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Tests available to detect Jewish genetic diseases double in last year

Jewish Press staff

There now are tests for 19 genetic diseases that affect Ashkenazi (of east European descent) Jews, double the number available in 2010, according to the Victor Center at the University of Miami School of Medicine.

The diseases include Tay-Sachs disease, Cystic Fibrosis, Gaucher Disease and Joubert Syndrome, according to Dr. Virginia Carver of the Victor Center, who spoke in January at a health fair at Temple B'nai Israel in Clearwater.

Risks for being a carrier of the diseases range from 1 in 15 Ashkenazi Jews for Gaucher Disease to 1 in 149 for NemaLine Myopathy. Sephardic Jews of Middle Eastern, African or Spanish descent are at risk for a different set of diseases.

It's what happens when a given people, such as Jews, were closed off from the outside world for generations by law or religious practice. The result is a limited gene pool.

The importance of testing for couples

thinking about getting married or having children is being emphasized more and more because there are no cures for these diseases and many cause death in childhood or at an early age.

That is why Helene Debowsky of Largo invited the Victor Center representatives to the health fair. Her son and daughter-in-law, Stuart and Sheri Debowsky of Miami, terminated the pregnancy of their first child after a test determined the child had Tay-Sachs disease. They now have a healthy 1-year old son.

"It is so vital for Ashkenazi Jews to know their risks through screening," Debowsky said.

The testing is a skin blood test, but it shows whether one, both or neither of the partners are carriers. One in five Jews in the United States is a carrier for a Jewish genetic disease, Carver said. That means they can pass the risk on to their children and should be screened through a blood test to give families an idea of the odds before they get married or get pregnant.

If both parents are carriers for the same disease, there is a one in four chance that each child they have will be affected. If only one parent is a carrier, the couple is not at risk for having an affected child, but their children could be a carrier of the disease. If neither parent is a carrier of a Jewish genetic disease, there is no increased risk of passing the disease on to that couple's children.

"It's preferable to test both partners at the same time," Carver said. "Share the information with other family members (brothers, sisters, cousins, etc).

"Everyone is a carrier of something. Everyone carries five to 50 genetic mutations," Carver said.

The Victor Center was started by Lois Victor, who lost two children to a Jewish genetic disease. There are centers in Miami, Philadelphia and Boston. More information can be found at the center's website, www.victorcenter.org.

Staff writers Robert Green and Bob Fryer contributed to this report.

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PARTNERSHIP

• CONTINUED from PAGE 10

The hospice rabbi is a full-time Menorah Manor employee. "We share in the cost of this position and we work together," Orloff said.

If a patient is affiliated with a congregation and wants their rabbi to render spiritual care, that is who is called on. But if that rabbi is not available or if the patient is not affiliated, but wants Jewish spiritual care, then Rabbi Herz will step in. "We share her. If there is a great need for a patient at Menorah Manor, then that is where she needs to be. Conversely, she may be working with a patient in their home spending time there. She goes where she is needed," Orloff said.

"The community pulpit rabbis have been very supportive," Seiden said.

Rabbi Herz received her ordination from Hebrew Union College-Jewish Institute of Religion in 2005. Prior to joining the Toby Weinman program, she was the rabbi at Temple Israel in Canton, OH, and prior to that was assistant rabbi at Temple DeHirsch Sinai, in Seattle and Bellevue, WA. She earned her bachelor's degree in psychology, and went on to receive her certification in dance, drama and music therapy. She has extensive experience working with senior populations, having volunteered frequently to lead Shabbat and holiday services in nursing centers. She has also taught classes for seniors and made hospital and hospice visits.

In addition to providing a rabbi, other services offered include nursing care, social services assistance,

home health aides, volunteers, physicians, equipment specialists, child and family support counselors, therapists and others trained in meeting specific needs. There is always a need for more volunteers, who receive training to they can offer practical and emotional support and companionship, Orloff said.

The services do not end with the patient's death. Bereavement services for family members, including children and grandchildren, are available "for as long as the family wants it," she said. Even long after death, if a family occasion such as a graduation or wedding prompts new feelings of loss, counseling is available, she noted. If family members of one who received hospice care in Pinellas County live in some other county and request counseling, it could be given via Skype or phone, or they could be directed to their local hospice, she noted.

While Medicare pays for the services in many cases, both Orloff and Seiden said that hospice care is always offered regardless of one's ability to pay.

"If there is a Jewish family in Pinellas County, and they have a family member who is pretty sick, we encourage them to contact us," Orloff said.

Why only Pinellas County? Although Menorah Manor, located in St. Petersburg, is a six-county regional Jewish nursing home and geriatric center, the Jewish Hospice program is mainly limited to Pinellas residents because there are several hospice programs elsewhere in the Tampa Bay area. The programs cooperate and try not to infringe on each other's territories.

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JCC Suncoast offers fitness classes tailored especially for seniors

The JCC Suncoast offers a wide range of senior fitness classes.

Classes that emphasize focused and appropriate exercise for older individuals are:

- Dynamic Senior Fitness at the St. Petersburg location, 5023 Central Ave., Tuesday and Thursday at 10:30 a.m.
- Senior Exercise at the Clearwater location, 2075 Sunnydale Blvd., Monday and Wednesday at 4 p.m.

Tai Chi, which is known for its particular ability to identify and remedy problems within the body, is also taught at the JCC. Recently,

the JCC's tai chi instructor, Jim Thuline, not only helped a woman become mobile after years in a wheelchair but she was also able to go bowling.

Other fitness classes, which can be beneficial to both seniors and others, include: circuit training, cardio sculpt, gentle meditation, contemporary yoga and bone density training.

These classes are free for senior members of the JCC Suncoast.

For more information, call the JCC at (727) 321-6100 or www.JCCSuncoast.org.

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