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Students Walk for FD
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Malka Eisenberg
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A child born with familial dysautonomia in 1970 had only a 50% chance of surviving until his fifth birthday.

Today a child born with this debilitating genetic disease has greatly increased chances of survival with 50% reaching their 40th birthday thanks to advances in medical care and therapies.

“The ultimate goal,” explained David Brenner, executive director of the Dysautonomia Foundation, and father of a 23-year-old son with FD, “is to find the definitive treatment and cure.”

To that end, students from Jewish organizations at New York University, Stern College for Women and Columbia University have banded together to raise money for and awareness of FD by holding a walk at 10 am on Sunday, November 14th. The seven-mile walk along the Hudson River will begin at the Bronfman center at NYU, continue along the walkway of the West Side Highway and turn back at 59th Street.

FD is a rare genetic disease carried by one in 27 Ashkenazic Jews. “It is the most Jewish of all the Jewish genetic diseases,” noted Brenner. He pointed out that the carrier rate for Tay Sachs and FD are “almost the same but there is only one case of FD that is non-Jewish, where the individual can’t trace their heritage to Jewish ancestors. Now there are more non-Jewish cases of Tay Sachs than Jewish cases—99.9% of all cases of FD are of Jewish ancestry, specifically Ashkenazy.”

A boy or girl born with this disease will have both parents as carriers. The baby’s autonomic and sensory nervous systems are compromised from birth affecting breathing, circulation, bones, digestion, and the eyes. The basic mechanisms that are run by the body do not function normally so their blood pressure and heart rate are uncontrolled and the normal sucking and swallowing reflexes do not function.

FD was discovered in 1949 and the Dysautonomia Foundation was founded in 1951. They are the “single largest source of funding for research for FD,” said Brenner. Some of the advances in FD research made possible by funding from the organization include diagnostic tests, discovering that it is a disorder of the nervous system, various medications and treatments and finding the gene for FD enabling prenatal diagnosis and carrier testing. Funding also enabled establishing the dysautonomia treatment and evaluation center at NYU Medical Center, a center in Israel at Hadassah Hospital-Mt. Scopus and two professorships in FD at NYU.

Until the gene was found the only way to find if a person was an FD carrier was if they had a child with the disease. Finding the gene prevents new cases of FD through screening for carriers and diagnosing when children develop this “mystery illness,” noted Brenner.

If a married couple is found to be carriers of the gene they can still have a baby using in-vitro fertilization (IVF) and pre-implantation genetic diagnosis (PGD). The egg is fertilized outside of the body, tested outside and then implanted. Brenner pointed out

that it was originally developed by Jews to avoid having children with Tay Sachs and is now used to avoid having a child “with this devastating disease.”

Many families where both parents are carriers have had healthy babies, said Brenner. “We stopped counting after 200 were born.”

This past summer Sarah Strongin, currently a junior studying nursing at NYU, worked as a counselor at a week-long travel camp for children with chronic illnesses, many with FD. The counselors were prepped on the various diseases and what problems they would confront. From that exposure, and the connection she and other NYU students forged with the campers with FD came the interest in trying to raise awareness and help support the foundation that works to fund research and discover treatments for this disease.

As of November 8th, 81 people registered and raised over \$11,000 through registration fees and sponsorship for the walk, said Strongin. “We’re aiming to reach out to the Jewish community to raise as much awareness and support as we can for this,” she said. “I’m excited about this. It’s amazing that we raised so much money and hope by next week we will have raised even more.”

Daniella Peretz of Stern College was also a counselor on that summer program. “I was very excited when I heard about the walk,” she said. “I felt connected to those campers from my trip suffering from FD and wanted to take part in this amazing opportunity.”

“We had very little time in between when we got the permit for the walk to when the fundraising and advertising had to begin,” noted Shira Falk, chesed chair on Shalhevet-the orthodox Jewish community board at NYU. She noted that planning the walk was a new activity and she found the appreciation of supporters and students from different schools working for a common goal inspiring.

“Once they found the gene,” said Brenner, “genetic therapies are just a matter of time. There is the real possibility that genetic therapy could correct the defect that causes FD.”

“Our hope for the future,” explained Brenner, “is to help people who have FD live healthy, productive lives, cure them so they can live normal lives and enable universal screening so there will be no more cases of FD. You might say that our goal is to put ourselves out of business by eradicating FD.”

For more information and to register for the walk go to www.familialdysautonomia.org/events/walk2010