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## Group Charged With 'Playing God' Over Genetic Testing

### Largest screening organization for Ashkenazi diseases accused of not notifying clients who have Gaucher's.

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Editor And Publisher

**A** national medical expert charged this week that the head of the leading organization screening for Jewish genetic diseases is "playing God" by withholding information from people who have tested positive for Gaucher's disease, a serious and often painful illness that effects one in 450 to 500 Ashkenazim, making it the most common of Jewish genetic diseases.

Dr. Stuart Ditchek, director of the Jewish Genetic Diseases Consortium, a nonprofit organization founded two years ago to increase education and awareness, and encourage genetic testing, told The Jewish Week that Rabbi Joseph Eckstein, the founder and director of Dor Yeshorim (Generation of the Righteous), the largest screening program of its kind, dissuades people from testing for Gaucher's so as not to discourage young men and women who may be carriers from marrying each other.

What's more, Ditchek charges that Rabbi Eckstein has acknowledged that he has not informed people who have tested positive for Gaucher's that they have the disease.

"He is playing God," Ditchek said of Rabbi Eckstein, asserting that there is no ethical or halachic basis for depriving such medical information from a patient.

Due to medical advances over the last two decades, enzyme replacement therapy has proven quite successful in treating and controlling Gaucher, with the best results occurring when it is detected before the patient reaches his or her late teens.

"Several medical experts and I have met with the rabbi and shown him the research, and explained that we can save these people from a life of suffering," said Ditchek, a Brooklyn-based pediatrician. "We told him we know he has the information and that he needs to inform these people [of the results], but he resisted."

Dor Yeshorim regularly tests some 17,000 people a year, almost exclusively in the Orthodox community here, in Israel and Europe, for a "panel" of nine genetic diseases, including Tay-Sachs and Familial Dysautonomia. The group used to include Gaucher's, but now only tests for it "by request only," according to its literature.

According to Ditchek, Rabbi Eckstein has said that he has blood samples from more than 100 people his organization tested more than 15 years ago, and whose results were positive for Gaucher's.

Contacted by The Jewish Week, Rabbi Eckstein denied that assertion, but said, "We don't believe it is right to say 'don't get married because of Gaucher's.'" He added that "years ago it was serious enough to test for it because people could die. Now that there is treatment for it, we feel uncomfortable telling young people [to be tested]. I believe it is a disservice to tell them not to get married."

He declined a full interview unless given the right to review and "veto" the story if it did not meet his approval. He said he mistrusted the media because it is prone to inaccuracy, particularly on "delicate" issues like this.

Rabbi Eckstein is no stranger to controversy. The pioneer in screening programs for Jewish genetic diseases, he founded his organization in 1983, dedicated to the elimination of Tay-Sachs — the rabbi lost four children to the disease — and the promotion of healthy marriages among chasidim, later expanded to the wider Orthodox community.

According to the organization's literature, Dor Yeshorim was established "to provide protection from predominantly Jewish genetic diseases, while safeguarding individuals from the psychological stigma of carrier status knowledge."

Most participants in the screening program are young couples considering marriage. They are tested through Dor Yeshorim and receive an identification number. They later call a hotline and are simply told whether or not they are compatible, based on the results of the screening. If both the man and woman are carriers of the same disease they are considered incompatible.

Dor Yeshorim is widely credited for helping to virtually eliminate new cases of Tay-Sachs from the community, but some critics oppose the organization's methods on moral grounds, primarily because it does not notify participants who test positive as to what disease they are carriers of or refer them for evaluation and treatment.

The medical data on Gaucher's is clear

that early detection and treatment can help a person avoid a life of increasing misery.

Dr. John Barranger, an international expert in the field from the University of Pittsburgh who has done groundbreaking work on Gaucher's, said "the disease is slowly progressive. It is highly treatable through enzyme therapy and, when found at a young age, a person can be disease-free." If not treated, though, "the ravages of the disease can lead to enlarged liver and spleen, bone marrow failure and erosion of the skeleton," and "can cause early death."

He said it was standard practice in the medical field for screening agencies to provide pre-test and post-test counseling, and for carriers to be given detailed information, including the risks to themselves and to having children.

Dr. Neil Weinreb, another world expert on Gaucher's and author of data on the benefits of prompt treatment, noted that Rabbi Eckstein's style in confidential testing is "unique" in its "paternalistic" approach to clients.

Weinreb said that some people with Gaucher's could live a full life disease-free while others can be "seriously affected."

"There is no question that if someone has the disease, he or she has the potential" for becoming seriously ill at some point and should be informed.

"As a physician," Weinreb added, "I feel people have the right to know and make decisions, based on ethical and halachic grounds."

He said he had heard the argument that if a person with Gaucher's has symptoms, he will go to the doctor and be diagnosed, so why inform such a person beforehand? But Weinreb dismissed such logic, asserting that besides being immoral, it is medically unsound because early detection is most effective and because some people could be misdiagnosed.

"It can be fatal," he said.

But Dr. Edwin Kolodny, medical director of Dor Yeshorim, said it was unfair to accuse Rabbi Eckstein of "playing God," noting that the focus of the anonymous screening programs is to determine, if two specific individuals were to marry, whether they would

be at risk of having children with a severe, incurable disease, and to prevent the stigmatization of families.

"A person is not told if he or she is a carrier because that is not relevant to the program, which is not obligated to disclose disease information," said Kolodny, who chairs the department of neurology at NYU Medical Center. "It is designed to let people know they can reproduce without fear, and to avoid any stigma in the community."

He did acknowledge that not informing clients that they have Gaucher's "does raise an ethical question," pitting a doctor's responsibility to provide medical information against Dor Yeshorim's conviction that pregnancies should not be terminated in the case of Gaucher's. That is because in most cases it does not create a significant medical problem, he said, with many people living healthy lives and never knowing they have Gaucher's. And if there is a problem, he added, it can be diagnosed and treated, though he noted that the disease often is misdiagnosed.

Kolodny also pointed out that some experts believe people with Gaucher's have an intellectual advantage. (For example, Rabbi Adin Steinsaltz, considered a genius by many for his monumental work in translating the Talmud into Hebrew, has been treated for Gaucher's.)

But critics in the medical community insist that Dor Yeshorim must change its policy and inform clients found to have Gaucher.

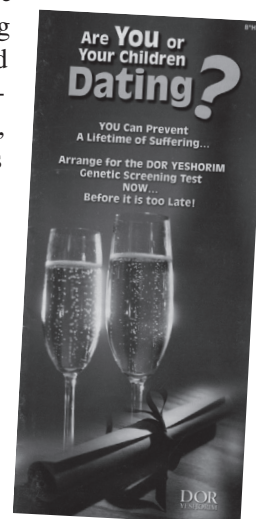
"Hiding behind confidentiality is just not appropriate," said Ditchek of the Jewish Genetic Diseases Consortium. "You have to break your rule when not to do so may relegate a person to a more painful life," or even shorten it.

Ironically, the tagline on Dor Yeshorim's brochure, recruiting for its genetic screening test, states: "You can prevent a lifetime of suffering."

That's exactly what Ditchek is saying, in effect, to Rabbi Eckstein. ■



*Whistleblower: Genetic disease expert Dr. Stuart Ditchek urges change in Dor Yeshorim's confidentiality policy.*



*A Dor Yeshorim brochure. The medical director for the group, Dr. Edwin Kolodny, acknowledges that not informing clients that they have Gaucher's "does raise an ethical question."*