

Talking about Breast Cancer

By Renée Rosenfeld



Rochelle Shoretz, founder of an organization that helps young women fighting breast cancer.

An attorney and mother of two, Rochelle Shoretz served as a law clerk to US Supreme Court Justice Ruth Bader Ginsburg, becoming the first Orthodox Jewish woman to clerk for a Supreme Court judge. Two years ago, at the age of 28, Shoretz was diagnosed with breast cancer. A few months after her diagnosis, Shoretz, who lives in Teaneck, founded a national non-profit organization that provides support for young Jewish women fighting cancer. Sharsheret (Hebrew for chain) pairs up Jewish women in their 20s and 30s with other young breast cancer survivors (called "Links").

What compelled you to launch Sharsheret only months after being diagnosed with breast cancer yourself?

When I was diagnosed, I asked everybody I knew to help me find someone

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Jewish, my age, with small children with whom I could speak. A mutual friend introduced me to Lauryn.

Lauryn walked me through every stage of the disease—from coping with diagnosis, scheduling surgery and dealing with chemotherapy, to family and personal issues. Our experiences were similar enough to make speaking with her extremely valuable. One thing that struck both of us, however, was how difficult it had been to find each other. We knew there must be hundreds of other women with breast cancer looking for someone they could speak with.

How did you manage to take on the work of organizing Sharsheret while undergoing treatment?

Chemotherapy definitely weakens you. I am grateful that I was able to anticipate my stronger and weaker moments. I organized Sharsheret during those times when I thought I could handle it.

I also had help from many dedicated individuals. One law firm donated hours to help set up the shell of the organization. Additionally, once a month, volunteers in the Tri-State area

meet to send out mailings, organize fundraising and encourage others to support our efforts. Regional coordinators work to bring Sharsheret to every state in the country. Our Community Advisory Board, comprised of influential health care professionals, members of major Jewish organizations and young Jewish women who have been diagnosed with breast cancer, is a gathering of people from different fields who are committed to Sharsheret's mission.

How does Sharsheret pair up individuals?

When women call, they are asked to describe the issues foremost on their minds. One woman might say, "I am single and would like to speak to another single woman who's had the same surgery." Another caller might say, "I have three children and would like to speak to another mother who has lost her hair, to discuss the ways in which she's prepared her children."

Sharsheret pairs up individuals based upon our callers' needs. Women with varied stages of breast cancer and across the entire Jewish spectrum—

Chassidic, Orthodox, Conservative, Reform and unaffiliated—call Sharsheret.

Some of our callers have not been diagnosed with breast cancer but have tested positive for the BRCA1 or BRCA2 mutation [see accompanying sidebar] and want to speak to someone who has tested similarly. A caller may have chosen to get tested because her mother died of breast cancer at the age of 40 and she wants to find out whether she is a carrier. Another woman may call to discuss if she should go for genetic testing. People have questions: *What happens if I test positive? if I test negative? Should I consider prophylactic surgery?* Although Sharsheret does not offer medical referrals or advice, we help women by pairing them up with others who've faced similar questions.

In terms of anonymity, there are those who are comfortable only revealing their first names; others share everything. Some women prefer to speak to someone in their own community. Others will specifically request not to. Every level of privacy is respected. Our aim is to support women according to their needs.

Sharsheret focuses on younger women with breast cancer. What are some of the challenges that are specific to these patients?

Detection. There have been a number of callers who first detected their lumps either during pregnancy or while nursing their newborns. We've heard of doctors who delayed making a diagnosis and asked patients to return after their pregnancy or when they finished nursing, only to discover that the lumps they had thought were benign were actually malignant. Women may detect a lump and think to themselves that it must be due to pregnancy or nursing. Our callers who've found lumps during pregnancy urge women who feel something abnormal to have it checked out, regardless of when they find it.

When I first felt the lump, I knew it was abnormal. I had a feeling that there was something in my body that should-

n't be there. I didn't have any idea that it was cancer. I'd always associated breast cancer with older women. When I heard I had cancer, I was shocked.

A lot of women worry that they're going to get breast cancer but I don't think anyone really believes it's going to happen to them. I remember asking the doctor, not, "Why is this happening to me?" but "How is this happening to me? How did an otherwise healthy young woman develop breast cancer?"

Another challenge for a young woman is that treatment affects one's fertility. A woman in her childbearing years will probably opt for different types of treatment than a woman past those years. There's also the religious importance of childbearing in the Orthodox community. From those perspectives, being a young woman is very significant.

We've had a few phone calls from women who let us know they've given birth to two or three children after being treated for breast cancer. Those stories are very heartening. Many women call wanting to know about others who have had children after treatment; it's rewarding for us to be able to share those stories with them.

Recently, one Link took awhile to connect with us; it was so difficult to get in touch with her because she was busy preparing for her son's Bar Mitzvah! It's very meaningful to me to hear about someone who has lived through breast cancer and is involved in a *simchah* that all of us look forward to experiencing someday.

What are some of the difficulties that may arise when a breast cancer patient is also a mother of young children?

A mother has the added stress of worrying about her family and making sure the home life continues to run as smooth as possible. Additionally, children may express their fears with questions such as, "Is cancer contagious?" "Did I cause my Mommy's cancer?" "Can I do anything to make it go away?" The most difficult question for any mother to face from her children

is, "Will Mommy die?"

No one knows a child better than his mother, and she needs to choose what information to share. I have addressed many of those questions with my own son. Sharsheret advocates sharing child-appropriate as opposed to age-appropriate information. Not every six year old can handle the same information.

Some types of chemotherapy result in hair loss, which is traumatic for anyone. Would you say that women who cover their hair for religious reasons handle the loss better?

Having to cover your head because you've lost your hair to chemotherapy is a very different experience than choosing to cover your hair because you have assumed a religious obligation. When one gets married and decides to cover her hair, she is embracing a positive religious heritage. When one has to cover her hair because she has lost it to cancer, the emotional issues are very different.

For a religious single woman who loses her hair and has to cover her head, the issues are compounded by the fact that she's doing something which is associated with being a married woman in her community. Dealing with cancer is difficult for any person and much more so when one has the added anxiety of dating and worrying about her ability to build a family.

Hair loss, resulting from chemotherapy, encompasses all body hair including one's eyebrows and eyelashes; the struggle with body image issues needs to be supported.

Another body image issue uniquely Jewish in nature is mikveh-related. Are mikveh attendants sensitive to women who suffer from the effects of chemotherapy or surgery?

I am sure that *mikveh* attendants are accustomed to dealing with a wide range of health issues that affect women. Some of our Sharsheret callers phone their *mikveh* attendants in advance to make special arrangements. Sharsheret's first national mailing, in fact, was to all of the

mikvaot across the country. Our aim was to arm *mikveh* attendants in every state with information, so they would know where women in their communities could turn to if diagnosed with breast cancer. We hope to be able to reach women outside of the Tri-State area and we've already been getting calls from different parts of the country.

What are your goals for this organization?

At Sharsheret's very first volunteer meeting, we talked about our goals for the year. We agreed that if we helped five women over the course of the entire year, we would've accomplished something significant. In our first few months, we've received over 35 phone calls from young Jewish women fighting breast cancer. Over 250 phone calls have come in from doctors; health care, Jewish and women's organizations and others interested in learning more about the work we are doing.

We've begun to set up programs and symposiums. We have an established web site (www.sharsheret.org) and office space. Most significantly, we have been able to help so many women in such a short time. For the long term, there are so many educational, awareness and support programs that we could put into place. We're always adding to our growing list of ambitions.

Has having breast cancer changed you in any profound way?

I'd like to think that before I was diagnosed with cancer, I was the kind of person who appreciated everything she had, but I can't help but feel that now I appreciate things a bit more. Seeing my children to and from the school bus every day has become extremely meaningful to me. I want to be the person who stands there and gets that first hug when they come home from school.

Sharsheret can be reached toll-free at 866-832-9909 or e-mail info@sharsheret.org.

The Facts Breast Cancer and Young Women

Despite the prevailing opinion that young women don't get breast cancer, the reality is that they can and they do. In fact, one in every 258 women between the ages of 30 and 40 will be diagnosed with breast cancer within the next 10 years. Following are some additional startling facts about breast cancer in young women:

- Breast cancer is the leading cause of death in women ages 15-40.
- Approximately 10,600 women under the age of 40 will be diagnosed with breast cancer this year, and close to 1300 will die.
- There are nearly 250,000 women in the United States under the age of 40 currently living with breast cancer.
- Young women's cancers are generally more aggressive and result in lower survival rates.
- When breast cancer is caught in its earliest stages, the 5-year survival rate is 82 percent for women under the age of 40.
- Young women with breast cancer struggle with many issues that their post-menopausal counterparts don't face, including the possibility of early menopause, pregnancy after diagnosis, generally more advanced cancers at diagnosis, and higher mortality rates.
- Young women are virtually excluded from breast cancer studies; most are conducted on women over the age of 45.

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The Facts Breast Cancer and Ashkenazi Women

All women have a lifetime risk of 8-12 percent of developing breast cancer.

- *One in 40-50 Ashkenazi Jewish women carries a BRAC1 or BRAC2 gene mutation which can lead to developing hereditary breast cancer.*
- *Those who carry a gene mutation have a 50-60 percent risk of actually getting breast cancer.*
- *Due to the presence of the mutation, the estimated lifetime risk of developing breast cancer for an Ashkenazi Jewish woman is approximately one to two percent higher than that facing the rest of the population.*
- *Genetically linked breast cancer accounts for only 5-10 percent of all breast cancers.*

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