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# Symposium: Get tested for the BRCA gene!

Teaneck-based Sharsheret's Elana Silber among participants at research conference in Israel

BY ABIGAIL KLEIN LEICHMAN | July 21, 2016, 11:55 am |

A symposium of American, European, and Israeli breast-cancer researchers in Israel concluded with the consensus that all Ashkenazi Jews, both women and men, and perhaps even the general population, should be tested routinely for inherited predisposition to breast cancer.

The test should not be reserved only to those people who have a family history of mutations of the BRCA1 and BRCA2 gene.

Citing data that indicates that current international testing parameters leave out half of people who would be found to have BRCA mutations, the group urged a change in policy so that many more people could learn their status and take preventive measures.

Women carrying a BRCA mutation have up to an 85 percent chance of developing breast or ovarian cancer in their lifetimes. Men carrying such mutations, which can be passed down from either mother or father, also are at increased risk for breast cancer.

The group of 30 invited participants included just one advocacy professional: Elana Silber, executive director of Teaneck-based Sharsheret (Hebrew for "chain"), a national not-for-profit organization supporting the entire family of young Jewish women diagnosed with breast cancer or ovarian cancer and those who are at increased genetic risk.

Offering culturally relevant connections with networks of peers, health professionals, and related resources, Sharsheret has reached about 60,000 men, women, children, healthcare professionals, and college students since its founding in 2001. "On a monthly basis, we help about 300 women and families from across the country," Ms. Silber said.

She explained that Sharsheret was invited to the July 10 symposium "in order to share our expertise in addressing the urgent concerns of individual women and their families."

“I was the only advocacy group representative among the medical professionals, and it was important to have the patient voice heard,” Ms. Silber said. “We understand what it’s like to be a Jewish woman facing these issues. We provide psychosocial support and information before, during, and after diagnosis. Genetic testing can happen at any of those points.”

Chaired by Dr. Larry Norton, medical director of the Evelyn H. Lauder Breast Center of Memorial Sloan Kettering Medical Center in New York, the symposium was sponsored by the Cure Breast Cancer Foundation of Clifton. The foundation’s founder, Andrew Abramson of North Caldwell, previously supported a study at Soroka University Medical Center in Beersheba on the possible links between breast cancer and bone health. That study also involved Dr. Norton.

Mr. Abramson said that the hospital’s diverse and stable patient population in Israel’s Negev region provides a unique opportunity for retrospective studies.

This year’s symposium was held in cooperation with Soroka and the Israel Healthcare Foundation, an independent American non-profit organization that promotes and represents Clalit, Israel’s largest healthcare network. Soroka is a Clalit hospital.

“We were gratified to hear much agreement among a diverse group of experts from the U.S., Europe, and Israel — all key regions in this issue,” Dr. Norton said at a press conference in Jerusalem the day after the meeting.

“We found that if you are in certain groups, not having a family history does not mean that you should not be tested since you might have a cancer-causing mutation. Indeed, testing all Ashkenazi Jews, as an example, finds twice as many people with mutations as testing just those with family histories.”

Dr. Norton urged a change in rules for testing. “Knowing that one has a dangerous mutation could well be lifesaving since one can do things that minimize one’s risks,” he said. At the same time, he acknowledged that “the psychological, medical, and economic consequences of broader testing need to be evaluated.”

While Sharsheret does not provide medical advice or referrals, Ms. Silber said that in response to the symposium’s recommendation, “we are ready to serve as the national resource for women and families debating about genetic testing. We have skilled professionals in our clinical team to address any questions about genetic counseling and testing.

“We also have the opportunity through our peer support network to have women talk to others who have contemplated and considered preventative measures when they discovered they carried a BRCA mutation.”

The Basser Center at the University of Pennsylvania partners with Sharsheret to share information with patients and advocates about BRCA mutation research, including informational resources for rabbis and congregations participating in the annual Sharsheret Teal/Pink Shabbat.

Sharsheret also is working with the U.S. Centers for Disease Control “to amplify and scale up programs and messaging for young Jewish women with breast cancer,” Ms. Silber said.

Based on the recommendation of the symposium participants, Ms. Silber expects Sharsheret to have an increasingly important role in providing guidance to Jewish families considering genetic testing.

“We are the first call you should make whether or not you have a family history,” Ms. Silber said. “We’re always here for you as you respond to the recommendations offered by the experts in the field. Ultimately, saving lives is a team effort of the medical and advocacy communities coming together.”

The researchers said they will write a paper summarizing their findings and plan to meet again for follow-up work.

Among those present were Dr. Ehud Davidson, director-general of Soroka University Medical Center; Dr. David Geffen, chief of breast oncology services at Soroka; Dr. Kenneth Offit, head of clinical genetics at Memorial Sloan Kettering, and Dr. Judy Garber, past president of the American Association for Cancer Research.