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Genetic Health Education Gets Foundation Nod

By TOBY TABACHNICK

Staff Writer

The Jewish Healthcare Foundation (JHF) has approved a \$45,000 grant to fund the development of a genetic health curriculum for middle school students at Pittsburgh's three Jewish day schools: Community Day School; Hillel Academy of Pittsburgh; and Yeshiva Schools.

JHF hired Jonathan Weinkle, a pediatrician and internist who provides primary care and chronic disease management at the Squirrel Hill Health Center, and professional educator Nina Butler to work with the three schools and other communal agencies to develop a curriculum and materials that integrate scientific advancements in genetic health care with Jewish ethics.

The initiative, called "Incorporating Scientific Discovery in Health and Lifestyle Decision-Making," aims to increase education and screening for Jewish genetic diseases and increase the uptake of vaccination, including the HPV vaccine, which can prevent certain cancers.

All three day schools are on board with the project, according to JHF chief program officer and chief operating officer Nancy Zions.

"It sounds like the schools are excited about it," said Weinkle. Because of the enthusiasm for the project, the curriculum could be in place by early 2015.

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Science and Judaics will be woven together into an integrated curriculum, he explained, noting that once developed it could see national appeal. "I haven't seen anything in other day schools [throughout the country] with anything like this.

"Nina has a lot of experience working with curriculum with a national spread to it," he added. "It's neat to be at the epicenter. This could be another Pittsburgh legacy."

Students will learn the genetic principles at work due to their Jewish ethnic heritage, which makes them more likely than members of other ethnic groups to be carriers of certain diseases. One in four Jews, for instance, is a carrier for at least one of 19 genetic diseases, which can be tested for by a simple blood test.

"Knowing as much as you can, especially the importance of getting screened before becoming pregnant, can make all the difference," said JHF president and CEO Karen Wolk Feinstein in a statement. "Although being a carrier doesn't affect you, if both partners are carriers for the same disease, there is a 25 percent chance of having an affected child.

"We don't know what our grandparents died of, or why. We need to be talking about it."

— Nina Butler

"There are still options for having healthy children even if this is the case," she continued, "but you need to be armed with the information in order to make informed decisions that will affect the rest of your life and potentially the life of your child."

The idea for the new curriculum came in February during a weekend of Jewish genetic awareness events spearheaded by Butler and her husband, Danny Butler, in memory of their son, Mikey, who died at the age of 24 after a very public battle with cystic fibrosis 10 years ago.

"The weekend resonated with the Jewish Healthcare Foundation," said Butler, adding that the organization quickly signed on as a co-sponsor for that weekend's events.

During that weekend, it became evident that Jewish teenagers were open to and interested in information regarding Jewish genetic health, said Butler. "We saw the reaction of the high school girls during the discussion. They immediately engaged, they had the most compelling questions, and their eagerness to learn more left everyone excited.

"The Jewish Healthcare Foundation practices what it preaches," continued Butler. "They were eager to take it to the next step. And this is the next step. We have to span all age groups."

For Butler, it is critical that people learn their family's medical history.

"How many of us actually knows our own family's medical history?" she said. "Everyone has at least one grandparent that they were told died of old age. It's still taboo. We don't know what our grandparents died of, or why. We need to be talking about it."

Such information is particularly important in the current environment of rapidly changing medical advancements, said Butler. "We live in a dramatically different world, where genetics is going to play an increasing role in people's health. Science is advancing at such a fast clip, and we need to do what we can to help kids make good choices."

Increasing community awareness is key to promoting good health, she said. "We have to cooperate to raise community awareness and pass on scientific advances through our Jewish lens to benefit our endogamous community. It's about improving genetic health in the whole community."

In working with the three day schools, Butler said that the curriculum would be designed taking into account "Jewish sensitivities which vary slightly between our schools."

"Part of the process will be to engage each of the day school's educational leadership to make sure what we're creating is something they're excited about and comfortable with," she said.

(Toby Tabachnick can be reached at tobytabachnick@thejewishchronicle.net.)