EDUCATIONAL BOOKLET SERIES

Your Jewish Genes

Hereditary Breast Cancer and Ovarian Cancer

Endorsed By National Society of Genetic Counselors

SHARSHERET®

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Hereditary Breast Cancer and Ovarian Cancer

TABLE OF CONTENTS

Stories from Your Sharsheret Community

GET TO KNOW SHARSHERET

Sharsheret supports young Jewish women and families facing breast cancer and ovarian cancer at every stage—before, during, and after diagnosis.

Our name, Sharsheret, means "chain" in Hebrew and represents the strong, nurturing connections we build to support Jewish women and their families at every stage of breast cancer and ovarian cancer. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources and create programs for women and families to improve their quality of life.

We understand that young Jewish women have unique concerns when it comes to breast cancer and ovarian cancer, and we are the only organization that specializes in serving them. Our programs are easy to access. From Boston to Burbank, Milwaukee to Miami, Sharsheret is wherever you are.

Sharsheret is a growing community of women and families. Together, we are creating a chain of strong links that reaches across the country so that no woman or family of Jewish descent needs to face the challenges of breast cancer or ovarian cancer alone.

Visit **www.sharsheret.org** or call us at **866.474.2774** to participate in our programs and to become a link in the Sharsheret chain. All inquiries are confidential and answered by qualified staff who can help.

OUR PROGRAMS

The Link Program®

- **Peer Support Network**, connecting women newly diagnosed or at high risk of developing breast cancer or ovarian cancer one-on-one with others who share similar diagnoses and experiences
- **Embrace®**, supporting women living with advanced breast cancer or recurrent ovarian cancer
- **Genetics for Life®**, addressing hereditary breast cancer and ovarian cancer
- **Busy Box®**, for parents facing breast cancer or ovarian cancer while raising children or teens
- **Best Face Forward®**, addressing the cosmetic side effects of treatment
- **Family Focus®**, providing resources and support for caregivers and family members
- **Ovarian Cancer Program**, tailored resources and support for young Jewish women and families facing ovarian cancer
- **Sharsheret Supports™**, developing local support groups and programs
- **Thriving Again®**, providing individualized support, education, and survivorship plans for young breast cancer survivors

Education and Outreach Programs

- **Health Care Symposia**, on issues unique to younger women and Jewish women facing breast cancer and ovarian cancer
- **Sharsheret on Campus™**, outreach and education to students on campus
- **Sharsheret Educational Resource Booklet Series**, culturally relevant publications for Jewish women, their families, and health care professionals

WHAT'S JEWISH ABOUT HEREDITARY BREAST CANCER AND OVARIAN CANCER?

One in 40 men and women of Ashkenazi (Central or Eastern European) Jewish descent carries a genetic mutation, or pathogenic variant, that greatly increases the risk of developing breast cancer and ovarian cancer. Because of this alteration, women of Jewish descent have been the subject of much recent research in the field of hereditary breast cancer and ovarian cancer. Whether or not general cancer rates are higher in women of Jewish descent as compared to the general population is still an unanswered question. However, researchers have determined that women of Ashkenazi Jewish descent have an increased genetic susceptibility to breast cancer and ovarian cancer, primarily due to the increased likelihood of carrying a mutation in the BRCA1 or BRCA2 gene. If you or your partner is of Ashkenazi descent, genetic counseling and testing can help you determine if either of you carries a BRCA gene mutation. Knowing this information can impact the course of action you and your family choose to pursue.

In this booklet you will find some frequently asked questions about breast cancer and ovarian cancer and their impact on women and families.

If you've been diagnosed with breast cancer or ovarian cancer, learning more about your genetic background may influence your surgery and treatment decisions. If you haven't been diagnosed, but you have a strong family history of cancer, learning more about your genetic background may help you identify options that could reduce your risk of developing cancer and assist in early cancer detection. Knowing more information about your and your partner's genetic background may also help you answer any potential questions you may have about passing these genes on to the next generation.

One in 40 people of Ashkenazi Jewish descent are at risk.

Regardless of whether or not you decide that genetic counseling or genetic testing is right for you and your family, your Sharsheret community is here to support you through this journey and beyond.

As with all important medical decisions, be sure to discuss your unique concerns with a health care professional as well.

QUESTIONS AND ANSWERS ABOUT HEREDITARY CANCER AND BRCA GENES

Here are answers to some questions commonly asked about hereditary breast cancer and hereditary ovarian cancer.

How common are hereditary breast cancer and hereditary ovarian cancer?
Most breast cancers and ovarian cancers are not hereditary. However, approximately 5-10% of these cancer diagnoses are estimated to occur as a result of an inherited predisposition caused by a gene mutation or alteration. In families with an inherited predisposition, cancers may occur in several family members and at younger ages than usual. Mutations in at least two genes, BRCA1 and BRCA2, are known to be responsible for this inherited predisposition to breast cancer and ovarian cancer. In addition to BRCA1 and BRCA2, there are other genetic mutations currently being studied that may indicate increased risk for hereditary cancers.

What are BRCA1 and BRCA2 genes?
BRCA1 and BRCA2 are genes found in both men and women. While both men and women can carry an altered BRCA1 or BRCA2 gene, inherited alterations in these two genes make female carriers more susceptible to developing breast cancer and ovarian cancer, accounting for up to 5-10% of all breast cancer and ovarian cancer cases.[1] However, these may not be the only genes that cause hereditary cancers, and researchers continue to search for other genes that may also increase cancer risk.

The likelihood that breast cancer and ovarian cancer are associated with BRCA1 or BRCA2 genes is highest in families with histories of multiple cases of breast cancer, cases of both breast cancer and ovarian cancer, families where one or more family members have two primary cancers, ovarian cancer at any age, or families of Ashkenazi Jewish background. Not every person in such families carries an alteration in the BRCA1 or BRCA2 genes.

Young Jewish women have unique concerns when it comes to breast cancer and ovarian cancer, and we are the only organization that specializes in serving them.

What is the difference between genetics and genomics?
Genetics is the study of heredity. In terms of cancer genetics, it is the study of the risk of getting cancer based on one's genes. Genomics is the study of the genes themselves: how they function and interact with each other and the body. If you have been diagnosed with cancer, your doctor may use genomic testing on the tumor itself to help identify the properties of the genes in your tumor to influence treatment decisions.

How do alterations in BRCA1 and BRCA2 affect the risk of breast cancer and ovarian cancer in a woman of Jewish descent?
A woman's lifetime risk of developing breast cancer or ovarian cancer is greatly increased if she inherits an altered BRCA1 or BRCA2 gene. Recent studies suggest that for those carrying mutations, the risk for breast cancer may be as high as 50% to 80%, and for ovarian cancer, it may be as high as 44%.[2] This is in comparison to the average woman's lifetime risk for breast cancer of approximately 12% and ovarian cancer of 1-2%[3]. However, not all carriers of a BRCA1 or BRCA2 mutation will develop breast cancer or ovarian cancer.

Among individuals of Ashkenazi Jewish descent, research scientists have found that approximately 1 in 40 individuals carries an altered BRCA1 or BRCA2 gene, as compared to approximately 1 in 345 individuals in the general population.[4] Among alterations in the BRCA1 or BRCA2 genes, three in particular have been found to be most common in the Ashkenazi Jewish population—two in the BRCA1 gene and one in the BRCA2 gene. While there is still debate as to whether breast cancer and ovarian cancer rates are higher in women of Jewish descent as compared to the general population, the proportion of hereditary breast cancer and ovarian cancer is higher in women of Ashkenazi descent. Because of this risk, a woman of Ashkenazi descent with breast cancer or ovarian cancer, and men and women with a family history of these cancers, may want to consider genetic counseling and testing. BRCA gene mutations that are most common in Ashkenazi Jews have also been found in Jews of Sephardi (Spanish, Middle Eastern, or North African) descent[5]. If you are of Sephardi Jewish descent, and have a family history of cancer, you may want to consider genetic counseling to discuss your risk of hereditary cancer and whther genetic testing is appropriate for you and your family.

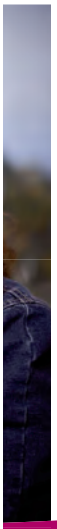
How are BRCA1 or BRCA2 mutations inherited?
Both men and women can carry a BRCA1 or BRCA2 mutation and have a 50% chance of passing that alteration on to each of their sons and daughters. Not all children of people who have an altered gene will inherit the alteration, and not all of those who inherit the alteration will develop breast cancer or ovarian cancer in their lifetime.

Are there other cancers associated with BRCA1 and BRCA2 mutations?
The principal cancers associated with the BRCA mutations are breast cancer and ovarian cancer. However, depending on which gene is involved, there are small associated risks for melanoma, pancreatic, prostate, and perhaps uterine cancers. Screening for these associated risks should be discussed with a certified genetic counselor or health care provider.

Should men consider being tested for the BRCA1 and BRCA2 mutations?
A man with a mutation has a 50% chance of passing it to each of his offspring, so this information may be valuable for his children. In addition, although the risk is greater in women, men can get breast cancer. Because men don't think of examining their breasts, and often their doctors don't either, it is important to identify those men who may be at increased risk. Men with BRCA mutations also have an increased risk of prostate cancer and may be advised to undergo screening at an earlier age than recommended for the general population.

What is breast cancer and ovarian cancer genetic testing?
Genetic testing is a process that begins with a risk assessment consultation with a certified genetic counselor who will explore the benefits and limitations of testing. Because there are other genes besides BRCA1 and BRCA2 that may also increase cancer risks, risk assessment based on a detailed maternal and paternal family history is a vital component of genetic testing. After genetic counseling, a blood sample is taken. The blood can be drawn in a laboratory, doctor's office, hospital, or clinic and is then sent to a laboratory to check for alterations in the BRCA1 and BRCA2 genes. A saliva test is available for those for whom a blood test is problematic. Testing is not generally recommended for individuals before age 18.

Where can I get more information about genetic testing for breast cancer and ovarian cancer risk?
If you are considering genetic testing, you should speak with a health care professional who is trained and certified as a genetic counselor before making a decision. Genetic counseling can help you identify and understand what particular traits you may have inherited and your options following testing.



Certified genetic counselors are trained to be sensitive to your background and to supply the information you need to make your own decisions regarding genetic testing based on your family history, the genetics of breast cancer and ovarian cancer, the benefits and risks of testing, the implications of positive and negative results, and any other factors that may influence your decision-making process. They can also explain issues of confidentiality and insurance reimbursement for genetic counseling and testing. If you opt for testing, genetic counselors will also help you understand the implications of the results for you and your family members. You can find certified genetic counselors in your area through your physician, a major medical center's genetics program, a cancer center, or the National Society of Genetic Counselors at www.nsgc.org. At Sharsheret, we offer the opportunity for consultation with our support staff who can answer your questions and help you make an informed decision about whether or not genetic testing is right for you and your family. If you would like to participate in the genetics program, please call us toll-free at **866.474.2774**.

What can I do to prepare for my genetic counseling appointment?
Prepare for your genetic counseling appointment by collecting information about your family history ahead of time and bringing it to your appointment, including information about family members who have had cancer, ages of diagnoses, types of cancer, any previous genetic testing reports in the family, and pathology reports/medical records regarding any cancer in family members. Visit www.sharsheret.org to download and complete your own family tree to bring to your genetic counseling appointment.

How do I determine what type of genetic testing may be right for me?
As the field of genetics advances, there have been many modifications to genetic testing technology beyond traditional BRCA testing. With your genetic counselor, you will discuss who in your family has had which type of genetic testing for hereditary breast and ovarian cancer. Knowing this information can help you and your genetic counselor decide which type, if any, of additional genetic testing may be beneficial for you and your family.

Not all women who inherit an altered BRCA gene will develop breast cancer or ovarian cancer.

Should I be concerned about insurance or employment discrimination if I decide to have genetic testing?
Effective in 2009, Congress passed the Genetic Nondiscrimination Information Act (GINA) into law. This law provides protection against discrimination in health insurance coverage and employment settings based on an individual's genetic information. GINA prohibits employers from firing, refusing to hire, or otherwise discriminating against employees with respect to compensation,

terms, conditions, or privileges of employment, as well as disclosing personal genetic information. It also prohibits insurance issuers from basing eligibility determinations or adjusting premiums based on an individual's genetic information.[6] Although GINA provides protection from discrimination in employment and health insurance coverage, the law does have limitations. GINA does not cover the use of genetic information for life insurance, disability, or long-term care insurance policies. Additionally, protections may be limited for members of the military and some small business employees. A certified genetic counselor can help answer any personal questions you have about how genetic testing may affect your insurance or employment status.

What are my options if I test positive for a BRCA1 or BRCA2 mutation?
A positive test result indicates that you have inherited a known mutation in the BRCA1 or BRCA2 gene and have an increased risk of developing certain cancers. A positive result provides information only about your risk of developing cancer. It cannot be used to predict whether cancer will actually develop—or when. Not all individuals who inherit an altered gene will develop cancer as a result of the alteration. If you have not been diagnosed with breast cancer or ovarian cancer, test results may help you make choices that could reduce your risk of developing cancer or help detect cancer early. Genetic counselors can guide you and explain all of your options thoroughly with you.

As a cancer survivor, what are the benefits of genetic counseling and testing?
If you have already been diagnosed with breast cancer or ovarian cancer,

Options you may consider if you test positive:

- **Increased surveillance:** being monitored more closely for any sign of breast cancer or ovarian cancer. Monitoring may include starting mammograms at a younger age than usual and/or more frequent sonograms, MRIs, breast exams by your doctor, and breast self-exams, as well as transvaginal (through the vagina) and pelvic sonograms, and more frequent exams by your gynecologist.
- **Risk-reduction surgery:** choosing to have at-risk breast and/or ovarian tissue removed in order to reduce the risk of developing cancer.
- **Chemoprevention:** choosing to use natural or synthetic substances to reduce the risk of developing cancer or to reduce the risk that cancer will return.
- **Participation in a research study:** joining a research study that is exploring ways to reduce cancer risk. A continually updated list of breast cancer and ovarian cancer research studies is available through the National Cancer Institute, U.S. National Institutes of Health at www.cancer.gov.

test results may influence your surgery and treatment decisions. Genetic testing once you have begun or finished treatment can help you make informed decisions about ongoing screening and inform discussions with your family about potential inherited risks.

How should I be monitored if I test negative for a BRCA1 or BRCA2 mutation?
If you test negative for a BRCA1 or BRCA2 mutation, it may be useful to consult with a certified genetic counselor or other health care professional (e.g., breast surgeon or gynecologist) about appropriate screening and heightened surveillance. Your health care team can help you determine the best methods for monitoring breast and ovarian health. They can also keep you apprised of developments in genetic research and testing as it becomes available. A strong family history of cancer cannot be ignored even if you do not have a BRCA1 or BRCA2 mutation, since researchers have not yet identified all mutations or genes involved in hereditary cancer.

What impact will genetic counseling or testing have on the other members of my family?
The genetic information you receive can influence your family members' health care decisions. A certified genetic counselor can help you determine the ways in which your family may be affected by counseling or testing and how health information can be shared responsibly.

What are my options if I choose not to be tested?
Should you choose not to be tested, a health care professional (e.g., breast surgeon or gynecologist) can help you determine appropriate screening and surveillance. You can also learn more about breast cancer and ovarian cancer risk, and speak with your doctor about healthy lifestyle choices.

Are there any issues of Jewish law related to hereditary breast cancer and ovarian cancer or genetic counseling and testing?
Questions of Jewish law may arise with regard to surgery and treatment decisions. If this issue is of concern to you, questions are best addressed by a Rabbi or spiritual leader who can answer them with sensitivity to your unique medical situation.

References

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5. Sagi, M: Two BRCA1/2 Founder Mutations in Jews of Sephardic Origin. Familial Cancer: 59-63, 2011.
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STORIES FROM YOUR SHARSHERET COMMUNITY

Leah's Story

I had always thought that when breast cancer's origin is genetic, the mutation travels through the maternal side of the family, and so I would be spared even though my father's sister died of the disease as a young woman. After my diagnosis at age 25, my family struggled to understand the reason, finding it almost impossible to admit that genetics may have come into play. I vaguely remember my surgeon gently telling me to consider genetic testing, but I was too stunned and frightened at the time to think about anything but the immediate present and how I was going to make it through one more minute, one more day.

As the months passed, however, and I began to breathe again, I started to read about BRCA1 and BRCA2 and realized that testing was something I wanted to pursue at some point. When my surgeon informed me at a follow-up visit that she had found residual cancer in my breast despite a lumpectomy and chemotherapy, and that I would need a mastectomy after all, I decided to meet the genetic counselor and have the test done. If I tested positive, I would opt for a bilateral mastectomy and then get on with the rest of my life.

The counselor was kind and informative, spending more than two hours with my parents and me to answer our questions and to discuss all of the options for myself and the other women in my family were I to test positive as a carrier. She made sure to explain that surgery, albeit the most aggressive approach, was not the only option for reducing the risk of a second cancer.

"You tested positive for a BRCA2 mutation..."

Waiting for the results was terrifying, but hearing the counselor say the words "You tested positive for a BRCA2 mutation" was actually a relief. While it was scary to think about the implications for the future, I finally had both an explanation for what had happened to me in the prime of my life, and a clear plan for what to do next. Now, as I am slowly adjusting to my newly reconstructed breasts, I feel comfortable with the decisions that I made both for my sake and for that of my husband and children. I only hope that by the time my baby daughter is old enough to worry, there won't be a reason to worry anymore.

Rachel's Story

When I was first diagnosed, I knew very little about breast cancer genetics. A family member asked me if I had considered genetic testing before surgery. I vaguely recalled having read about it. As an Ashkenazi Jew diagnosed in my late 20's, I felt I needed all the information I could gather, and I began to ask questions about BRCA gene mutations and their connection to Jewish women.

I met with an informative and reassuring genetic counselor. She answered my questions, as well as those of my mother and sister who accompanied me. The four of us sat together to explore our family's medical history. It was painful to recognize how much history we had lost during the Holocaust. With the information she gathered, the genetic counselor thought it likely that I would not be a carrier of a BRCA gene mutation. Regardless, she took the time to review with me the benefits and downsides of testing. Ultimately, she left this important decision to me.

"When the genetic counselor called to tell me I had tested negative..."

I chose to be tested because, at the time, I was struggling to decide whether to opt for a lumpectomy or a mastectomy. Raising young children, and terrified of the prospect of developing breast cancer a second time, I was prepared to have a bilateral mastectomy if I tested positive as a carrier. However, if I tested negative, I was comfortable with my doctor's recommendation to have a lumpectomy.

Waiting for the results was anxiety-provoking. I worried about the effects of the decision on my mother and my sisters, and second-guessed whether or not I would be strong enough to undergo more difficult surgery if I was a carrier.

When I learned I had tested negative, I was flooded with a mix of emotions. I felt relieved that I did not have the added anxieties of a carrier, but I felt as though I were back where I began — 28 years old with breast cancer of unknown origin. Even today, I wonder if there are gene alterations, as yet unidentified, that could explain how breast cancer struck a woman as young and as healthy as I felt the day I was diagnosed.

I feel comfortable with my decision to have undergone genetic counseling and genetic testing. Ultimately, I believe I had all the information I needed to make important decisions about my health; decisions that will benefit my family for years to come.

Sara's Story

Even before I was diagnosed with breast cancer, I knew a great deal about genetic testing. Many of my family members had been tested because of a strong family history of breast cancer and ovarian cancer. I even participated in a study about familial cancers, which included optional genetic testing. Nevertheless, I chose not to be tested.

Once I was diagnosed with breast cancer, I chose to have a bilateral mastectomy and an oopherectomy, surgeries that I was informed would significantly reduce the chances that I would develop ovarian cancer or again be faced with breast cancer during my lifetime. I chose not to be tested because I made the same medical decisions I would have made had I tested positive. I was also afraid of the effect a positive test result might have on my family and my health insurance. I had heard that there are laws to protect me against discrimination by health insurers, but I wasn't ready to take the risk. Finally, on an emotional level, I needed to cling to the hope that maybe, just maybe, my breast cancer was simply the result of bad luck and that I was not at greater risk than anyone else.

"Nevertheless, I chose not to be tested..."

I do worry about the possibility of passing a genetic predisposition for breast cancer and ovarian cancer on to my children. My hope is that there will be an actual cure for breast cancer in the next 20 years and that genetic testing will not be an issue. For now, I have chosen not to be tested. Perhaps one day I will reconsider, if my children want to know the results. I can always change my mind.

Rebecca's Story

I was fourteen when my mother was diagnosed with breast cancer, just six months after her sister completed treatment. They both knew that they were at risk because my grandmother died at an early age from breast cancer. My mother always described herself as a "patient in waiting", suspecting that one day she would face her own fight against breast cancer.

"Prophylactic surgery may significantly decrease the risk..."

Although chemotherapy saved my mother's life, I remember how she struggled after each treatment. Was this my destiny? I spent 20 years as a "patient in waiting," that is, until my mother and I went to a conference on genetics and breast cancer. I had always feared that if I carried the BRCA mutation I, too, would inevitably have breast cancer. However, the presenter said something that would change the course of my history. He said that prophylactic surgery may significantly decrease the risk of my ever getting breast cancer. That is when I made my decision to find out more about genetic testing.

The next day, I made an appointment with a genetic counselor and discussed my options. Would I be able to remove currently healthy parts of my body to decrease my risk? My family had mixed reactions, causing me increased anxiety and stress. My mother said the words I needed to hear: "I would have done that if I could have." I looked into her eyes and I understood. I tested positive for the BRCA gene mutation, and chose a prophylactic bilateral mastectomy. I find comfort knowing that although I cannot change my genetic history, perhaps I have shaped my future.

Beth's Story

When my sister, Sharon, was diagnosed with breast cancer at age 47, we were all shaken by what she would have to endure. There was no cancer in the family other than our paternal grandmother, who was diagnosed at age 79.

When my sister's oncologist suggested that she undergo genetic testing, it suddenly occurred to us that perhaps I, and my two other sisters, could also be at risk. We made an appointment with a genetic counselor who explained that Sharon's young age at diagnosis, coupled with our Ashkenazi background, suggested that there may be a genetic predisposition in our family, not only to breast cancer but also to ovarian cancer. She told us that if Sharon was found to carry a BRCA mutation, the rest of us could then test to find out if we also carried the mutation. If Sharon tested negative, however, we were not home free, as a negative result is not 100% definitive because there may be mutations in other genes that cannot be detected yet. We agreed that the testing had to be done. Sharon had her blood drawn and we held our collective breath while we waited for the results.

The test result showed that there was a genetic mutation in our family. The next step was to test the rest of us, because each of us had a 50% chance of also carrying that mutation. I found out that I did not carry it. The genetic counselor explained that, despite having a mutation in the family, my risk for breast cancer and ovarian cancer was the same as the risk in the general population. I was what was called a "true negative," which only occurs after a mutation has already been identified in the family.

"We all made an appointment with a genetic counselor..."

My youngest sister is not going to test; she does not want to know if she carries the mutation. My other sister tested positive and is planning prophylactic surgery to mitigate the chance of cancer. Each of us faced our family history and made the decision that we felt most comfortable choosing.

We are blessed to live during a time when we have the opportunity to learn about our health history and therefore can find tremendous relief or take advantage of options to try to avoid cancer. We now realize that Sharon's cancer and genetic results led us to a different understanding of ourselves.

Steve's Story

When I was two years old I lost my grandmother to ovarian cancer. She was 47. I was 19 and my mother was only 45 when she died of breast cancer. Over the years since that time, I have spoken to various doctors about what I perceived to be a risk of passing some sort of predisposition to these cancers on to my daughters. I was always told, "Breast cancer and ovarian cancer are passed from mother to daughter." And then, at age 36, one of my daughters was diagnosed with breast cancer. Even though she told her surgeon about our family's extensive breast cancer and ovarian cancer history, as well as the fact that we are Ashkenazi, the surgeon never recommended genetic counseling or testing. My daughter's pathology report showed a triple negative, invasive cancer. It was only then that it was mentioned to me that my daughter should seek genetic counseling and testing for a BRCA mutation.

"We both tested positive for a BRCA1 mutation..."

We both met with a genetic counselor and we both tested positive for a BRCA1 mutation. I had been through the breast cancer journey before with my mom and it was, and still is, an extremely painful experience. Although I do not feel guilty about passing this mutation on to my daughter, I do feel profoundly sad that she inherited it and developed breast cancer at such a young age.

I have five other children and have spoken to all of them about BRCA gene mutations and the 50% chance each of them has of testing positive for a mutation. So far, two of my children have decided to undergo testing, and they are both negative. Three of my children remain to be tested but one of them, a son, has told me that at this point, he does not want to know whether or not he carries the BRCA mutation. That is his right, but at least I feel I have met my responsibility as a dad by informing them about the potential risk of carrying the BRCA mutation.

Eve's Story

When I was eight years old, my mother died of "female problems", as they were called in my family. My father and I were devastated, but it never occurred to either of us that I had anything to worry about. The "problem" didn't even have a name. It wasn't until years later that I realized that "female problems" was the term used years ago when the word "cancer" was taboo and that all the information about hereditary breast cancer also applied to hereditary ovarian cancer. This realization and information inspired me to begin to question my own family history.

"Knowing your family history can guide you to making decisions that could save your life..."

Ultimately, I found out that a first cousin was recently diagnosed with breast cancer. I was lucky because with that information and following my conversation with a genetic counselor, I decided to undergo genetic testing. I found that I carry a BRCA mutation, a genetic predisposition to breast cancer and ovarian cancer.

Given my family history, genetic predisposition, age, and the fact that I never had any children, I decided to undergo a prophylactic oophorectomy. Though it was a hard decision, having my ovaries removed likely saved my life. While I had no specific signs or symptoms of disease, the doctors found a very small malignant tumor in my fallopian tube that, if left undetected, could have taken my life, just as it probably did my mother's.

HOW CAN SHARSHERET HELP ME?

Sharsheret's programs provide support, resources, and information about hereditary breast cancer and ovarian cancer. Our support staff is available to answer questions and guide you to the most appropriate resources.

Sometimes it helps to talk to someone who's been there. Sharsheret's Peer Support Network connects women of Jewish descent diagnosed with breast cancer or ovarian cancer, or at increased risk of developing these cancers, with other women who volunteer to share their personal and medical experiences. If you are concerned about hereditary breast cancer or ovarian cancer, and are considering genetic counseling and testing, or have been diagnosed with breast cancer or ovarian cancer, Sharsheret can connect you with other women who have shared similar experiences.

We also offer the transcripts of Sharsheret's helpful symposia online at www.sharsheret.org, covering topics such as, "Breast Cancer and Ovarian Cancer: Exploring the Connection" and "Breast Cancer Survivors: What You Need To Know About Recent Developments in Genetics," and "Taking Charge: Cancer Screening Updates Every Woman Needs to Know." Check our website for the continually updated list of relevant transcript topics. If you do not have access to the internet, you can call our office to learn about other relevant transcripts available to you.

For more information about Sharsheret's programs, please contact us toll-free at **866.474.2774** or at **info@sharsheret.org**. Sharsheret's programs are open to all women and men. All inquiries are confidential.

Remember, wherever you are, Sharsheret is, and we will be there for as long as you need us.

RESOURCE DIRECTORY

Sharsheret
866.474.2774
www.sharsheret.org
info@sharsheret.org

Organizations Addressing Cancer Genetics

Bright Pink
312.787.4412
www.brightpink.org

Center for Jewish Genetics
312.357.4718
www.jewishgenetics.org

FORCE: Facing Our Risk of Cancer Empowered
866.288.7475 (Helpline)
www.facingourrisk.org

National Society of Genetic Counselors
312.321.6834
www.nsgc.org

NCI Cancer Genetics Services Directory
800.4.CANCER
www.cancer.gov/cancertopics/genetics/directory

Breast Cancer Organizations

Breastcancer.org
www.breastcancer.org

Dr. Susan Love Research Foundation
866.569.0388
www.dslrf.org

Living Beyond Breast Cancer
855.807.6386
888.753.5222 (Helpline)
www.lbbc.org

National Breast Cancer Coalition
800.622.2838
www.natlbcc.org

National Breast Cancer Foundation
www.nationalbreastcancer.org

SHARE (Self-Help for Women with Breast or Ovarian Cancer)
866.891.2392
www.sharecancersupport.org

Susan G. Komen for the Cure
877.465.6636
www.komen.org

Young Survival Coalition
877.972.1011
www.youngsurvival.org

Ovarian Cancer Organizations

Foundation for Women's Cancer
312.578.1439
800.444.4441 (Hotline)
www.foundationforwomenscancer.org

Gilda Radner Familial Ovarian Cancer Registry
800.682.7426
www.ovariancancer.com

HERA Women's Cancer Foundation
972.948.7360
www.herafoundation.org

National Ovarian Cancer Coalition
888.682.7426
www.ovarian.org

Ovarian Cancer National Alliance
202.331.1332
866.399.6262
www.ovariancancer.org

Ovarian Cancer Research Fund
212.268.1002
www.ocrf.org

Survivorship

American Cancer Society Survivors Network
www.csn.cancer.org

LIVESTRONG Foundation
855.220.7777
www.livestrong.org

National Coalition for Cancer Survivorship
877.622.7937
www.canceradvocacy.org

Thriving Again® (A Sharsheret Program)
866.474.2774
www.sharsheret.org

Please visit Sharsheret's website at **www.sharsheret.org** for a continuously updated online resource directory.

BOOKLETS AVAILABLE IN THIS SERIES

Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer

Facing Breast Cancer as a Jewish Woman

Facing Breast Cancer as an Orthodox Jewish Woman

Facing Ovarian Cancer as a Jewish Woman

Breast Cancer and the Ritual Bath: A Guide for Mikvah Attendants

Thriving Again®: For Young Jewish Breast Cancer Survivors

Our Voices: Inspiring Words from the Women of Sharsheret

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