

## When you need a shoulder to lean on

Jun. 21, 2008

Judy Siegel-Itzkovich , THE JERUSALEM POST

You don't have to be Jewish to get breast cancer, but it "helps." Women in developed countries have a one-in-nine to one-in-seven lifetime risk of this disease, with about 90 percent of breast cancer developing spontaneously and not as a result of inheriting the well-known BRCA 1 or BRCA 2 genes.

No study so far has shown that breast cancer is more common in Jewish women than in the population at large. Yet it is clear that over the millennia, due to marriage within small populations of Ashkenazim (and perhaps among Sephardim as well), more Jewish than non-Jewish women carry these defective genes that increase their risk of breast as well as ovarian cancer. While a BRCA gene is carried by one in 345 people in the world population, one in 40 Jews - men as well as women - carry one of them. Hereditary breast or ovarian cancer generally appears in younger women (and a small minority of men) and may be more difficult to combat.

The last thing a young woman in her 20 or 30s - busy with family, home and career - expects to encounter is breast cancer, and after the initial shock, she needs help. But the rarity puts those young women who do contract the disease in an especially uncomfortable position. BRCA carriers also have a higher-than-average risk of pancreatic, prostate and even skin cancer than noncarriers.

Thus it was quite natural that a handful of American Jewish women who were diagnosed at a relatively young age with breast cancer got together in 2001 to establish a support and information organization. For Jewish women, the effect of breast cancer may extend to religious life, spiritual views and values, family, community, dating, fertility, marriage and parenting.

LESS THAN a year after the founding of Sharsheret ("chain" in Hebrew, with a Web site at [www.sharsheret.org](http://www.sharsheret.org)), *The Jerusalem Post* interviewed the main founder, Orthodox Jewish lawyer Rochelle Shoretz - married and then the mother of two preschool boys - who had contracted breast cancer at the age of 28. Instead of succumbing to depression or pessimism, Shoretz turned her personal struggle into a positive effort to help other young Jewish women in her situation. Sharsheret, which she set up in her Teaneck, New Jersey home, was aimed at linking new patients by phone with those who have already been treated and recovered.



Sharsheret's Eillene Leistner was treated with 33 radiation treatments and Tamoxifen after being diagnosed with ductal breast cancer in 2005.

Photo: Judy Siegel-Itzkovich

Although her malignancy was diagnosed at a fairly advanced Stage II that required surgery, chemotherapy and radiation followed by taking the drug Tamoxifen for five years to reduce the risk of recurrence, today she is fine. She has set aside being full-time executive director of the organization and returned to her work as a lawyer but remains involved in Sharsheret.

Her replacement over the past year or so is Eillene Leistner , who a few weeks ago came to Israel on yet another visit.

"I have been here 15 or 20 times before," she says in an interview, "since 1972, when I was 19. We also have family and friends in Israel" Her 20-year-old daughter plans to study at the Hebrew University of Jerusalem next year.

Since its founding, Sharsheret has fielded more than 10,000 calls for help and information from those affected by breast cancer, health care professionals, concerns about fertility and the need for support during treatment and beyond. Although it has no branch in Israel, it does have numerous connections inside the Israel Cancer Association and other groups that help patients and BRCA carriers. A professional fundraiser and former manager of non-profit organizations who worked for American friends organizations of the Israel Museum, Dorot (a Manhattan organization for the Jewish elderly) and others, Leistner speaks Hebrew fluently.

She met Shoretz through a mutual friend and gave her advice about running non-profit organizations. Then Leistner suddenly had more in common with her: In 2005, she was diagnosed with breast cancer. "I had ductal breast cancer *in situ*, treated with 33 radiation treatments and Tamoxifen." She was tested for BRCA mutations and found to be free of them.

"All our services are free," says Leistner. "People give to people. People give when moved. There are still wealthy Jews who understand how cancer has afflicted people; they want to help." Just one fundraising luncheon Sharsheret held before Leistner left for Israel raised over \$300,000.

Focused on young women and breast cancer, Sharsheret does not reject requests for help from older women, says Leistner. It also does not turn down calls from non-Jewish women. There have even been calls from former Jews who converted and have a family history of BRCA. It does not, however, handle questions about other "Jewish" genetic diseases such as Tay-Sachs, Canavan's disease or familial dysautonomia.

DEPENDING SOLELY on two full-time professional staffers and hundreds of volunteers, Sharsheret is supported by individual donations, private foundations and grants. It has developed nicely and literally created a "chain" of nearly 600 Jewish women who advise others. "For example, we received queries from a haredi woman in New York who was diagnosed with Stage II breast cancer after giving birth to her seventh baby. She wanted to talk about sexuality after taking hormone treatment, but couldn't bear the thought of consulting someone in her community," relates Leistner. "As part of our peer-support network called the Link Program, we matched her with a woman active in the Reform community in California. They became close and shared their innermost feelings and thoughts."

Women who learn they have a first-degree relative with a BRCA mutation are given information about genetic counselling. "We tell women to go for genetic counseling," notes Leistner, "as it is too complex and too difficult not to have a genetics counsellor to help you through the process."

"My grandmother and my aunt were both diagnosed with breast cancer," says one such woman. "When I was diagnosed, I wanted to understand more about hereditary breast cancer so I could determine the best treatment plan. Then I began to worry about my sisters and daughters. With the information I have gathered, I can begin to make important decisions for my family."

THE ORGANIZATION'S education and outreach programs include medical conferences addressing the concerns of Jewish women facing breast cancer; its Sharsheret Forum is an online message board for women affected by the disease and their families. When Leistner and colleagues learn of a young woman with children who has been diagnosed, she is sent a "Busy Box" with toys to keep them busy. The Best Face Forward Program addresses the cosmetic side effects of chemotherapy (including hair loss) and radiation treatments. "When a woman has surgery, we send her a beautiful embroidered pillow to lean on that is donated by a Madison Avenue store. When someone we know is about to undergo chemo, we send her a package of cosmetics, resources and information on how to wear wigs," says Sharsheret's executive director.

Another support program called Embrace targets women living with advanced breast cancer. And finally, its Empower Program provides resources and information packets focusing on issues unique to single women facing breast cancer. One such young patient who became active in Sharsheret recalls: "When I was first diagnosed, I panicked. Who will marry me? Will I ever be able to have children? I felt overwhelmed having to manage the breast cancer ordeal without a partner. When you have a spouse, you have a sounding board, someone to discuss treatment decisions and surgery options, someone to care for you when you cannot care for yourself. It made all the difference when I realized that there were other young women out there living with breast cancer - people I could speak with over the telephone who could help me understand what to expect."

BUT EVEN married women often feel at a loss. "Surgery had a serious impact on my body image," said one wife who was helped by Sharsheret. "I felt a sense of loss, and it was painful and embarrassing. My husband and I both needed to adjust to this change in our relationship. I found it very reassuring when we were able to discuss our feelings openly."

Some of those who have been struck by breast cancer are Orthodox, while others are somewhat traditional or nonbelievers. For the former, prayer, healing services and meditation can be helpful during treatment. Preparing for and celebrating Shabbat and Jewish holidays and observing rituals with family and friends, says Leistner, can create feelings of warmth and security during a time that may feel unstable. Non-observant women who previously did not feel connected to Judaism are often motivated by illness to search Jewish tradition for meaning, guidance and an answer to the almost automatic question: "Why me?"

Says one observant woman: "I truly believe that Jewish tradition can provide some of the tools we might need to face the difficult realities of cancer treatment... Instead of 'Why?' - throughout my treatment I found that 'Why?' was transformed in the questions 'What?' and 'How?' and 'When?' What is there to learn from the challenges each of us must face in our lives? How might we garner the strength to face what might lay

ahead? When will we know that this experience is yet one more fold in the fabric of our life? In grappling with these questions, I discovered that my faith, my spiritual life and my deep connection to community were vital."

Says another: "I began chemotherapy treatments right around Rosh Hashana. It was challenging to prepare for guests when I felt numb and disconnected from the routines of Jewish life. But that year my prayers took on greater meaning as I prayed for healing, health and a long life of celebrations. Though the holidays brought a rollercoaster of emotions - fear, anxiety and deep sadness - they also created some moments of true calm and connection to the friends and family whose support proved invaluable."