon by Rabbi Jeffrey Gale of Wantaugh, New York, got the *Rabbis' Corner* off to a great start. •

◀ Rabbi Jeffrey Gale of The Suburban Temple, Wantaugh, Long Island, first contributor to the new *Rabbis' Corner* at www.canavanfoundation.org

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CANAVAN DISEASE is an inherited, degenerative disease that is found most frequently among Jews of Ashkenazi descent (from Central and Eastern Europe). The disease is also seen in other ethnic groups. Babies with this disease are severely incapacitated both physically and mentally, and they eventually die—usually in young childhood.

Approximately 1 in 40 Ashkenazi Jews is a carrier of the defective gene. For a child to have Canavan disease, both parents must be carriers. A child with Canavan disease has two defective genes for the disease, one from the mother and one from the father. When both parents are carriers, there is a one-in-four chance (25%) with each pregnancy that their child will be born with Canavan disease. Now, however, prospective parents can have a simple blood test to determine whether they are carriers.

The CANAVAN FOUNDATION is a not-for-profit organization that was founded in 1992 by the parents and friends of children affected by Canavan disease. Its mission is to provide the latest information for the at-risk population (including the latest list of testing sites), to educate medical and other professional communities, and to support research.

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