



Tuesday, October 25, 2005 5:22 pm EDT

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2003-03-14

'It's In the genes'
Panel to discuss genetic testing, dilemmas

By Robert Miller THE NEWS-TIMES
DANBURY — What would you do if you learned you could be carrying a gene that may cause a chronic illness, or be passed on to the next generation? Get tested for the gene? Chose to live in a principled oblivion?

What would your employer, your insurance carrier do if they knew you had a gene that could increase your chances of becoming seriously ill? Ignore the information? Or drop you and cut their losses?

These are some of the issues a panel of doctors, geneticists, activists and clergy will discuss Sunday at a conference at Danbury Hospital entitled "It's In the Genes." The conference, sponsored by the Jewish Federation and Hadassah, will run from 1 to 5 p.m.

While the conference will focus, in part, on Jewish genetic diseases, it will also explore a much broader range of issues, such as the ethics of genetic testing, the potential for discrimination and the hope offered by gene therapy.

"We will talk about specific diseases, but also about genetic diseases in general," said Dr. Eitan Kilchevsky, a Danbury Hospital neonatologist who will moderate the panel. "It's something people should know about."

"I'm really happy," said Helene Karlin, a New Fairfield psychotherapist who helped organize the event. "It's the first conference of its type in the area."

Life forced Karlin and her husband, Dr. Roger Karlin, an internist, to learn about genetic diseases. Their 8-year-old daughter, Lindsay, has Canavan disease. This illness, one of a family of rare diseases called leukodystrophies, prevents Lindsay from developing myelin, the essential fatty sheath that covers nerves and allows them to carry a message.

Their commitment to helping their daughter has led to the creation of the Canavan Research Fund. In turn, that led to work on one of the first gene therapy research projects — a project the Karlins credit with saving and extending their daughter's life. Dr. Paolo Leone, who led the project, will speak at Sunday's conference on the field of gene therapy — replacing flawed genes with healthy ones and thus reversing the course of a disease.

There are several other genetic diseases that Ashkenazi Jews — Jews from central and northern Europe — are prone to. These include Tay-Sachs disease and Gaucher disease — two rare metabolic diseases — cystic fibrosis, and the family of nerve diseases known as dystonias.

"We were all told about Tay-Sachs," said Judy Prager, executive director of the Jewish Federation. "But now we know there's a whole list of these diseases and people don't know about them. We felt it was our responsibility to educate people."

For many of the diseases, prospective parents can get simple blood tests that can tell them if they carry the mutated genes. Deborah Starkman-Hindin, a genetic counselor at Danbury Hospital, will talk about the issue of testing, explaining what it can and can't do for people.



News-Times file photo

Lindsay Karlin, now 8, with her special education teacher, Heidi Carlin, at Project Succeed in Danbury. Lindsay has Canavan disease, a rare genetic illness that prevents her nerves from carrying messages. Her mother, Helene Karlin, has organized a conference on genetic diseases and gene therapy at Danbury Hospital on Sunday.

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"People can be apprehensive about this," Starkman-Hindin said. "My job is to educate them, and help them find out what's best for them."

This might mean that a young couple — finding they have mutated genes — might choose adoption over bearing a child with a high risk of developing a debilitating, incurable illness. Starkman-Hindin said fertility clinics can now choose healthy sperm and eggs — without the errant genes — and conceive a child in vitro, then implant the embryo back in the mother.

There is a darker side to genetic testing as well. Abby Meyers, director of the Danbury-based National Organization for Rare Diseases, said knowledge that a person has certain troublesome genes could be a source of discrimination. Insurers could drop coverage; an employer might fire a person, or at least not advance him, knowing he or she may be prone to certain illnesses.

"Congress has considered a bill on this for five years," she said. "So far, they've done nothing."

Karlin pointed out that in years to come, both the promise of gene therapy and the problems of gene testing will grow. Hence, the need for a conference like this one.

"The genomic revolution is here," she said. "It's time to think about it."

"It's In the Genes", sponsored by the Jewish Federation and Hadassah, will be held at Danbury Hospital on Sunday from 1 to 5 p.m. For information and reservations, call the federation at (203) 792-6353

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