

FLORENCE AND JOSEPH APPLEMAN
EDUCATIONAL BOOKLET SERIES

Hereditary Cancer: Your Jewish Genes



**THE PUBLICATION OF THIS BOOKLET WAS MADE
POSSIBLE WITH GENEROUS SUPPORT FROM**

**Max and Anna Baran, Ben and Sarah Baran and
Milton Baran Endowment Fund of the Jewish
Community Foundation of Los Angeles**

**The Cooperative Agreement DP19-1906 from the
Centers for Disease Control and Prevention**

The Marcus Foundation



**Sharsheret does not endorse any specific genetic testing options, sites, or
companies. Please consult with your healthcare professional about testing
options and any test results you have received.**

Hereditary Cancer: Your Jewish Genes

TABLE OF CONTENTS

| | |
|---|-------|
| Get to Know Sharsheret..... | 2 |
| Our Programs..... | 3 |
| What’s Jewish About Hereditary Breast Cancer and Ovarian Cancer?..... | 4 |
| Questions and Answers About Hereditary Cancer and BRCA Genes..... | 5-11 |
| Stories from Your Sharsheret Community..... | 12-20 |
| How Can Sharsheret Help Me?..... | 21 |
| Resource Directory..... | 22-26 |
| Hereditary Cancer Screening Questionnaire..... | 27 |

Stories from Your Sharsheret Community

| | | | |
|---|----|--|----|
| Leah’s Story..... “You tested positive for a <i>BRCA2</i> mutation...” | 12 | Steve’s Story..... “We both tested positive for the <i>BRCA1</i> mutation...” | 16 |
| Rachel’s Story..... “When the genetic counselor called to tell me I had tested negative...” | 13 | Eve’s Story..... “Knowing your family history can guide you in making decisions...” | 17 |
| Sara’s Story..... “Nevertheless, I chose not to be tested....” | 14 | Emily’s Story..... “I began reading about multi-gene sequencing....” | 18 |
| Rebecca’s Story..... “Prophylactic surgery may significantly decrease the risk....” | 14 | David’s Story..... “Having a genetic test might be able to identify a genetic change in me...” | 19 |
| Beth’s Story..... “We all made an appointment with a genetic counselor....” | 15 | | |

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.

Sharsheret specifically provides support to those who are at increased risk for breast and ovarian cancer related to hereditary mutations. *BRCA1* and *BRCA2* are a particular concern

to those with Ashkenazi Jewish ancestry, but mutations in other genes, like *ATM*, *BRIP1*, *CHEK2*, *PALB2*, *PTEN*, *RAD51C*, *RAD51D*, *TP53*, and genes associated with Lynch syndrome may also increase the risk for breast and ovarian cancer. Mutation in these genes may also increase the risk of pancreatic, male breast, melanoma, prostate, uterine, colon, thyroid, and other cancers. If you have any questions about genetics, you can set up an appointment to speak with our certified genetic counselor, free of charge.

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.

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.

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 diagnosis and experiences
- **The Margot Rosenberg Pulitzer and Sheri Rosenberg Kanter Embrace® Program**, providing support 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
- **The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward Program**, addressing the cosmetic side of treatment
- **Best Face Forward 2.0**, providing services and financial subsidies to enhance women's quality of life
- **The Florence and Laurence Spungen Family Foundation Family Focus® Program**, providing resources and support for caregivers and family members
- **Health Care Symposia**, on issues unique to younger women and Jewish women facing breast cancer and ovarian cancer
- **Ovarian Cancer Program**, tailored resources and support for young Jewish women and families facing 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
- **Sharsheret Supports™**, developing local support groups and programs
- **Thriving Again®**, providing individualized support, education, and survivorship plans for young breast and ovarian cancer survivors

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 their risk of developing breast, ovarian, male breast, pancreatic, prostate cancer, or melanoma. Because of this alteration, individuals 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 individuals 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. Sephardic Jews may also be genetically predisposed to hereditary breast and ovarian cancer, but their risk to carry a BRCA mutation isn't as high as the risk for Ashkenazi Jews. In addition to the high risk of breast and ovarian cancer in women, there is also an increased risk of pancreatic cancer and melanoma for both men and women, as well as an increased risk of breast and prostate cancer in men. In addition to the *BRCA1* and *BRCA2* gene mutations, there are a variety of additional gene mutations such as *CHEK2*, *PALB2*, *CDH1*, *ATM*, *PTEN*, *TP53*, and genes associated with Lynch Syndrome

(hereditary colon, endometrial, and ovarian cancer) that may be identified on panel testing. Mutations in these genes may predispose an individual to breast, colon, pancreatic, prostate, stomach, ovarian, and other types of cancer.

Genetic counseling and testing can help you determine if you carry 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 cancer and their impact on individuals and families. If you have been diagnosed with breast cancer or ovarian cancer, learning more about your genetic background may influence your surgery and treatment decisions. If you have not 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 you 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. 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. We are happy to set you up with an appointment with our certified genetic counselor, free of charge. As with all important medical decisions, be sure to discuss your unique concerns with a healthcare 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 aren't hereditary. However, approximately 5-20% 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 that may indicate increased risk for hereditary cancers, including *CHEK2*, *PALB2*, *CDH1*, *ATM*, *PTEN*, *TP53*, and genes associated with Lynch Syndrome (hereditary colon, endometrial, and ovarian cancer).

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, ovarian, melanoma or pancreatic cancer and male carriers more susceptible to developing male breast, melanoma, prostate and pancreatic cancer. However, these are not the only genes that cause hereditary cancer. Testing for other genes that predispose to cancer is readily available through multi-gene panel testing. Although families may have a strong history of hereditary cancer, results from multigene panel testing can still produce negative results for already known genetic mutations and therefore,

researchers continue to search for other genes that may also increase cancer risk. Talk to a certified genetic counselor or healthcare provider to find out more about multi-gene testing. 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, metastatic prostate, or pancreatic cancer at any age, or families of Ashkenazi Jewish ancestry. Not every person in such families carries an alteration in the *BRCA1* or *BRCA2* genes.

What is the difference between hereditary genetic testing and genetic testing on tumor tissue?

Genetic testing may be done for two different reasons in women with cancer. The first test looks for hereditary cancer - it assesses if a cancer is inherited. This kind of genetic testing is always done on normal cells and may be done on blood or saliva. Looking at these normal cells gives a picture of what mutations were present before a person was born, because they were inherited from a parent. The second kind of test, done on the tumor itself,

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.

looks for the particular mutations that occurred in the body cells that led to the development of the cancer. This kind of testing is called biomarker testing. This is a newer term to differentiate these two major types of genetic testing. Every breast cancer is a little bit different from every other breast cancer. Cancer develops slowly over time as genetic mutations, or mistakes, accumulate in one line of cells. These mutations gradually change the way the cells behave, changing them from normal cells to cancer cells. The particular mutations that are present in the cells can impact the way the cancer is treated.

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 in those carrying mutations, the risk for breast cancer may be as high as 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 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 400 individuals in the general population.⁴ These are called the Ashkenazi Jewish founder mutations. 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, individuals of Ashkenazi descent with breast, ovarian, pancreatic, male breast or prostate cancer, or 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 Sephardic (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 whether genetic testing is appropriate or 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 children. 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, ovarian, male breast, pancreatic, prostate cancer, or melanoma in their lifetime. Most other cancer genes are inherited in this way as well.

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 cancer, prostate cancer, and male breast cancer (especially in *BRCA2* mutation carriers). There may also be a slightly increased risk for papillary serous uterine cancer and colon cancer with *BRCA1*. Screening for these associated risks should be discussed with a certified genetic counselor or healthcare provider.

Should men consider being tested for the *BRCA1* and *BRCA2* mutations?

Men and women with BRCA genetic mutations, have a 50% chance of passing it to each of their offspring, so this information may be important for their children. In addition, although the risk is greater for women, men can get breast cancer. Because men often do not think of examining their breasts, and often their doctors do not 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. Finally, men who carry a mutation in *BRCA1* or *BRCA2* may have an increased risk of developing pancreatic cancer or melanoma.

Are there other cancers associated to *BRCA1* and *BRCA2* mutations? What is my risk?

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 cancer, prostate cancer, male breast cancer, and uterine cancer. With a *BRCA2* mutation, there is a 3-5% risk for melanoma, compared to 1-2% in the general population. Pancreatic cancer is difficult to screen for, yet with a *BRCA2* mutation, the lifetime risk for pancreatic cancer is about 3-5%, with *BRCA1* about 2-3%, and slightly less than a 1% risk in the general population. Men with *BRCA1* or *BRCA2* are at risk of developing prostate cancer. Men with a *BRCA2* have about a 20-30% risk of developing prostate cancer, compared with a 16% risk in the general population, while men with a *BRCA1* mutation have a smaller unspecified increased risk for prostate cancer. Men with *BRCA2* mutations have as high as a 7% risk of developing male breast cancer,

compared to the risk of 0.1% in the general population. Incidence of male breast cancer is also increased with *BRCA1* mutation carriers, but not to the same extent. For women with *BRCA1* mutations, there is a very slight increased risk of developing an aggressive form of uterine cancer. Individuals with a *BRCA1* mutation may also have a slightly increased risk of developing colon cancer, but no specific screening changes are recommended as compared to the general population.

What are the most common mutations people test for in addition to BRCA and why?

Most testing for inherited cancers is done by panel, which means that the test includes a group of genes that have something in common. Some panels are specific for a cancer type, other cover many types of cancer. You should ask a certified genetic counselor about what type of panel(s) makes the most sense. In addition to *BRCA1* and *BRCA2*, a breast cancer panel might include *TP53*, *PTEN*, *STK11*, *PALB2*, *ATM*, and *CHEK2*; an ovarian cancer panel might include *TP53*, *PTEN*, *STK11*, *PALB2*, *ATM*, *BRIP1*, *RAD51C*, *RAD51D*, and genes associated with Lynch syndrome.

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 healthcare 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 genetic counselor who can answer your question 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 should I do to manage my risk of developing other cancers?

For men only: Since prostate cancer in mutation carriers is sometimes diagnosed at earlier ages and can be more aggressive, men who test positive for a *BRCA1* or *BRCA2* mutation should speak to their physicians about high risk prostate cancer screening as early as age 40. Men with a *BRCA1* or *BRCA2* mutation should have a breast exam completed by their physicians every year, and may consider having annual mammograms. For women only: Women who test positive for a *BRCA1* or *BRCA2* mutation and who are planning to have their ovaries and fallopian tubes removed may consider having their uteruses removed as well. For men and women: It is recommended that both men and women who test positive for a *BRCA1* or *BRCA2* mutation have a skin

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

exam done by a dermatologist 1-2 times a year. Also, for those concerned about pancreatic cancer, it may be beneficial to participate in a pancreatic cancer screening study.

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, or use the hereditary cancer screening questionnaire on page 31 of this booklet, and share your results with your clinician to help determine if further genetic evaluation is right for you.

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'll discuss who in your family has had which type of genetic testing for hereditary 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.

I see that some direct to consumer genetic tests offer screening for the Ashkenazi Founder mutations in *BRCA1* and *BRCA2*? Should I consider genetic testing through a direct to consumer lab?

You may want to discuss with a healthcare professional which type of test is best for you. Most direct to consumer tests do not sequence the full genes, but look at SNPs (single nucleotide polymorphisms) which are small differences in the genes between unique individuals. The Ashkenazi founder mutations may be identified by a test looking only at specific SNPs, but thousands of other mutations would be missed. If you're concerned about hereditary cancer, you may want to get a medical grade test, which is considered to be a higher quality test. Medical grade testing of hereditary cancer involves a method referred to as next generation or parallel sequencing. This kind of testing can determine all of the chemicals that make up each of the tested genes, and can test a large amount of DNA sequence at one time.

I had a genetic test done through a direct to consumer lab, what should I do next if I tested positive or negative?

A genetic result obtained by a direct to consumer lab needs to be confirmed by a medical grade test. You should speak to your healthcare provider, or speak with us at Sharsheret if you need assistance in arranging this kind of testing.

Will genetic counseling and/or genetic testing be covered by my insurance?

Coverage is variable, and it's best to ask this information up front when you make an appointment. There are generally two charges associated with the genetic counseling and testing process. The first is the charge for the consultation, whether it is with a genetic counselor or another healthcare provider. The second is the cost of the test itself, and that charge will come from the laboratory. Each insurance company has its own guidelines, which may or may not match up with the national guidelines that have been set up by experts in the field. Most hospitals don't run the genetic testing in their own labs, and the testing is usually sent out to specialty labs. Sometimes, insurance companies have contracts with certain labs and not with others. This might mean that if your testing is sent to Lab A, you might not be covered, while if your sample is sent to Lab B, you will be covered. If you're told that the testing isn't covered, it is important to find out the reason why. Also, it can be possible to get a discounted cash price for the laboratory test when insurance won't cover. This price may be as low as \$250 at some labs for an extensive medical grade test. If you can't afford testing, genetic labs may take your income into account, and some have assistance programs available to help with coverage. It's important to provide income information to the lab if there is any out of pocket cost.

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.

Should I be concerned about insurance or employment discrimination if I decide to have genetic testing?

Effective in 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA) into law. This law provides protection against discrimination in health insurance coverage and employment 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 hereditary cancer mutation?

A positive test result indicates that you have inherited a known mutation in a 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 an alteration. If you have not been diagnosed with cancer, test results may help you make choices that could reduce your risk of developing

cancer or help detect cancer early. The recommendations will depend on the specific genetic mutation identified, and the recommendations may differ depending on each person's situation. The options may include using a higher level of screening than the general population (i.e. adding an annual breast MRI) or beginning typical screening at an earlier age. Some individuals might take a medication to reduce their risk of developing cancer. Finally, some individuals consider prophylactic, or risk reducing surgery. For example, a woman with a BRCA mutation might remove either ovaries, fallopian tubes or breasts before cancer has a chance to develop. Genetic counselors can guide you and discuss 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, 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. Those who test positively may be able to use medications that specifically target cancer in individuals who carry a hereditary mutation. Finally, results for a person in the family who has had cancer can help interpret negative results for other family members who have not been diagnosed.

Do I require further genetic testing if I test negative for a BRCA1 or BRCA2 mutation? What if my test was done years ago?

If you previously tested negative for a BRCA1 or BRCA2 mutation, consult with a certified genetic counselor about whether further additional genetic testing is recommended. A variety of genetic panels is now available to test for additional genes such as CHEK2, PALB2, CDH1, ATM, PTEN, TP53 and genes associated with Lynch syndrome

(hereditary colon, endometrial, and ovarian cancer). Mutations of these genes can predispose people to breast, ovarian, pancreatic, prostate, colon, endometrial, stomach and/or other cancers. Your personal genetics don't change over the course of your life. What changes is the science. Upgraded tests can find something that wasn't looked at in the past. There is not a specified number of years after which one should have an upgraded test. That's why it's so important to talk with a certified genetic counselor who can advise whether or not upgraded testing makes sense for you, based on what test was done originally, and whether testing is likely to be covered by your insurance.

What if after reading through these questions and answers, I still need help understanding my particular situation with regards to genetics?

While you can speak to your own healthcare providers, Sharsheret also offers the opportunity to speak with our certified genetic counselor; these conversations are free of charge and confidential. While she can't order a test for you, she can answer questions about whether a test makes sense for you and where to get it done. She can also discuss the implications of genetic testing you have already had done, and whether your testing should be updated.

How should I be monitored if my genetic testing is negative?

If you test negative for any hereditary cancer mutation, it may be helpful to consult with a certified genetic counselor or other health professional (e.g. breast surgeon or gynecologist) about appropriate screening and heightened surveillance. They can also inform you of developments in genetic research and testing as it becomes available. Even if you test negative for

a hereditary cancer mutation, a strong family history of cancer should not be ignored, as researchers have not yet identified all of the 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' healthcare 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 healthcare professional (e.g., breast surgeon or gynecologist) can help you determine appropriate screening and surveillance. You can also learn more about cancer risk by speaking 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.

1. National Cancer Institute: Genetics of Breast and Ovarian Cancer (PDQ[®]), 2004. 2. King MC, Marks J, Mandell J: Breast Cancer Risks Due to Inherited Mutations in *BRCA1* and *BRCA2*. *Science* 302:643-646, 2003. 3. National Cancer Institute: Surveillance, Epidemiology, and End Results Program. Stat Fact Sheet, 2011. 4. Scheuer L, Lauff N, Robson M, et al: Outcome of Preventative Surgery and Screening for Breast and Ovarian Cancer in *BRCA* Mutation Carriers. *J Clin Oncol* 20:1260-1268, 2002. 5. Sagi, M: Two *BRCA1/2* Founder Mutations in Jewish of Sephardic Origin. *Familial Cancer*: 59-63, 2011. 6. U.S. Equal Opportunity Commission "The Genetic Information Nondiscrimination Act of 2008" n.d.

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 breast, 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, 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 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, and 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 cancer, 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 oophorectomy, 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 was not 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'll reconsider, if my children want to know the results. I can always change my mind.

Rebecca's Story

I was 14 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 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 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 my sisters and I could also be at risk. We made an appointment with a genetic counselor who explained that Sharon's young age at diagnosis, couple with our Ashkenazi background, suggested that there may be 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 weren't 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 the mutation. I found out that I didn't carry it. The genetic counselor explained that, despite having a mutation in the family, my risk for breast cancer and ovarian cancer was most likely the same risk as 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 isn't going to test; she doesn't 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're 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 didn't 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, had told me that at this point, he doesn't 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.

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

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.

Emily's Story

I come from a long line of Ashkenazi Jewish breast cancer survivors. My mother's paternal grandmother died of breast cancer at age 52; my mother's maternal grandmother had breast cancer in her 80s; my maternal grandmother had breast cancer in her 70s; her sister, my maternal great aunt, had breast cancer in her 60s; and my mother was diagnosed with breast cancer when she was 51.

With a history like mine, a BRCA gene mutation seemed like the likely explanation. So a few years before my mother was diagnosed, she decided to test for a BRCA gene mutation. The results shockingly and thankfully came back negative. Despite her negative results, her family history still dictated close monitoring and a few years later she was unfortunately diagnosed with Stage I breast cancer.

"I began reading about multi-gene sequencing..."

Following my mother's diagnosis, her medical team decided that even though she had tested negative for BRCA, it was still wise for me to test for a BRCA gene mutation. Waiting for my results was agony. Ever since my mother's diagnosis, I felt like a "patient in waiting," but finding out in my early 20s, just a year after getting married, if I carried a BRCA gene mutation, was a whole different story. I remember feeling like my heart was in my throat when I got

the call at work. "Your test came back negative." I was so relieved, but at the same time I surprisingly felt so confused because outside of sheer bad luck, there was nothing concrete to explain my family history.

About two years after testing for a BRCA gene mutation, I began reading about multi-gene sequencing and other genetic mutations responsible for an increase in breast cancer risk. After speaking with Sharsheret's genetic counselor, I tried convincing my mother to meet with a genetic counselor about multi-gene sequencing. At the time my mother wasn't interested in further genetic testing. The thought of finding out "too much information" frightened her but she understood my interest in informing our family and agreed to multi-gene sequencing.

My mother's results came back positive for a mutation called *CHEK2*. It is responsible to a significant lifetime increased risk of breast and colorectal cancer. With this information in hand, my sister and I decided to further test as well. My sister thankfully came back negative and I unfortunately came back positive. While my mother was hesitant to test initially, once I received my results, she was grateful that I had pushed her to get tested so that I could now take the appropriate steps to protect my health and decrease my chances of dealing with a breast cancer diagnosis.

David's Story

When I was a young child, several of my father's relatives died of pancreatic cancer. We always thought that this was related to exposures, as some of these relatives were regular smokers and/or drinkers. No one in the family had any other kind of cancer. It was not until about a year ago that my doctor told me that there had been a change in the testing criteria for hereditary cancer, and it now included having a family history of pancreatic cancer. Apparently, pancreatic cancer is pretty rare, not as common as it has been in my family. Having multiple family members with pancreatic cancer is actually unusual.

My doctor recommended that I see a genetic counselor. She took a detailed family tree and told me that there could be a hereditary predisposition to pancreatic cancer in my family. She said that my Ashkenazi Jewish ancestry made it more likely that a mutation in *BRCA1* or *BRCA2* might be implicated, but she recommended testing for a broader panel of genes associated with pancreatic cancer. Having a genetic test might be able to identify a genetic change in me, and possibly explain the family history of cancer. All of the family members had pancreatic cancer had passed away already, so a negative result might be a false negative, meaning that the pancreatic cancer was still linked to a genetic mutation. She told me that there are hereditary factors

that predispose to cancer that we do not know how to look for.

My blood was drawn and shipped to a specialty genetics lab. They checked my insurance to be sure that the testing would be covered. The genetic

“Having a genetic test might be able to identify a genetic change in me, and possibly explain the family history of cancer...”

counselor called me two weeks later to let me know that the results were positive, and that she wanted me to come back in to discuss them with her.

I tested positively for a mutation in *BRCA2*. She was surprised that no one in the family had been diagnosed with breast, ovarian or prostate cancer, since these are the cancers that are more commonly seen with a *BRCA2* mutation. She told me that there can be wide variability in the patterns of cancer that are seen, even in families carrying the identical *BRCA2* mutation. Unfortunately, pancreatic cancer is very difficult to screen for, and removing the pancreas before cancer develops is out of the question. The pancreas is very important for maintaining our health.

I had already made it to age 60 without developing cancer, but this didn't put me in the clear. I started by increasing the frequency of my prostate cancer screening. I had never been too careful about prostate cancer screening in the past, because no one in my family had ever been diagnosed with prostate cancer. My urologist told me that men with *BRCA1* or *BRCA2* mutations are more likely to develop prostate cancer at a younger age and tend to have more aggressive tumors. I also set up an appointment with a dermatologist for a skin exam, since mutations in *BRCA2* also increase the risk of melanoma

Finally, the genetic counselor suggested that I could consider pancreatic cancer screening under the auspices of a study. There's a specialized pancreatic cancer center near me that is doing research on people in my situation.

While screening isn't yet proven to improve survival from pancreatic cancer, there are some promising developments. By participating in a study, I can help provide information for future generations who may develop pancreatic cancer.

Now, my brothers, sisters, and children are planning to have genetic testing. They each have a 50% chance to have inherited the family mutation in *BRCA2*. I have also let my extended family know about the results. So far, I have two paternal cousins who have tested positively for the same mutation. Both male and female relatives have been pursuing testing. We know that early detection saves lives, and my family members are thankful that we have a more clear answer who in the family is at increased risk for cancer.

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 has 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 cancer, with other women who volunteer to share their personal and medical experiences. If you're concerned about hereditary breast cancer or ovarian cancer, and are considering genetic 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 don't have access to the internet, you can call our office to learn about 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

Cancer Genetics

American College of Medical Genetics and Genomics

301.718.9603
www.acmg.net

American Society of Human Genetics

866.HUM.GENE
www.ashg.org

Basser Center for BRCA-Education and Outreach

215.662.2748
www.basser.org

BFOR BRCA Founder Outreach Study

www.bforstudy.com

Bright Pink

312.787.4412
www.brightpink.org

Center for Disease Control and Prevention

www.cdc.gov/genomics/disease/breast_ovarian_cancer/index/htm

FORCE: Facing Our risk of Cancer Empowered

866.288. RISK
www.facingourrisk.org

Genetic Alliance

202.966.5557
www.geneticalliance.org

Genetics For Life® (A Sharsheret Program)

866.474.2774
www.sharsheret.org

JScreen

www.jscreen.org
404.778.8640

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

Norton and Elaine Sarnoff Center for Jewish Genetics

312.357.4718
www.jewishgenetics.org

Right Action for Women

www.rightactionforwomen.org/assistance

Breast Cancer Organizations

Are You Dense?

www.areyoudense.org

beBRCAware

www.bebrcaaware.com

Breast360.org

www.breast360.org

Breastcancer.org

610.642.6550
www.breastcancer.org

Breasthealth.org

www.breasthealth.org

Breast Cancer in Focus:

Breast Cancer in Men

www.lbbc.org/infocusmen

Breast Cancer Research Foundation

866.FIND.A.CURE
www.brcrfcure.org

Dense Breast-Info: An Education Coalition

www.densebreast-info.org

Dr. Susan Love Research Foundation

310.828.0060
www.dslrf.org

Living Beyond Breast Cancer

855.807.6386
888.753.5222 (Helpline)
www.lbbc.org

Male Breast Cancer Coalition
www.malebreastcancercoalition.org

National Breast Cancer Coalition
800.622.2838
www.Breastcancerdeadline2020.org

National Breast Cancer Foundation
www.nationalbreastcancer.org

SHARE: Self-Help for Women with Breast or Ovarian Cancer
866.ASK.SHARE
www.sharecancersupport.org

Susan G. Komen Breast Cancer Foundation
877.456.6636
www.komen.org

Tiger Lily Foundation
888.580.6253
www.tigerlilyfoundation.org

Triple Negative Breast Cancer Foundation
877.880.TNBC
www.tnbcfoundation.org

Triple Step Toward the Cure
877.880.8622
www.triplesteptowardthecure.org

United Breast Cancer Foundation
877.UBC.4CURE
www.ubcf.org

Young Survival Coalition
877.972.1011
www.youngsurvival.org

Ovarian Cancer Organizations

Camp Mak-A-Dream-Adult Retreats
406.549.5987
www.campdream.org

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

HERA Ovarian Cancer Foundation
970.948.7360
www.herafoundation.org

National Ovarian Cancer Coalition
888.OVARIAN
www.ovarian.org

Ovarian Cancer Research Alliance
202.331.1332
866.399.6262
www.ocrahope.org

Roswell Park Familial Ovarian Cancer Registry
800.682.7426
www.ovariancancer.com

Sandy Rollman Ovarian Cancer Foundation
610.446.2272
www.sandyovarian.org

SHARE: Self Help for Women with Breast or Ovarian Cancer
866.ASK.SHARE
www.sharecancersupport.org

Young Women Facing Breast Cancer

Stupid Cancer
877.735.4673
www.stupidcancer.org

Ulman Foundation
888.393.FUND
Ulmanfoundation.org

Young Survival Coalition
877.YSC.1011
www.youngsurvival.org

Survivorship

2Unstoppable
www.2unstoppable.org

American Cancer Society Survivors Network
800.227.2345
www.csn.cancer.org

Breastcancer.org

610.642.6550
www.breastcancer.org

LIVESTRONG Foundation

855.220.7777
www.livestrong.org

Living Beyond Breast Cancer

888.753.5222 (Survivor's Helpline)
www.lbbc.org

National Coalition for Cancer Survivorship

877.NCCS.YES
www.canceradvocacy.org

Survivor.net

www.survivor.net.com

Thriving Again (A Sharsheret Program)[®]

866.474.2774
www.sharsheret.org

Young Survival Coalition

877.YSC.1011
www.youngsurvival.org

Jewish Organizations Addressing Cancer and Health-Related Issues**Bikur Cholim, Partners in Health**

845.425.7877
www.bikurcholim.org

Chai4ever

646.519.2190
www.chai4ever.org

Chai Lifeline

877.CHAI.LIFE
www.chailifeline.org

Hadassah

888.303.3640
www.hadassah.org

Network of Jewish Human Service

Agencies
201.977.2400
www.networkjhsa.org

Nishmat: Women's Health and Halacha

877.963.8938
www.yoatzot.org/home

The Jewish Board

844.ONE.CALL
www.jewishboard.org

Cancer Organizations**American Cancer Society**

800.ACS.2345
www.cancer.org

American Psychosocial Oncology Society Helpline

866.276.7443
www.apos-society.org

Cancer101

646.638.2202
www.cancer101.org

CancerCare

800.813.HOPE
www.cancercare.org

Cancer Hope Network

877.HOPE.NET
800.552.4366 (Helpline)
www.cancerhopenetwork.org

Cancer.Net

888.651.3038
www.cancer.net

Cancer Support Community

888.793.9355
www.cancersupportcommunity.org

Imerman Angels

866.IMERMAN
www.imermanangels.org

National Cancer Institute

800.4.CANCER
www.cancer.gov

Patient Resource

800.497.7530
www.patientresource.com

LGBTQ Community

Center Link, The Community of LGBT Centers

954.765.6024

www.lgbtcenters.org

National LGBT Cancer Network

212.675.2633

www.cancer-network.org

Family, Friends, and Caregivers

American Cancer Society:

Road to Recovery

800.227.2345

www.cancer.org/treatment/support-programs-and-services/road-to-recovery.html

Busy Box (A Sharsheret Program)

866.474.2774

www.sharsheret.org

Camp Kesem

253.736.3821

www.campkesem.org

Fighting Pretty

www.fightingpretty.org

Gilda's Club New York City

212.647.9700

www.gildasclubnyc.org

Kids Connected

949.484.9092

www.kidsconnected.org

Lotsa Helping Hands

www.lotsahelpinghands.org

Men Against Breast Cancer

866.547.MABC

www.menagainstbreastcancer.org

Mommy has Breast Cancer

877.386.7322

www.mommyhasbreastcancer.org

Mothers Supporting Daughters with Breast Cancer

410.778.1982

www.mothersdaughters.org

SHARE Dedicated Experienced Support for Women Facing Breast or Ovarian Cancer

844.ASK.SHARE

www.sharecancersupport.org

Sister to Sister

718.338.2943

www.sistertosisternetwork.org

Take Them a Meal

800.951.7715

www.takethemameal.com

Telling Kids About Cancer

www.tellingkidsaboutcancer.com

The Breathing Butterfly

www.elfenworks.org/butterfly

The Florence and Laurence Spungen Family Foundation Family Focus Program™

866.474.2774

www.sharsheret.org

Wonders & Worries, We Will, Together

512.329.5757

www.wondersandworries.org

Fertility, Pregnancy, and Nursing

Alliance for Fertility Preservation

www.allianceforfertilitypreservation.org

A T.I.M.E (Torah Infertility Medium of Exchange)

718.437.7110

www.atime.org

Bonei Olam

718.252.1212

www.boneiolam.org

Hasidah

415.323.3226

www.hasidah.org

**Hope for Two- The Pregnant
with Cancer Network**

800.743.4471

www.hopefortwo.org

Livestrong Fertility

855.220.7779

[www.livestrong.org/we-can-help/
livestrong-fertility](http://www.livestrong.org/we-can-help/livestrong-fertility)

**Oncofertility Consortium-
Northwestern University**

312.503.2504

www.savemyfertility.org

Path2Parenthood

888.917.3777

www.path2parenthood.org

Puah

708.336.0603

www.puahonline.org

Reprotech

www.reprotech.com

**Resolve, The National Infertility
Association**

703.556.7172

www.resolve.org

Will2Love

www.will2love.com

Yesh Tikva

www.yeshtikva.org

Health Insurance

#Coverage4All

www.coverage4all.info

Benefits.gov

800.333.4636

www.benefits.gov

Breast Cancer: Covered or Not

800.215.7494

[www.pabreastcancer.org/uploads/
userfiles/files/pdfs/insurance-
guidebook.pdf](http://www.pabreastcancer.org/uploads/userfiles/files/pdfs/insurance-guidebook.pdf)

Cancer Insurance Checklist

www.cancerinsurancechecklist.org

Center for Patients Partnerships

608.890.0321

www.patientpartnerships.org

**Financial Wellness Tool Kit
(A Sharsheret Resource)**

866.474.2774

www.sharsheret.org

HealthCare.gov

www.healthcare.gov

**Triage Cancer-How to Pick a Health
Insurance Plan Video**

www.triagecancer.org/animatedvideos

Technology Based Resources

Caring Bridge

651.789.2300

www.caringbridge.org

Cancer Support Community

888.793.9355

www.mylifeline.org

Helpful Bikur Cholim Links

[www.jewishboard.org/resources/helpful-
bikur-cholim-links](http://www.jewishboard.org/resources/helpful-bikur-cholim-links)

Meal Train

www.mealtrain.com

Navigating Cancer

800.925.4456

www.navigatingcancer.com

Think About Your Life

818.695.4334

www.thinkaboutyourlife.org

Clinical Trials

About Clinical Trials

www.learnaboutclinicaltrials.org

American Cancer Society

www.cancer.org

Basser Center for BRCA

www.basser.org

BreastCancerTrials.org

www.breastcancertrials.org

CancerCare

www.cancercare.org

Central Watch

www.centerwatch.com

Clinical Trials and Me

www.clinicaltrialsandme.com

Dr. Susan Love Research Foundation

www.drSusanLoveResearch.org

eCancerTrials

www.ecancertrials.com

Emerging Med

877.601.8601

www.app.emergingmed.com/emed/home

FORCE: Facing Our Risk of Cancer

Empowered

www.facingourrisk.org

Massive Bio

844.627.7246

www.massivebio.com

MBC Alliance

www.mbcalliance.org/metastatic-trial-search-expands

National Cancer Institute

800.4.CANCER

www.cancer.gov/clinicaltrials

National Institute of Health

www.clinicaltrials.gov

Search Clinical trials

877.MED.HERO

www.searchclinicaltrials.org

Susan G. Komen Breast

Cancer Foundation

800.IM.AWARE

ww5.komen.org

Advanced Breast Cancer

ACOR (Association of Online Cancer Resources)

listserv.acor.org

Expert Tips Shared with Women Living with Advanced Cancer

www.sharsheret.org/resource/read-expert-tips-shared-with-women-living-with-advanced-cancer

Living Beyond Breast Cancer

610.645.4567

www.lbbc.org

MBC Connect

www.mbcconnect.org

Metastatic Breast Cancer Information and Support

www.bcmets.org

Metastatic Trial Search

www.bcmets.org/

Online Resources for People Living with Advanced Breast Cancer

www.advancedbreastcancercommunity.org

The Margot Rosenberg Pulitzer and Sheri Rosenberg Kanter Embrace™ Program

866.474.2774

www.sharsheret.org

Jewish Organizations Addressing Spirituality

Aneinu: International Tehillim Organization

516.239.6083

917.575.8719

www.aneinu.com

Institute for Jewish Spirituality

646.461.6499

www.jewishspirituality.org

Mayyim Hayyim Living Waters Community Mikkveh and Paula Brody & Family Education Center

617.244.1836

www.mayyimhayyim.org

Ritualwell

215.576.0800
www.ritualwell.org

Shira Ruskay Center

212.632.4608
www.jewishboard.org/about-us/
programs-services/jewish-community-
services/shira-ruskay-center

Breast Cancer Organizations in Israel**Beit Natan**

011.972.2.644.6052
www.beitnatan.org

Bracha

011.972.72.233.2974
www.bracha.org.il

Israel Cancer Association

011.972.3.572.1616
www.cancer.org.il

Lemonade Fund: Emergency Financial Relief for Israeli Women Recently Diagnosed with Breast Cancer

www.lemonadefund.org

One in Nine

011.972.3.602.1717
www.onein9.org.il

Stop Cancer

www.stop-cancer.co.il

Tishkofet-Ma'agan

011.972.2.631.0803
www.lifesdoor.org

Legal Assistance**Cancer Legal Resource Center**

866.THE.CLRC
213.736.1455
www.disabilityrightslegalcenter.org/
cancer-legal-resource-center

Law Help

www.lawhelp.org

Lawyer Referral Service

www.americanbar.org/groups/legal_ services

National Cancer Legal Services Network

www.NCLSN.org

Patient Advocate Foundation

800.532.5274
www.patientadvocate.org

Male Breast Cancer**American Cancer Society**

www.cancer.org/cancer/breast-cancer-
in-men/about/what-is-breast-cancer-
in-men.html

Breastcancer.org

www.breastcancer.org/symptoms/
types/male_bc

Komen

ww5.komen.org/BreastCancer/
BreastCancerinMen.html

Living Beyond Breast Cancer

www.lbbc.org/man-diagnosed-
breast-cancer

Male Breast Cancer Coalition

www.malebreastcancercoalition.org

Men Against Breast Cancer

www.menagainstbreastcancer.org/
information-for-male-breast-cancer

National Cancer Institute

www.cancer.gov/types/breast/patient/
male-breast-treatment-pdq

HEREDITARY CANCER SCREENING QUESTIONNAIRE

Although rare, a hereditary predisposition can lead to more than one type of cancer in both men and women. For example, prostate, pancreatic, and breast cancer may all be caused by a single genetic variant. Therefore, it is important to accurately identify which of your family member(s) had what type of cancer(s) and at what ages.

The following questions will help your clinician determine whether further genetic evaluation for certain hereditary conditions may be recommended.

A **CANCERS ON YOUR FATHER'S SIDE**

Has your father been diagnosed with cancer?
 NO IF YES, WRITE "1" DON'T KNOW

Aunts or uncles on your father's side?
 NO IF YES, HOW MANY? DON'T KNOW

Cousins on your father's side?
 NO IF YES, HOW MANY? DON'T KNOW

Grandparents on your father's side?
 NO IF YES, HOW MANY? DON'T KNOW

B **CANCERS ON YOUR MOTHER'S SIDE**

Has your mother been diagnosed with cancer?
 NO IF YES, WRITE "1" DON'T KNOW

Aunts or uncles on your mother's side?
 NO IF YES, HOW MANY? DON'T KNOW

Cousins on your mother's side?
 NO IF YES, HOW MANY? DON'T KNOW

Grandparents on your mother's side?
 NO IF YES, HOW MANY? DON'T KNOW

C **CANCERS IN YOUR IMMEDIATE FAMILY**

| | |
|---|--|
| Have you ever been diagnosed with cancer? NO <input type="checkbox"/> IF YES, WRITE "1" <input type="checkbox"/> DON'T KNOW <input type="checkbox"/> | Brothers or sisters? NO <input type="checkbox"/> IF YES, HOW MANY? <input type="checkbox"/> DON'T KNOW <input type="checkbox"/> |
| Children or grandchildren? NO <input type="checkbox"/> IF YES, HOW MANY? <input type="checkbox"/> DON'T KNOW <input type="checkbox"/> | Nieces or nephews? NO <input type="checkbox"/> IF YES, HOW MANY? <input type="checkbox"/> DON'T KNOW <input type="checkbox"/> |

D PLEASE ANSWER THE FOLLOWING QUESTIONS

| | NO | YES | DON'T KNOW |
|---|----|-----|------------|
| Has anyone in your family had genetic testing for cancer risk? | | | |
| Has anyone in your family been diagnosed with ovarian cancer or male breast cancer? | | | |
| Was anyone in your family diagnosed with cancer at or before age 50? | | | |
| Has anyone in your family had 10 or more colon polyps? | | | |

This questionnaire is intended for use with your clinician. Even if the information you receive does not reveal a particular hereditary disease or condition, you may still be at risk. Our understanding of genetic conditions continues to evolve rapidly and your determined risk may change. The questionnaire is not a diagnostic tool and is not intended to provide or substitute for professional or medical advice.

BOOKLETS AVAILABLE IN THIS SERIES

Hereditary Cancer:
Your Jewish Genes
.....

Facing Breast Cancer as
a Jewish Woman
.....

Facing Cancer as a Frum 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
.....

From the Practical to the Spiritual:
Caring for Loved Ones Living with
Advanced Cancer

ACKNOWLEDGMENTS

We are grateful to all of the women and men of the Sharsheret community who contributed their thoughts and experiences to the development of this booklet. Additionally, we are thankful for the guidance of the organizations and healthcare professionals who provided invaluable input.

.....

For information about this booklet and other Sharsheret publications,
E-mail: info@sharsheret.org
Call Toll-Free: 866.474.2774

