OCTOBER 13 -31, 2023

DIGITAL RESOURCE PACKET

SHARSHERET SUMMIT

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Thank you to our generous Summit sponsors:

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Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. Sharsheret does not endorse or promote any specific medication, treatment, product or service, and makes no guarantees regarding the effectiveness of the product discussed herein. The information provided herein is not a substitute for professional medical advice or treatment. You should always seek the advice of your physician or other qualified health provider.

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This resource is brought to you by

AstraZeneca

SPONSORED CONTENT:

This resource is brought to you by

Pfizer Oncology

THIS IS **LIVING WITH** CANCER™

A program for people living with cancer and those who love them

This Is Living With Cancer™ is a free online resource developed by Pfizer Oncology for all people living with cancer.

Download the free LivingWith® app

Support to help you live life beyond your diagnosis

This Is Living With Cancer™ is a free online resource developed by Pfizer Oncology for all people living with cancer, regardless of age, income, race, location, cancer type or stage of disease.

This comprehensive program is available to anyone in the United States whether they're on a Pfizer treatment or not, with a growing focus on those facing challenges accessing care.

We offer articles on healthy living, support resources and inspiration for all people living with cancer and those who love them.

Personalize your

support resources

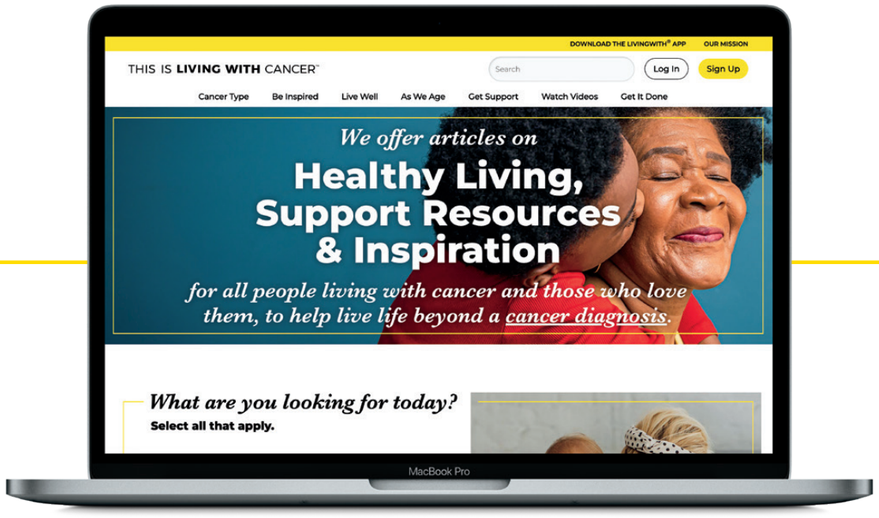
If you or your loved one is looking for specific information, you can create a profile to personalize your site experience.

And even if you didn't sign up yet, you can still access over 150 topics including educational materials, cancer planning information, wellness content and more.

Visit **ThisIsLivingWithCancer.com** to learn more.

Scan this QR code with your phone's camera to:

- Sign up
- Start building your customized website experience



This Is Living With Cancer™ has brought together a community of people living with cancer and those who love them across Facebook, YouTube and Instagram.

Follow us **@thisislivingwithcancer**

Discover resources for your

patient journey

PATIENT ADVOCACY RESOURCES

Get access to resources developed by advocacy partner organizations and find specific resources by cancer type. **This Is Living With Cancer™** is a proud partner of over 50 organizations.

Pfizer Oncology partners include:

ZERO—THE END OF PROSTATE CANCER
ZEROcancer.org

LUNGEVITY
Lungevity.org

BREASTCANCER.ORG
Breastcancer.org

THE LEUKEMIA & LYMPHOMA SOCIETY®
LLs.org

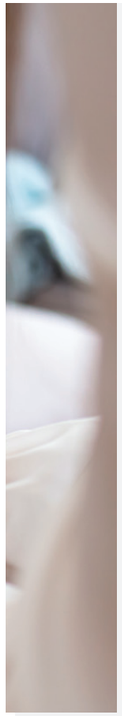
Visit **ThisIsLivingWithCancer.com/get-support/advocacy-partners** for more information.

SCREENING FOR CANCER

Cancer screenings and follow-ups can't wait. Find resources to help guide conversations with your healthcare team and make a plan to keep your checkup appointments.

INSPIRATIONAL STORIES

Hear the real stories of people living with cancer. Their journeys may be different, but they all share strength, resilience and inspiration.



AFTER DIAGNOSIS

Cancer can be complex. Learning new information about common cancer terms, the clinical trial process and the role of biomarker testing in cancer treatment can help.

NUTRITION & WELLNESS

Find articles about healthy living, exercise and dietary considerations, as well as resources on managing depression, anxiety, pain and more.

Download LivingWith® for free

LivingWith® helps keep track of the everyday details so you can focus on the big picture.

Use the app to stay connected by inviting friends and family to join your private circle of support, sending or receiving requests for help and sharing how you're feeling with loved ones.

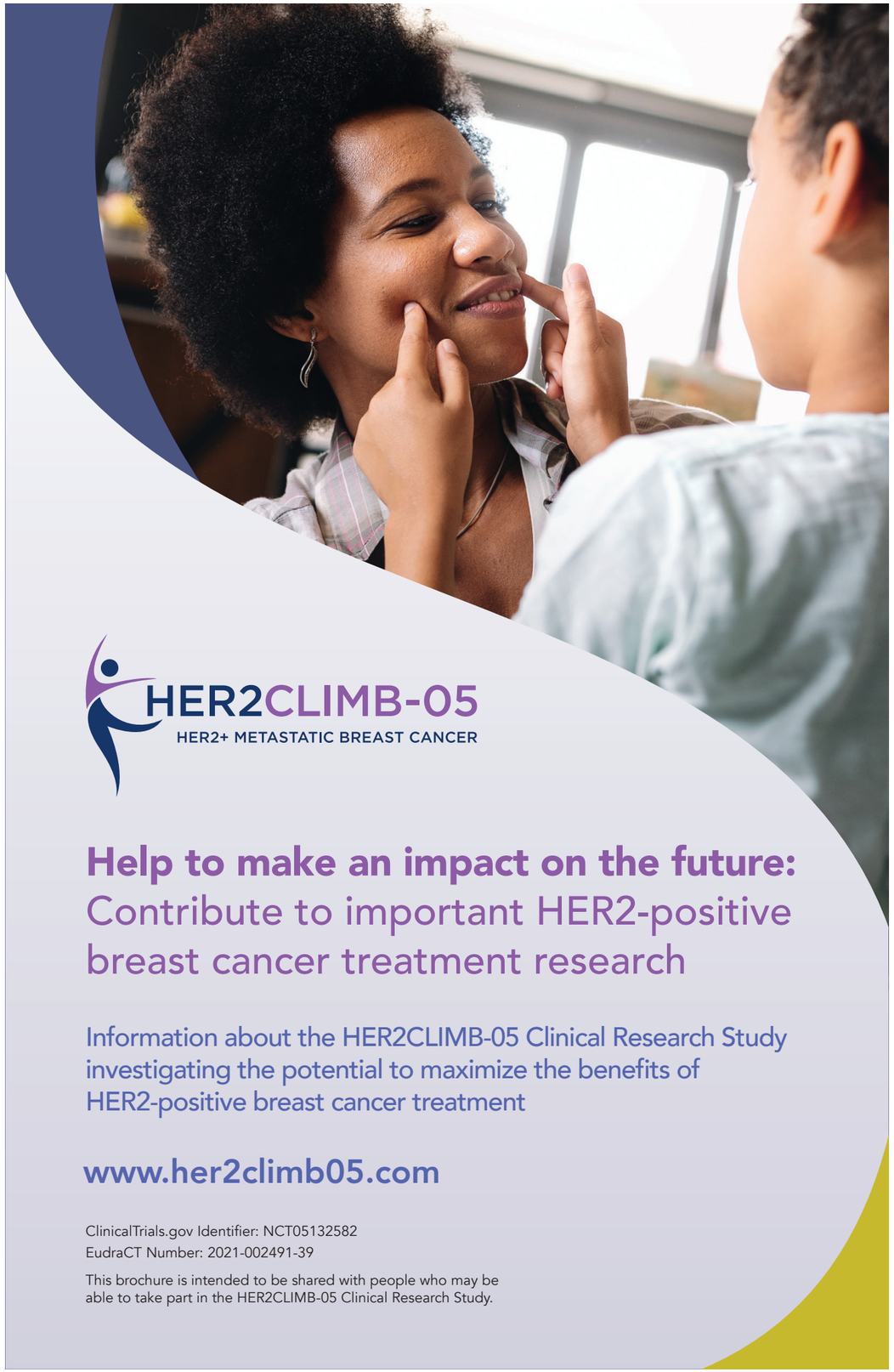
Available in English and Spanish, **LivingWith** may help you stay connected and organized, all in one place.

Scan this QR code with your phone's camera to download the app for free

SPONSORED CONTENT:

This resource is brought to you by

Seagen®



HER2CLIMB-05

HER2+ METASTATIC BREAST CANCER

Help to make an impact on the future:
Contribute to important HER2-positive breast cancer treatment research

Information about the HER2CLIMB-05 Clinical Research Study investigating the potential to maximize the benefits of HER2-positive breast cancer treatment

www.her2climb05.com

ClinicalTrials.gov Identifier: NCT05132582
EudraCT Number: 2021-002491-39

This brochure is intended to be shared with people who may be able to take part in the HER2CLIMB-05 Clinical Research Study.

About HER2-positive breast cancer

What is HER2-positive breast cancer?

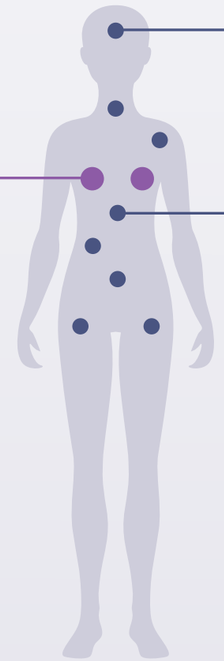
HER2 is a protein that is found in our cells, including our breast cells. A normal amount of HER2 is healthy — it helps to control how a cell grows, divides, and repairs itself. However, having high levels of HER2 can cause cells to grow out of control, which can lead to cancer.

If you have HER2-positive breast cancer, it means that your cancer cells have higher than normal levels of the HER2 protein. HER2-positive breast cancers tend to grow and spread faster than other breast cancers and can occur in both men and women.

What is "locally advanced" or "metastatic" HER2-positive breast cancer?

The HER2CLIMB-05 Clinical Research Study is exploring an investigational study drug for people living with **unresectable locally advanced** or **metastatic** HER2-positive breast cancer.

Unresectable
The cancer can't be removed by surgery.



Metastatic
The cancer has spread to other parts of the body outside of the breast, such as the liver, brain, or bones.

Locally advanced
The cancer has spread from the place it started, into nearby tissue around the breast.

About the HER2CLIMB-05 Clinical Research Study

The HER2CLIMB-05 Clinical Research Study is looking to explore how well an investigational study drug works as a maintenance therapy for metastatic HER2-positive breast cancer.

> *Maintenance therapy is a type of ongoing treatment that is given to help stop the cancer from coming back or getting worse, after the first treatment has been given.*

Previous research has shown positive results in the use of the investigational study drug for those living with metastatic HER2-positive breast cancer. This clinical research study will aim to find out whether the investigational study drug will improve current standard of care and improve the quality of life for those living with HER2-positive breast cancer.

> *People living with metastatic HER2-positive breast cancer are at a higher risk of developing cancer in the brain. If you have cancer in your brain, you may still be able to take part in this clinical research study.*

Who can take part?

You may be able to take part in the clinical research study if you:

- Are aged 18 years old or older
- Have HER2-positive breast cancer that has grown, spread to other parts of the body (is metastatic), or can't be removed by surgery
- Have received treatment or are about to start your first treatment with trastuzumab, pertuzumab and chemotherapy for HER2-positive breast cancer
- Have no signs of cancer in your brain, or have cancer in your brain that is stable and not showing any symptoms

Please note that this is not a complete list of criteria; you will need to answer some additional health-related questions and take part in some medical tests to confirm that you can join the clinical research study.

About the investigational study drug

What drug is being investigated in this clinical research study?

Tucatinib

Tucatinib has been approved by the U.S. Food and Drug Administration (FDA), European Medicines Agency (EMA), Swissmedic, Health Canada, and the Therapeutic Goods Administration (TGA) in Australia for those living with HER2-positive breast cancer that has grown, spread to other parts of the body, or can't be removed by surgery.

Alongside receiving the investigational study drug (tucatinib) or placebo, everyone who takes part in this clinical research study will have already received their first treatment with trastuzumab and pertuzumab, or the combination treatment Phesgo™, which are approved drugs that are often used to treat HER2-positive breast cancer.

> ***What does "investigational" mean?***
>
> *Tucatinib is investigational in this clinical research study because it has not yet been approved for use in combination with trastuzumab and pertuzumab and as a first-line maintenance therapy. This clinical research study will help us to prove how well tucatinib plus trastuzumab and pertuzumab works as a maintenance therapy, compared with trastuzumab and pertuzumab alone.*

How is the investigational study drug given?

The study drugs are given in 21-day cycles (every 21 days). The number of cycles will vary depending on your response to the study drug.

Tucatinib or the placebo will be taken by swallowing oval- or round-shaped tablets, twice a day, every day. You will receive a "dosing guide," which provides more information about the tablets, such as when and how to take them.

Trastuzumab and pertuzumab are given on day 1 of the 21-day cycle, and may be given to you:

- As an infusion into a vein in your arm (known as intravenous, or IV)
- As an injection under your skin
- As an IV and an injection under your skin

Taking part in the clinical research study

What happens before I take part?

To take part in the HER2CLIMB-05 Clinical Research Study, you will have already received your first treatment with trastuzumab and pertuzumab from your care team.

Upon entering the clinical research study, you will continue to receive trastuzumab and pertuzumab, and either the investigational study drug or placebo.

What happens during the clinical research study?

If you choose to join the clinical research study, you'll first have some tests to see if you are able to take part. This is called the "screening period."

If you can and choose to take part, you'll be randomly assigned (like flipping a coin) to receive the investigational study drug or a placebo, alongside trastuzumab and pertuzumab.

> *A placebo looks exactly like the investigational study drug, but it doesn't contain any active medicine.*

Placebos are an important part of clinical research studies as they provide researchers with a comparison against the investigational study drug. This is how research can prove the investigational study drug is safe.

Please note: If you are assigned to receive the placebo, you will still receive your current standard of care.

Why is this clinical research study important?

This clinical research study is important to find out whether the investigational study drug will extend the treatment benefits of the current standard of care for those living with HER2-positive breast cancer.

Throughout the clinical research study, assessments and procedures will take place to find out how well the investigational study drug works at helping to stop the cancer from getting worse, and if it improves the quality of life for those taking part. These may include:

- Questions about yourself, your health, and your day-to-day activities
- A physical exam
- Blood samples
- Brain and body scans
- A pregnancy test (if you are able to get pregnant)
- A sample of your tumor

How much of my time will be needed?

How long you take part in the clinical research study depends on how you respond to the treatment. If your cancer is stable or gets better, you may keep getting the study drugs until the study closes. Your study doctor will give you further advice throughout the clinical research study.

You can stop taking part in the clinical research study at any time by simply telling your study doctor. This won't affect your regular medical care.

> *The study doctor will review all known potential side effects with you so that you are fully informed and can ask any questions that you may have about participating in the study.*

The clinical research study appointment schedule

This table shows which days you need to visit the clinic, what happens during those visits, and how much of your time will be needed at each visit.

You will take the investigational study drug or placebo as a tablet twice each day.

Other assessments may take place outside of this schedule, such as brain or body scans every 9 or 27 weeks. Your study doctor will give you more information about this before you take part.

1 Every cycle 2–6 hours	2	3	4	5	6	7
8	9	10	11	12 Cycle 1 and 2 only 1–2 hours	13	14
15	16	17	18	19	20	21

Physical exam · Blood samples · Questionnaires · Administration of the study drugs

Other important information you should know

Before joining the clinical research study, you will be given an informed consent form (ICF), which will explain in further detail the information included in this guide. You will always be able to speak to your treating physician if you have any questions or concerns.

Will being in this research benefit you?

It is not known if taking part in this clinical research study will help you — your health may or may not get better. However, the information from this study will help doctors learn more about the study drugs, which could help those living with HER2-positive breast cancer in the future.

Are there any risks to taking part in this clinical research study?

The investigational study drug may cause side effects. A side effect is anything a drug does to your body that is not part of how the drug treats disease. Before you join the clinical research study, the study doctor will explain the potential side effects, and you will be closely monitored for any side effects throughout the clinical research study.

What happens to the information collected in this research?

Your information will be used for research purposes only. Any information shared outside of the study will not contain any personal information that could be used to identify you (like your name or address).

Are there any costs involved with this clinical research study?

Direct costs for those who take part will be limited. The sponsor of this clinical research study, Seagen, may pay for some of the costs involved in this study. More information about the costs involved is provided in the ICF or Travel Reimbursement Agreement.

Notes

If you have any questions, take note of them here, and please do not hesitate to ask a member of the study team.

Study team contact information:

Name:

Telephone:

Email:

www.her2climb05.com

HER2CLIMB-05 Patient Information Brochure_v1.1 [16MAY2022] US [EN]

Seagen®

SHARSHERET

KNOW

THE FACTS

LEARN

THE RISKS

TAKE

ACTION

SHARSHERET

Know the Facts

1 in 8 WOMEN will be diagnosed with **BREAST CANCER** in her lifetime

1 in 72 WOMEN will be diagnosed with **OVARIAN CANCER** in her lifetime

1 in 1,000 MEN will be diagnosed with **BREAST CANCER** in his lifetime

1 in 40 ASHKENAZI JEWS

CARRIES A BRCA GENE MUTATION

AS COMPARED TO 1 IN 400 IN THE GENERAL POPULATION

MEN & WOMEN

can both be carriers of BRCA gene mutations, with each having a 50% chance of passing it on to the next generation, and are at increased risk for breast, male breast, melanoma, ovarian, pancreatic and prostate cancers.

ONLY 10-20%

OF BREAST AND OVARIAN CANCER IS HEREDITARY

MULTI-GENE PANEL TESTING CAN IDENTIFY MUTATIONS IN BRCA1 OR BRCA2 AND OTHER GENES (E.G., ATM, CHEK2, OR PALB2) OR LYNCH SYNDROME, ANY OF WHICH MAY PREDISPOSE YOU TO A VARIETY OF CANCERS INCLUDING BREAST, COLON, MALE BREAST, MELANOMA, OVARIAN, PANCREATIC, PROSTATE, AND UTERINE.

SEPHARDI JEWS may also be genetically predisposed to hereditary breast and ovarian cancer.

Sagi, M., Eilat, A., Ben Avi, L. et al. Familial Cancer (2011) 10: 59. https://doi.org/10.1007/s10689-010-9395-9

Take Action

HEALTHY LIVING

Try to eat healthy, move more, and reduce stress to lower your risk.

SPREAD THE WORD

Share this life-saving information with others.

FAMILY HISTORY

Know your maternal and paternal family history. Call Sharsheret's genetic counselor with questions.

Ask Questions

(of your Primary Care Physician or Gynecologist)

RISK FACTORS

I have a history of cancer in my family. What does that mean for me?

What are my risk factors for breast cancer or ovarian cancer and what lifestyle changes could I make to reduce these risks?

Are there any indicators in my own health history that suggest I am at a higher risk?

Is my heritage a risk factor for breast cancer or ovarian cancer?

GENETICS

A family member on my father's side had breast cancer. How might this affect me?

Am I a candidate for genetic testing?

Should I test for cancer-related genetic mutations if I have no family history?

If I am found to carry a genetic mutation, what are my options?

Where should I get genetic testing done? How do I find out if my insurance will cover it?

SCREENING & EARLY DETECTION

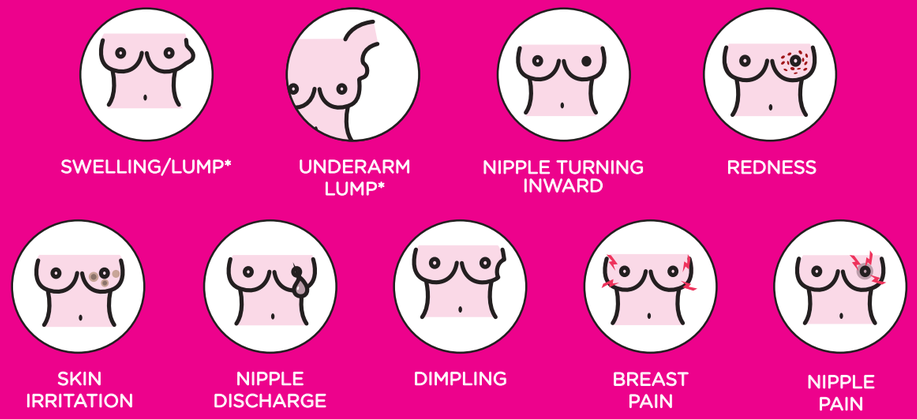
At what age and how often should I have mammograms? Do I need ultrasounds or MRIs? Am I being offered the latest 3D mammogram technology?

How do I perform self-breast exams correctly and how often?

How do I find out if I have dense breasts and how might this impact my screening plan?

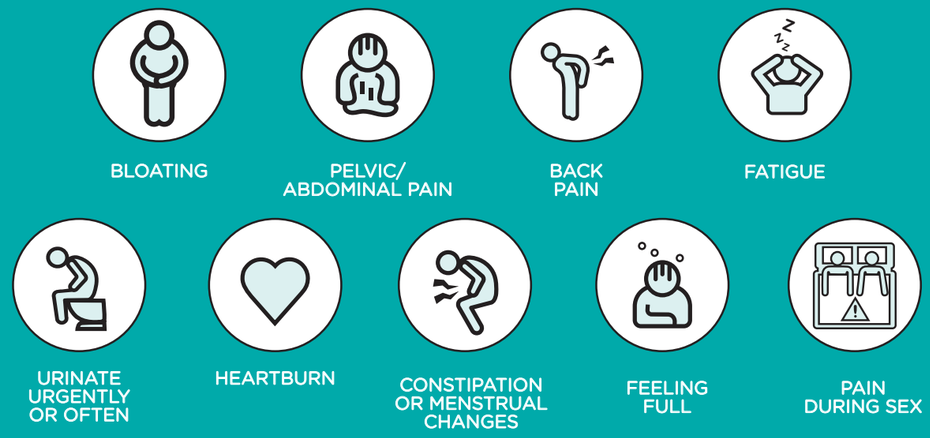
Please note: There is no reliable screening or early detection test for ovarian cancer. (CA-125 blood tests and transvaginal or pelvic ultrasounds may be used to diagnose ovarian cancer.)

BREAST CANCER SIGNS & SYMPTOMS



***PLEASE NOTE:** A palpable (usually painless) lump in the breast or armpit is by far the most common symptom presentation for breast cancer.

OVARIAN CANCER SIGNS & SYMPTOMS



AstraZeneca · BASSER CENTER FOR BRCA, Penn Medicine · The Marcus Foundation · SHARSHERET

Sharsheret improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support, and saves lives through educational outreach.

Have questions? Contact Sharsheret's genetic counselor or social workers.

sharsheret.org • 866.474.2774 • info@sharsheret.org

ALL MEN,

KNOW

THE FACTS

LEARN

THE SIGNS

TAKE

ACTION

SHARSHERET®

Know the Facts

1 in 8 MEN will be diagnosed with **PROSTATE CANCER**

1 in 1,000 MEN will be diagnosed with **BREAST CANCER**

Average lifetime risk of pancreatic cancer is about **1 in 64**

Lifetime risk for melanoma varies with skin color; those with fair skin have the highest risk.

1 in 40 ASHKENAZI JEWS **CARRIES A BRCA GENE MUTATION**

AS COMPARED TO 1 IN 400 IN THE GENERAL POPULATION

MEN & WOMEN can both be carriers of **BRCA gene mutations,** and are at increased risk for breast, male breast, melanoma, ovarian, pancreatic and prostate cancers.

Know your maternal and paternal family history; each parent has a 50% chance of passing a mutation on to the next generation.

Multi-gene panel testing can identify mutations in other genes that increases risk for cancer such as

- ATM
- CHEK2
- PALB2
- Lynch Syndrome

Learn the Signs

PROSTATE CANCER

Frequent urination especially at night; Blood in the urine

Weak or interrupted urine flow

New onset of erectile dysfunction

Discomfort or pain when sitting

MALE BREAST CANCER

- Lump/swelling (often painless)
- Skin dimpling
- Nipple turning inward
- Redness or scaling
- Nipple discharge

Take Action

GET SCREENED REGULARLY!

High risk screenings can include

Prostate Cancer
Rectal exam and a PSA blood test

Pancreatic Cancer
Endoscopic ultrasound and/or MRI recommended

Breast Cancer
Physician and self-breast exam

Melanoma Cancer
Skin exam by a dermatologist

Screening plans are gene mutation and age specific.
Consult your health care provider about your screening plan.

Ask Questions

(of your Primary Care Physician or Urologist)

RISK FACTORS

Female family members on my father's side have had breast and ovarian cancer. How might this affect me?

What are my risk factors for prostate, breast, pancreatic, and melanoma cancers and what lifestyle changes could I make to reduce these risks?

Are there any indicators in my own health history that suggest I am at higher risk?

Is my heritage a risk factor for cancer?

GENETICS

Am I a candidate for genetic testing?

Should I test for cancer-related genetic mutations if I have no family history?

If I am found to carry a genetic mutation, what are my options?

Where should I get genetic testing done?

How do I find out if my insurance will cover it?

SCREENING & EARLY DETECTION

At what age should I begin and how often should I be screened for cancer?

Are there self-exams I can do at home?

What are the signs & symptoms I should be aware of?

Are there any preventative measures I can take to decrease my risk of cancer?

PLEASE CONSULT YOUR HEALTH CARE PROVIDER IF YOU HAVE ANY CONCERNS ABOUT POSSIBLE SIGNS AND SYMPTOMS.

SUPPORTED BY A GENEROUS GRANT FROM:
MAX & ANNA BARAN, BEN & SARAH BARAN AND MILTON BARAN ENDOWMENT FUND OF THE JEWISH COMMUNITY FOUNDATION OF LOS ANGELES

The Jewish Breast and Ovarian Cancer Community.

Have questions?
Contact Sharsheret's genetic counselor or social workers.

Sharsheret.org/men
866.474.2774
info@sharsheret.org

Breast and Ovarian Cancer
Support At Every Stage

SHARSHERET

Concerned about breast or ovarian cancer?

We can help.

One-On-One Support

- Mental health professionals
- Genetic counselor
- Peer support
- Online 24/7 Live Chat
- Customized beauty kits
- Busy Boxes for children

Education & Outreach

- Healthcare webinars
- Campus outreach
- Community events
- Trainings for medical professionals
- Resource booklets

Community Action

- B'nai Mitzvah projects
- Team Sharsheret races
- Young Professionals Circle
- Volunteer opportunities
- Local fundraisers

Contact us today.

All Sharsheret programs, resources and kits are **free** and **confidential** – callers are welcome to remain **anonymous**.

Together we can ensure that no woman or family has to face breast or ovarian cancer alone.

866.474.2774
info@sharsheret.org
www.sharsheret.org

SHARSHERET

Sharsheret is a Jewish national not-for-profit organization supporting women and families facing breast and ovarian cancer.

CANCER GENETICS FAST FACTS

EVERYONE who carries a cancer gene mutation has a **50%** chance of passing it on to the **NEXT GENERATION**.

Multi-gene panel testing can **IDENTIFY MUTATIONS** in genes other than BRCA1 or BRCA2, such as ATM, CHEK2, Lynch or PALB2, that may predispose you to a variety of cancers including male breast, colon, pancreatic, prostate, uterine and melanoma.

If the results of genetic testing in a family are negative, it is **STILL POSSIBLE** that the cancer in the family is **INHERITED,** resulting from genetic mutations that we do not yet know how to identify.

1 IN 40

Ashkenazi Jews, **BOTH MEN AND WOMEN**, carries a BRCA1 or BRCA2 gene mutation.

Individuals who carry genetic mutations should **HAVE THE OPPORTUNITY** to make choices about high risk screening and risk-reducing surgery and treatment that can **SAVE THEIR LIFE.**

If you have any personal questions about your family cancer history or genetics, please contact our genetic counselor at genetics@sharsheret.org.

SHARSHERET
The Jewish Breast & Ovarian Cancer Community
866.474.2774 • info@sharsheret.org
www.sharsheret.org

FLORENCE AND JOSEPH APPLEMAN
EDUCATIONAL BOOKLET SERIES

Your Jewish Genes

Hereditary Breast Cancer and Ovarian Cancer

Endorsed By National Society of Genetic Counselors

SHARSHERET®

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The Marcus Foundation

AstraZeneca

BASSER CENTER FOR BRCA

Penn Medicine

Florence and Laurence Spungen Family 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.

4/2023

Your Jewish Genes

Hereditary Breast Cancer and Ovarian Cancer

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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 individuals (male and female) 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, melanoma, or prostate cancer. Because of this alteration, people with Jewish ancestry have been the subject of much recent research in the field of hereditary breast cancer and ovarian cancer. Whether 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 of carrying a BRCA mutation isn't as high as the risk is 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, uterine, and other types of cancers. 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 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 your and your partner's genetic background may also help answer any potential questions you may have about passing these genes on to the next generation. Regardless of whether you decide that genetic counseling or 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 schedule an appointment with our certified genetic counselor for you, 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 cancers and hereditary ovarian cancers?

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. These include, but are not limited to, *CHEK2, PALB2, CDH1, ATM, PTEN, TP53, BRIP1, RAD51C, RAD51D* and genes associated with Lynch Syndrome (hereditary colon, endometrial, and ovarian cancer).

What are BRCA1 and BRCA2 genes?

BRCA1 and *BRCA2* are genes normally found in all individuals, male and female. While anyone 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 (cancers that develop in the organ, and don't travel there from somewhere else), 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 people with cancer. The first test looks for hereditary cancer—it assesses if a cancer is inherited. This kind of genetic testing is always done

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.

on normal cells and may be done on blood or saliva. Looking at these normal cells creates a picture of what mutations were present before a person was born, because they were inherited from a parent. The second type of test, done on the tumor itself, 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 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 these 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 of approximately 12% and ovarian cancer of 1-2%. 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. 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) or Mizrachi (Middle Eastern) descent. If you are Jewish, but not Ashkenazi, 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 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 children. Not all children of people who have a mutation will inherit it, 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?

Anyone with a BRCA genetic mutation has a 50% chance of passing it to each of their offspring, so this information may be important for both parents. 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.

What are the risks for some of the other cancers associated with BRCA1 and BRCA2?

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* mutation 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 and others 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, CDH1, 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. Their guidance is 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 genetic testing is right for you and your family. If you would like to participate in the genetics program, please call toll free at 866.474.2774.

What should I do to manage my risk of developing other cancers?

For men only: In mutation carriers, prostate cancer 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 also have a breast exam completed by their physicians every year and may consider having

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

annual mammograms. For men and women: National guidelines do not mention screening for melanoma, but it may be beneficial for men and women who test positive for a *BRCA2* mutation to have a skin exam done by a dermatologist, and an eye exam one to two times a year. In addition, around age 50, it may be beneficial to begin participating in a pancreatic cancer screening study. These studies often include EUS (endoscopic ultrasound) and MRCP (magnetic resonance cholangiopancreatography).

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 involves a method referred to as next generation or parallel sequencing. This kind of testing can determine all the chemicals that make up each of the tested genes and can test a large amount of DNA sequence at one time, making medical grade testing a higher quality.

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 with the national guidelines that have been set 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 why. Also, it can be possible to get a discounted cash price for the laboratory test when insurance won't cover it. 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

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.

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.

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. 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. For women, 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. National guidelines recommend beginning breast cancer screening at 25 with an annual breast MRI, adding an annual mammogram at age 30 and alternating the tests every six months. Some individuals might take a medication like Tamoxifen to reduce their risk of developing breast 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. Women who test positive for a BRCA mutation and are planning to have their ovaries and fallopian tubes removed may consider having their uteruses removed as well. Women who have not had breast cancer are often candidates for hormone replacement until they reach the average age of menopause. Genetic counselors can guide you and discuss all of your options thoroughly with you.

What should I do to manage my risk of developing other cancers?

For men only: In mutation carriers, prostate cancer 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 also have a breast exam completed by their physicians every year and may consider having annual mammograms. For men and women: National guidelines do not mention screening for melanoma, but it may be beneficial for men and women who test positive for a *BRCA2* mutation to have a skin exam done by a dermatologist, and an eye exam one to two times a year. In addition, around age 50, it may be beneficial to begin participation in a pancreatic cancer screening study. These studies often include EUS (endoscopic ultrasound) and MRCP (magnetic resonance cholangiopancreatography).

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, positive results for an affected family member can help in the interpretation of other family members' results.

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, but science does change. Upgraded tests can find something that wasn't examined in the past. There's 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 upgraded testing makes sense for you, based on what test you had originally, your family history, 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 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.

How do I talk about my inherited mutation with other family members, including my children?

This part may be harder than it seems. While you might think that you should immediately call everyone you know, it may make sense to wait just a few weeks until your own anxiety level is lowered. You may not be able to communicate effectively with other family members until you have processed the news and what it means for yourself first. Take time to process your own thoughts and feelings. Some things to consider are the unique situation of each person with whom you share the news and what the best time and place would be to have this conversation. It may be hard to talk about at first, so consider practicing with a spouse or close friend who can help you craft the right words. Keep in mind that the first conversation about the topic may not be the right time to give family members advice. Listen to them and validate their concerns. Share with them how you understand that this may be difficult to talk about. This may need to be a conversation that is continued over a period of time, and you can eventually share more information with time. Please consider reading our booklet, "How Do I Tell My Children About My Cancer Gene Mutation," as well as speaking to our genetic counselor about ways to share the news and to schedule a family call.

Is it possible to avoid passing my BRCA mutation to the next generation?

To avoid passing a mutation to the next generation, it is possible to use IVF (in-vitro fertilization) with PGT-M (preimplantation genetic testing for the mutation). This means that eggs are harvested, fertilized, and grown into a small multicellular embryo. The embryo is biopsied to collect a few cells, which are tested for the mutation. Only embryos without the mutation are selected to be implanted. This option is not for everyone. It can be expensive, and is not always covered by insurance. You can contact your insurance provider to find out if this kind of testing is part of your policy. Check with Sharsheret to find out about organizations that provide financial support for couples in this situation.

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.

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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 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.

Although chemotherapy saved my mothers life, I remember how she

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

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 mothers 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.

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

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 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 theses 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 caner, 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

Bright Pink
312.787.4412
www.brightpink.org

Center for Disease Control and Prevention
https://www.cdc.gov/genomics/disease/breast_ovarian_cancer/

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

Breast Cancer Organizations

Are You Dense?
www.areyoudense.org

beBRCAware
www.bebrcaware.com

Breast360.org
www.breast360.org

Breastcancer.org
610.642.6550
www.breastcancer.org

Breast Cancer in Focus: Breast Cancer in Men
www.lbbc.org/infocusmen

Breast Cancer Research Foundation
866.FIND.A.CURE
www.bcrfcure.org

Dense Breast-Info: An Education Coalition
www.densebreast-info.org

Dr. Susan Love Research Foundation
310.828.0060
https://drsusanloveresearch.org/

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

Male Breast Cancer Coalition
https://www.thisislivingwithcancer.com/content/male-breast-cancer-coalition

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
https://patientresources.cityofhope.org/triple-step-toward-the-cure/

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
https://www.campdream.org/event/adult-retreats-ovarian-cancer-retreat-spring/

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
https://www.roswellpark.org/ovarian-cancer-registry

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.survivornet.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

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
https://www.aacr.org/patients-caregivers/patient-advocacy/resource/mothers-supporting-daughters-with-breast-cancer/

Red Door Community
212.647.9700
https://reddoorcommunity.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
https://www.livestrong.org/we-can-help

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

Cancer Insurance Checklist
www.cancerinsurancechecklist.org

Center for Patients Partnerships
608.890.0321
https://patientpartnerships.wisc.edu/

Financial Wellness Tool Kit (A Sharsheret Resource)
866.474.2774
www.sharhseret.org

HealthCare.gov
www.healthcare.org

Triage Cancer-How to Pick a Health Insurance Plan Video
www.triagecancer.org/animatedvideos

Clinical Trials

About Clinical Trials
https://clinicaltrials.gov/ct2/about-studies/learn

Abbvie Clinical Trials
https://www.abbvieclinicaltrials.com/

American Cancer Society
www.cancer.org

Basser Center for BRCA
www.basser.org

BreastCancerTrials.org
www.breastcancertrials.org

CancerCare
www.cancercare.org

Center Watch
www.centerwatch.com

Dr. Susan Love Research Foundation
www.drsusanloveresearch.org

Emerging Med
877.601.8601
https://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
https://www.mbcalliance.org/about-2/

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
www.komen.org

Jewish Organizations Addressing Spirituality

Aneinu: International Tehillim Organziation
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
https://www.beitnatan.com/en/homepage/

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
https://thedrlc.org/cancer/

Law Help
www.lawhelp.org

Lawyer Referral Service
www.americanbar.org/groups/legal_services

National Cancer Legal Services Network
https://triagecancer.org/national-cancer-legal-services-network

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
https://www.komen.org/breast-cancer/facts-statistics/male-breast-cancer/

Living Beyond Breast Cancer
www.lbbc.org/man-diagnosed-breast-cancer

Male Breast Cancer Coalition
https://www.thisislivingwithcancer.com/content/male-breast-cancer-coalition

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 ☐ IF YES, WRITE "1" ☐ DON'T KNOW ☐

Brothers or sisters?
NO ☐ IF YES, HOW MANY? ☐ DON'T KNOW ☐

Children or grandchildren?
NO ☐ IF YES, HOW MANY? ☐ DON'T KNOW ☐

Nieces or nephews?
NO ☐ IF YES, HOW MANY? ☐ DON'T KNOW ☐

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

Your Jewish Genes
Hereditary Breast Cancer and Ovarian Cancer

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

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

P 866.474.2774
E info@sharsheret.org
www.sharsheret.org

SHARSHERET®
The Jewish Breast & Ovarian Cancer Community