

Strength In Numbers



Elana Silber, Sharsheret director of operations, left, and the group's founder, Rochelle Shoretz, herself battling breast cancer. "What young women need is the ability to connect with young women with the same experience," Shoretz says.

by Sharon Udasin
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When Sarah tested positive for the BRCA1 breast cancer gene five years ago, her decision to have both her breasts removed was a simple one — her mother had died of the disease at the devastatingly young age of 42 and her grandmother at 49.

Luckily, Sarah discovered a network of young Jewish women who had tested positive for the same gene, had gone through the same prophylactic double mastectomy procedure and had made it through the grueling recovery period with young children at their sides.

Through a New Jersey-based national organization called Sharsheret, she and thousands of other women have found valuable genetic counseling and personal connections, as they go through the hardest moments of their lives.

"It's a Godsend, it's really revolutionizing women's

ability to face breast cancer and to fight it — it's incredible. My experience would not have been nearly as easy if I hadn't had Sharsheret in my life," said Sarah, now 35, who recently underwent chemotherapy after doctors found cancerous tissue in her breast removal.

Two of her sisters, 25 and 29, have tested positive for the BRCA1 gene as well, and the 29-year-old has already had a prophylactic mastectomy. Her third sister, who is only 18 and unmarried, however, has not yet been tested, and the family would like to protect their privacy and her marriage prospects by remaining anonymous. Cancer is still a bit of an uncomfortable subject among close-knit Jewish circles, a phenomenon that Sharsheret aims to improve, Sarah said.

Sharsheret, which is Hebrew for chain, was first established in 2001 by then 28-year-old Rochelle Shoretz, who was going through chemotherapy at the time and wished she had known other young Jewish women

facing similar battles against breast cancer, who could have shared their experiences with her. Since its beginning, Sharsheret has had over 15,000 phone calls from 37 states, as well as Israel, South Africa and the United Kingdom, and has developed a Genetics for Life program that familiarizes women with genetic predispositions for breast cancer.

“What young women need is the ability to connect with young women with the same experience,” said Shoretz, now 36, whose organization grew from a toll-free phone line based in her attic into a web of professionally managed support networks for patients, as well as culturally sensitive training sessions for large secular cancer organizations. “We didn’t set out to start an organization,” she added. “It was more a call for support and camaraderie.” Now battling her second breast cancer diagnosis, Shoretz is using these very resources that she initiated.

Cementing the healing process, Sharsheret matches the young women with others who have already undergone similar diagnoses and therapies, and the organization now has 805 women participating in the “link” program, according to the current executive director, Elana Silber. Through Sharsheret, the “links” are able to share all kinds of personal concerns — like how to attend a family milestone when not looking and feeling well, how to use the mikveh as a healing mechanism or how to deal with a positive test result for a BRCA gene.

“Because the percentage of Jewish women carrying the gene is so high compared to the general population, it really connects us all regardless of religious affiliation,” Silber said, noting that the BRCA genes are particularly common among Ashkenazi women.

Through Sharsheret’s year-old Genetics for Life program, women are able to better understand the complexities of hereditary breast cancer genes and learn about the often life-saving benefits of genetic testing. In its pilot year, the program had 66 calls, but already by the first quarter of this year, there were 30, Silber said.

“If you have a family history and you’re Ashkenazi Jewish and the family history includes people who have had breast or ovarian cancers at particularly young ages, that’s when the genetic testing would be recommended,” said Niecee Schonberger, Sharsheret’s genetics program coordinator, who specializes on genetic counseling for hereditary cancers.

As soon as she receives a call, Schonberger said she takes a detailed family history of the caller and then discusses both the benefits and limitations of testing. While she doesn’t offer medical advice or referrals to specific doctors, she helps callers understand what their options are before and after they have undergone genetic testing.

“People don’t always realize that a negative result is not always a definitive result,” Schonberger said, noting that 90 to 95 percent of breast cancer cases are not inherited and there may be genetic mutations that scientists have not yet discovered. Genetic maps among Ashkenazi Jewish families also tend to contain many irresolvable holes due to the Holocaust era, Shoretz added.

But when a patient does receive a positive test result or knows that she has a family history of breast cancer, she and her daughters may begin getting mammograms early, try a hormonal therapy or even consider prophylactic mastectomies, according to Shoretz.

Sharsheret’s board of directors and staff members continue to develop the Genetics for Life program, and they are now moving ahead to evaluate ovarian cancer needs, as well as the possibility that breast cancer genes can run through men, she said. By addressing these issues vocally, Shoretz hopes to disband any remaining taboo surrounding breast cancer discussion among Jews.

“Now the cancer conversation is much more comfortable in the Jewish community,” she said. “Armed with knowledge, we can save a lot of lives.”