Jewish Family Services

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Pick up SDS and vocabulary sheet to PPI and schedule an appointment.

Project GENE—Part II

By Penny Eisenberg

Project GENE, an acronym for Genetics: Everyone Needs Education, is the nationwide program recently launched by B'nai B'rith Women in cooperation with the March of Dimes, to educate the public about birth defects. This series of articles has been prepared by HaLailah B'nai B'rith Women to explain genetic disorders and the research that is being done in the field of genetic disease.

In addition to Tay Sachs disease there are six genetic disorders that are specific to Jewish people. They are Gaucher's disease, Bloom syndrome, Niemann-Pick, A-T, Torsion Dystonia and Dysautonomia.

Gaucher's disease is the most prevalent Jewish genetic disease affecting one in 2500 Ashkenazi Jews. One out of every 25 Jewish people carry the Gaucher's gene. Gaucher's is a biochemical genetic disorder involving a particular enzyme. There are three subtypes with differing symptoms. In Type 1, symptoms may begin in later childhood or adolescence. Symptoms may vary widely from joint pain, anemia, bruising, to enlargement of the spleen and liver causing chronic debility. Type 2 has its onset in infancy and is a fatal degenerative disorder similar to Tay Sachs. Type three is a juvenile onset form with neurologic involvement. At present there is no cure for Gaucher's disease. The March of Dimes is currently funding several research projects dealing with Gaucher's.

Bloom Syndrome is a rare disease but the recessive gene is common in Ashkenazi Jews, the carrier rate being greater than 1 in 120. The affected individual shows shortness of stature, skin problems with some disfiguration, ear infections, respiratory infections that can be life threatening, infertility in men and greater than normal cancer risk. Research is being done on the mechanism of genetic recombination which produces disorders such as A-T, Bloom Syndrome and Fanconia Anemia.

Over half of the reported cases of Niemann-Pick Disease have occurred in Jewish families. Although it is a rare disease, the carrier rate among Jews appears to be about 1:100. An enzyme deficiency causes an abnormal accumulation of fat in cells of the nervous system and other organs resulting in death between 1-3 years of age. Prenatal diagnosis is possible and should be explored if family history so dictates.

Ataxia-telangiectasia (A-T) is a disorder that affects Sephardic and Oriental Jews. It is a fatal disease from which the majority of patients die before or during their teens. Patients show progressive motor incoordination, recurrent respiratory infections, mental retardation and malignancies. The March of Dimes is currently funding projects to isolate the gene responsible for A-T, which would enable prenatal diagnosis of it.

Dysautonomia (Riley-Day syndrome), an inherited disease affecting Ashkenazi Jews, is characterized by insensitivity to pain, swallowing difficulties, lack of tears, physical retardation, episodic vomiting and numerous other problems.

Autosomal Recessive Dystonia, a disease that affects one in 20,000 Ashkenazi Jews, is characterized by bizarre twitching and torsion of the body and limbs, resulting in bizarre postures that become fixed over time. Surgery of the thymus can be done and has altered the life expectancy of these people. Research continues on finding a drug that will be effective in treating people with Torsion Dystonia.

The March of Dimes spends $1 million a year on research and counseling for Jewish genetic diseases. Your support is needed. Please send donations to: The March of Dimes, 2325 Randolph Rd., Charlotte 28207.

Super Sunday
Dec. 6

Thoughts From Adrienne

By Adrienne Rosenberg
JFS Director

In my younger social work days, I once worked for a welfare department in rural Indiana. That was my first experience in working with seniors. I recall a couple of them even now. Both of them —one male, one female—lived by themselves and had limited financial resources.

The man lived in a four-room shack near a railroad track. He had only a couch, a chair and a spittoon in his living room. In very cold days when I visited, he would put this chair close to the wood-burning stove in the middle of the room. He would have me sit there so I wouldn't get cold.

The woman lived in a farmhouse where she had resided for many years. Her husband had died several years before I became her caseworker. The farm was not on a main road; rather, it was off a dirt road that was not easily accessible when there were heavy snows. This person was a diabetic but could not always afford the diet her doctor recommended for her.

What I remember most about these two clients was their pride in maintaining their independence and being able to manage on their own. This was true despite the hardships of poor finances, poor health and their social isolation. I especially remember this push to maintain independence when I visited the woman in the hospital after her leg had to be amputated, and she begged me not to consider any plan that did not allow her to return home. Her doctor suggested she enter a nursing home or live with a relative; she insisted she would rather die than have that happen.

It was as a result of my involvement with these two clients that helped shape my philosophy in working with seniors. Above all, with the majority of older persons I have come into contact with, there is less depression and more pride when the older person is able to maintain the dignity of being independent and able to remain in their own homes as long as possible. Of course, assistance to do so is often required from family or home health services. It is a fact that 5% of the elderly do need residential care due to illness and confusion. But older persons in general share the same values as when they were younger — privacy, independence, and a home of one's own.

To age is to become more vulnerable to chronic illnesses, fewer financial resources, spouse and peer deaths and social isolation. None of this can be avoided. But to age can also mean that one can take charge of the time he or she has. We can't take the pain out of the fact that humans aren't immortal or that illnesses accumulate as we age. We can, however, refuse to believe that after a fixed age we become nonfunctioning, impaired or a person without worth.

There is no reason other than illness why memory, activity, sexuality, relationships, dignity and independence should not be maintained as long as possible. True, the older one is, the more help to remain independent may be required. It remains harder to be totally independent. But the important thing is that pride in being one's own person in one's own home is of vital importance for as long as possible.

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HEALTH n. A state of optimal physical, mental and social well-being, and not merely the absence of disease and infirmity.

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