Last spring, Producer Kevin McCollum gave an inside perspective on West Side Story Benefit Big Success and Charles Addams Foundation All artwork © Charles Addams. With permission of Tee McCollum described how he was able to approach van Foundation supporters at the festive dinner before our Spring 2009 theater benefit. Mr. tickets to supporters, we more than sold out our block of audiences. Thanks to the Canavan Foundation’s many (the original book writer), who felt that this ics was made by the director, Arthur Laurents (not the TV show). The show stars the inimi- 
sparking options. Your tax-deductible contributions help 
speaking to couples who are planning or starting 
diseases. Please help spread the word by 
spending the natural time for Jewish couples to start thinking about the 
most couples’ decision to get tested before pregnancy. 
engaged or newly married and thinking about starting a family. 
awareness of Jewish genetic diseases is couples who are 
our research showed that the critical audience for testing and 
our survey of factors influencing Jewish genetic diseases testing, 
Partners, Inc. Levine and Orren Alperstein followed the survey 
Utah Bariatric Center, Salt Lake City, UT, and 
the Addams Family, A New Musical

The Addams Family, a new musical, has been chosen for the Canavan Foundation’s spring 2010 theater benefit on May 5, 2010 at the Lunt-Fontanne theater. The Addams Family is based on the characters, stories and setting from the original Charles Addams cartoons (not the TV show). The show stars the inimitable Nathan Lane as Gomez, and who could play the dark and willowy Morticia better than two-time Tony winner Bebe Neuwirth? A spread in the December Vanity Fair shows the famously ghoulish family ready for the Broadway stage. Please look online in January at www. canavanfoundation.org and click on “Events & Benefits” for more information and to reserve tickets for the 2010 benefit and show.

About the Canavan Foundation

The Canavan Foundation is a non-profit organization dedicated to educating at-risk populations and encouraging carrier testing for Canavan Disease and other Jewish Genetic Diseases, and facilitating research toward the treatment and cure of Canavan Disease.

How You Can Help

Education leads to screening, the first line in prevention of genetic diseases. Please help spread the word by speaking to couples who are planning or starting a family, to make sure they understand their testing options. Your tax-deductible contributions help fund education, outreach and research programs important to our mission.

Market research funded by the Canavan Foundation over the past year showed that the critical audience for testing and awareness of Jewish genetic diseases is couples who are engaged or newly married and thinking about starting a family. A doctor’s recommendation was the most powerful factor in most couples’ decision to get tested before pregnancy. Following are some highlights of our research findings:

- A higher than expected number of respondents had been tested for Jewish genetic diseases. Nearly 90 percent of the women in our survey who had been married in the past ten years had been tested.
- Only half of the women had been tested before becoming pregnant, when the test is most useful in planning for a healthy family. Half of the women weren’t tested until they were pregnant.
- The majority of respondents were tested in their doctor’s office. Most testing was covered by insurance.
- Almost all testing was done after marriage. This seems to be the natural time for Jewish couples to start thinking about the health of future generations.
- Discussions with family and friends were less important than the doctor’s recommendation in the decision to be tested.

Couples Planning Families Are Prime Audience for Testing & Education

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Acetate Therapy Research Shows Promise

Most inherited diseases cannot be treated with a dietary supplement, but Canavan Disease may be an exception.

Dr. Chikkathur Madhavarao completed his third year of Canavan Foundation-funded research on the benefits and dangers of dietary acetate supplements in patients with Canavan Disease. Last year we reported that Dr. Madhavarao had found that tremor rats, which like Canavan patients have a deficit of nerve-insulating myelin, responded to dietary supplements of acetate. After eating the supplements, the rats showed improved motor skills and increased levels of some myelin lipids. Female rats improved even more than males.

Normally, the human body breaks down elements of its diet into acetates, which are used as building blocks of the myelin lipids that form sheaths around nerve cells in the brain. Dr. Madhavarao and his mentor Dr. Aryan Namboodiri and coworkers hypothesize that children who have Canavan Disease cannot produce sufficient acetates by metabolism at the sites needed for producing myelin sheaths. They propose that eating acetates in a form that can be made available at these sites may help the brain of these patients build better nerve insulation.

This year Dr. Madhavarao was able to test a low dose of oral acetate dietary supplement on two babies with Canavan Disease in collaboration with Dr. Yair Anikster, at the Safra Childrens Hospital in Israel. This was the first trial of dietary supplementation of acetate on Canavan patients, and the Institutional Review Board approved a very low dose for trial due to safety concerns about the supplement.

The trial revealed that the children tolerated the acetate supplement well. Also, even at a very low dose the children appeared to not deteriorate over the time course of the trial, about four months.

In order to convince the medical community that this research is worth pursuing, Dr. Madhavarao and coworkers also demonstrated that in both tremor and normal rats higher doses (up to 4 times higher than the human equivalent dose used in the trial) of the acetate supplement did not cause adverse effects as determined by both examinations and biochemical analyses. A slight drop in weight gain in the treated group was attributed to the bitter taste of the supplement additive in the rat feed that led to lower consumption.

Dr. Madhavarao believes that his research results warrant a broader test of the effects of dietary acetate therapy in a larger human population. His research was published in August, 2009 in the Journal of Inherited Metabolic Diseases.