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## HEALTH & WELLNESS

# A Community's Twist on Genetic Tests

## *Orthodox Jews Screen for Recessive Diseases Before Marrying, but Are Only Told So Much*

By AMY DOCKSER MARCUS

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NEW YORK—In Williamsburg, a bustling Brooklyn enclave across the East River from Manhattan, a sect of ultra-Orthodox Jews dresses in garb common to 18th- and 19th-century Europe and adheres to even more-ancient religious traditions. Yet they are wrestling with the most modern of questions: When it comes to genetic testing, how much does a person need to know?



Rabbi Josef Ekstein, left, and lab manager Saul Wasserman, right, at Shiel Medical Laboratory in the Brooklyn Navy Yard, in New York. Rabbi Ekstein founded Dor Yeshorim, which uses Shiel to test couples to determine if they are carriers for genetic diseases. *Bryan Derballa for The Wall Street Journal*

The community has deployed a unique screening program that addresses a genetic issue arising from the fact that Jews in Central and Eastern Europe once lived and married within small, tightly bound communities. As a result, Jews who trace ancestry to this region have a higher risk of carrying gene mutations that could lead to bearing children with a number of devastating hereditary genetic conditions.

Many Jews who know their ancestry now get tested to see if they carry such mutations. But in many Orthodox communities, the kind of genetic screening typically used in the wider world is complicated by privacy needs, religious prohibitions,

and clashes with some of their communal values.

So community members devised an approach to identify people carrying gene mutations for the same diseases who, if they were to marry one another, might bear children with lethal conditions (such offspring have a 1 in 4 chance of inheriting a so-called recessive condition.)

Rabbi Josef Ekstein, who had four children die of Tay-Sachs disease, a fatal neurodegenerative condition, founded a program called Dor Yeshorim to screen people and create a database with the test results while providing participants with anonymity. Young people—typically from age 17 to their early 20s—who get tested are assigned a personal identification number and birth date without the year. The program screens for nine conditions common among Ashkenazi Jews—those who can trace ancestry to Central and Eastern Europe—and the information is kept in a database by Dor Yeshorim, which means "upright generation" in Hebrew.



Blood samples that Shiel is testing *Bryan Derballa* for  
*The Wall Street Journal*

Before a couple is betrothed, or sometimes even meet, their families call Dor Yeshorim with the identification data and are told whether the prospective couple is "compatible" or—if both carry a gene mutation for the same disease—"not compatible." In the latter case, the relationship is typically abandoned.

The program is unusual not for what it tells people, but for what it doesn't.

Typically, a person who is sent for or requests genetic screening is told if he or she is a carrier for a wide variety of conditions.

Rabbi Ekstein, though, tells a recent visitor that he didn't envision Dor Yeshorim that way. "We are a prevention program," he says. The purpose isn't to expand an individual's personal medical knowledge, but to prevent the births of doomed children by alerting potential spouses to the risk.

How much to reveal to people remains a contentious issue in the gene-testing field. Some geneticists argue that scientists still have no grasp of most gene mutations' relevance, and that sharing information whose meaning is uncertain is potentially harmful. In some cases, people might endlessly worry or alter their lives because of a mutation for which there is no effective treatment or that turns out to be benign; others may ignore medical advice because genes show they aren't predisposed to a particular condition, even though screening can't rule out the possibility a disease will develop.

Many believe people have a right to know everything, and withholding any information amounts to a kind of genomic paternalism.

Rabbi Ekstein recognizes that, in some respects, withholding all information other than people's compatibility may seem old-fashioned in an age when technology can tell people about all kinds of genetic risks. He argues that too often, people don't consider the "negative part of knowing" one is at risk. Everyone talks about the right to know, the rabbi says, but there should be equal attention paid to "the right not to know."

Those who use Dor Yeshorim aren't told for which diseases they are carriers unless they insist. Among the concerns: If word were to get out in the tightknit Orthodox community, the stigma of carrying a faulty gene might make it hard to find a spouse not just for that person, but for his or her siblings as well. And screening is done only for recessive diseases, for which each parent must contribute a faulty gene in order for a child to be affected.

Yaniv Erlich, a geneticist at the Whitehead Institute in Cambridge, Mass., who works with Dor Yeshorim on research projects, says the group's decision to share only what it considers "actionable information" is a stance taken by many geneticists. What's unusual is that, in this case, "the marriage is the actionable information," he says.

Dor Yeshorim's story is really Rabbi Ekstein's story.

The rabbi's first child, a boy born in 1965, seemed to be developing normally. But at around 6 months old, he started losing muscle tone, had seizures and experienced trouble swallowing. Eventually, he went blind. The boy was diagnosed with Tay-Sachs at age 2, and died at age 4. Four more children were born; three also died of Tay-Sachs.

After burying his fourth child, Rabbi Ekstein says, "it came to my mind that maybe this has a purpose." Screening tests had been developed that could let people know if they were carriers of diseases and, while it was too late to help him and his wife—who have five healthy children—Rabbi Ekstein sought a way to help others in the community.

In Williamsburg, which boasts one of the largest populations of Satmar Hasidic Jews—a branch with roots in Hungary and Romania—couples tend to have many children, and find spouses who are usually chosen or approved by their families. In most cases, abortion is prohibited, sperm and egg donation isn't an option and in vitro fertilization is financially prohibitive. The only practical way to stop children from being born with these diseases is to prevent carriers from marrying.

Rabbis and other community leaders debated Dor Yeshorim's mission for some time before giving their approval. A paramount concern was the confidentiality aspect. There also was considerable debate about which diseases to test for: How severe does a disease have to be to justify providing information that could thwart marriage plans?

Today, the number of children born with Tay-Sachs in the Jewish community in the U.S. and Canada each year has dropped to between three and six from between 30 and 40. The Dor Yeshorim database now includes information from 330,000-340,000 people from Orthodox communities around the world. One in 100 prospective couples are found to be incompatible, the group estimates.

Still, researchers believe that while risk can be lowered, it can never be completely eliminated. In genetics and love, says Edwin Kolodny, professor emeritus in neurology at New York University Medical Center and chairman of Dor Yeshorim's medical advisory board, "Marriage in most situations remains a lottery where we just take our chances."

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### **Corrections & Amplifications**

Rabbi Josef Ekstein and Shiel Medical Laboratory were both misspelled in captions accompanying earlier versions of this article.

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