

# Sharsheret

## Digital Resource Packet

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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.

# 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/3D mammograms? Do I need ultrasounds or MRIs?

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



BREAST  
PAIN



NIPPLE  
PAIN



NIPPLE TURNING  
INWARD



REDNESS



SKIN  
IRRITATION



NIPPLE  
DISCHARGE



DIMPLING



UNDERARM  
LUMP



SWELLING/LUMP

# OVARIAN CANCER SIGNS & SYMPTOMS



BLOATING



PELVIC/  
ABDOMINAL PAIN



BACK  
PAIN



FATIGUE



URINATE  
URGENTLY  
OR OFTEN



HEARTBURN



CONSTIPATION  
OR MENSTRUAL  
CHANGES



FEELING  
FULL



PAIN  
DURING SEX



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®

# 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](https://www.sharsheret.org/men)

866.474.2774

[info@sharsheret.org](mailto:info@sharsheret.org)



# 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**  
**PALB2**

**CHEK2**  
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)
- Redness or scaling
- Skin dimpling
- Nipple discharge
- Nipple turning inward

## 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.

# 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 CHEK2 or PALB2, that may predispose you to a variety of cancers.



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 were not identified or tested.



**1 IN 40**

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



Individuals who carry mutations in the BRCA1 or BRCA2 genes should **SPEAK TO THEIR DOCTORS** about increased screening, possible risk-reducing surgery and other therapies that may **REDUCE THEIR RISK OF CANCER**.

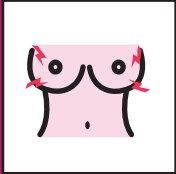


**SHARSHERET**  
Your Jewish Community Facing Breast Cancer

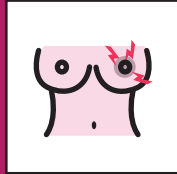
**For more information and with personal questions about your family cancer history:**  
<https://link.sharsheret.org/signs>

866.474.2774 • [genetics@sharsheret.org](mailto:genetics@sharsheret.org)  
[www.sharsheret.org](http://www.sharsheret.org)

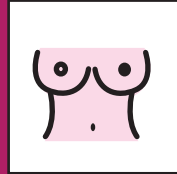
# BREAST CANCER SIGNS & SYMPTOMS



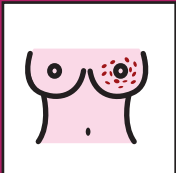
BREAST PAIN



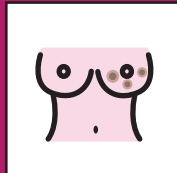
NIPPLE PAIN



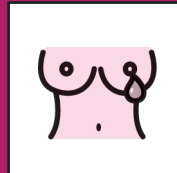
NIPPLE TURNING INWARD



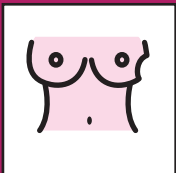
REDNESS



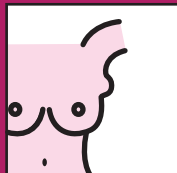
SKIN IRRITATION



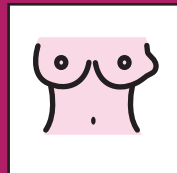
NIPPLE DISCHARGE



DIMPLING



UNDERARM LUMP



SWELLING/LUMP



BLOATING



PELVIC/ABDOMINAL PAIN



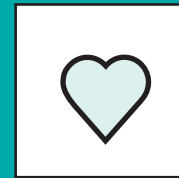
BACK PAIN



FATIGUE



URINATE URGENTLY OR OFTEN



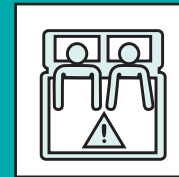
HEARTBURN



CONSTIPATION



FEELING FULL



PAIN DURING SEX

# OVARIAN CANCER SIGNS & SYMPTOMS

If you are experiencing any of these breast or ovarian cancer signs and symptoms on a persistent basis, please consult with your healthcare professional.



## EXPLORING WAYS TO IMPROVE WELL-BEING THROUGH CLEAR COMMUNICATION ABOUT OVARIAN CANCER

As a woman living with ovarian cancer, you and your family may have questions for your healthcare providers at any point – whether it's at your initial diagnosis, during treatment or when you are in remission. There are steps you can take to gain more control over your experience, which includes having a clear dialogue with your loved ones and oncology care team.

To better understand the needs of the advanced ovarian cancer community, GSK, with input from the National Ovarian Cancer Coalition (NOCC) and the Ovarian Cancer Research Alliance (OCRA), conducted a national survey\* of patients and healthcare providers. The survey results indicate there is uncertainty among patients about what to expect after diagnosis – whether they are initially diagnosed or actively seeking greater resources and connections to lessen the burden of the disease.

**GSK hopes to improve understanding of advanced ovarian cancer by fostering a stronger, more effective dialogue between women and healthcare providers.**

### THE SURVEY REVEALED IMPORTANT INFORMATION ABOUT THE DIALOGUE BETWEEN WOMEN AND HEALTHCARE PROVIDERS.

There is uncertainty among patients about what to expect when facing ovarian cancer.



**49%** OF THE PATIENTS

who are in treatment or who have been treated admit that they find **not being sure of the path forward** after diagnosis to be very or extremely challenging.

**47%** OF THE PATIENTS

who are in treatment or who have been treated admit that they find **not knowing what to expect after treatment** to be very or extremely challenging.



**71%** OF OVARIAN CANCER PATIENTS

reported **feeling very anxious before visits** to their healthcare provider.



**34%** OF HEALTHCARE PROVIDERS

are unsure if, or do not feel that, they give their ovarian cancer patients **all of the information they need about ovarian cancer.**

Patients and healthcare providers vary with regard to their perceptions of how frequently they discuss certain topics.

**91%** of HCPs [   ] **40%** of patients

say they discuss expectations for treatment often or at every visit.

**69%** of HCPs [   ] **38%** of patients

say they discuss recurrence often or at every visit.

**55%** of HCPs [   ] **29%** of patients

say they discuss the emotional challenges of ovarian cancer often or at every visit.

\* The Our Way Forward survey was conducted online in the U.S. by Harris Poll on behalf of GSK between April 13 and May 2, 2017, among 254 women 18+ years of age living in the U.S. who have been diagnosed with ovarian cancer. Survey respondents were selected from individuals who had agreed to participate in surveys through the Harris Poll and their partners or were recruited to participate by patient advocacy organizations, NOCC and OCRA. Results are not weighted and are therefore representative of only those surveyed. A parallel survey was conducted between April 17 and May 5, 2017, among 232 physicians who treat ovarian cancer patients in the U.S. consisting of 201 medical oncologists and 31 gynecologic oncologists. Survey respondents were selected from physicians who had agreed to participate in surveys through the Harris Poll and their partners. Weights for gender by years in practice and region were applied to align the data with the population parameters for medical oncologists and gynecologic oncologists, separately. A post weight was then applied to combine the two medical specialty groups in proper proportion for the total.



# COMMUNICATION BETWEEN YOU AND YOUR ONCOLOGY TEAM IS IMPORTANT

The following are some questions to help prepare you and your loved ones for meaningful conversations with your oncology care team during the course of your treatment.

## BEFORE YOUR APPOINTMENT

- Prepare a list of specific questions for your doctor and prioritize based on your needs at that moment – and the questions that may come up before your next visit.

*We have provided potential questions below that may be relevant to you.*

- Consider if you want a family member or close friend to come with you to the appointment for support and to take notes.

- Bring this discussion guide, extra paper and a pen to write down key points from your conversation.

## CONVERSATION CUES

The hardest part of any conversation is simply getting it going. It's a good idea to keep a journal or notes about symptoms or side effects you are experiencing, including frequency and severity, and bring it to each appointment. You may also want to note any changes in your day-to-day life, personal and treatment goals, and your concerns, as all of these are important for your healthcare provider to know.

Along with your journal, and your specific questions that you bring to your appointments, the below may help to kick-off a meaningful discussion with your doctor to ensure you leave feeling that your questions were answered.

### For all patients:

What is your preferred method of contact for additional questions? Email? Phone? How long will it take for you or your staff to get back to me?

### If you are newly diagnosed:

What do I need to know about my treatment plan? How do my treatments work?

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Should I consider *BRCA* testing and genetic counseling?

- Do I need those results before I start treatment?
  - What are my options once I get the results back?
- 

What side effects should I expect? How will this impact my life? What do I need to know about ongoing monitoring?

---

Are my treatments covered by my health insurance?

---

What else do I need to do to take care of myself? Why is it important that I do it?

---

What happens after I finish treatment?

- What are my chances of recurrence?
  - What are my options if my cancer recurs?
- 

Are there any support groups or online resources I can look into to be better informed and get peer-to-peer support?

### If your treatment is ongoing:

Do I have new test results since my last appointment? What do the results mean? What will happen next? What treatment options are available at each stage throughout my treatment experience?

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Is my current treatment plan still the best option for me?

- How do I know if my treatment is working?
  - Are there other treatment options I should consider?
- 

If new options are suggested:

- Why do I need this new option?
  - What do I need to know about this treatment? How does it work? How is it administered?
  - What side effects should I expect? How will this impact my life? What do I need to know about ongoing monitoring?
  - Is this treatment covered by my health insurance?
  - What else do I need to do? Why is it important that I do it?
- 

Should I consider a clinical trial?

### If you are in remission:

How frequently should I come in for check-in visits to monitor my disease?

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What do I do while my ovarian cancer is in remission?

- Do you have any recommendations, tips, or approaches to help me minimize or manage any anxiety I may feel during this time when my disease is in remission, but we are monitoring the cancer's growth?
- 

What are my chances of recurrence?

- How long are most women in remission before the ovarian cancer might return?
- 

What symptoms should I look for that would signal a recurrence?

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Why would my ovarian cancer recur?

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What do I do if my cancer recurs?

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I've heard the term "watchful waiting" used – what does it mean?

- If I am not in treatment now, does it mean I get a "vacation" from my treatment? What side effects and impact on my lifestyle should I expect?
- 

What does progression free survival mean? How is that related to remission?

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What is maintenance treatment?

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Should I consider a maintenance treatment during remission?

- What are my options for maintenance treatment?
  - How will maintenance treatment impact my daily routine and lifestyle?
  - How are maintenance treatments administered?
  - Are there oral treatment options available? How frequently would I have to take it?
  - What side effects should I be aware of with maintenance treatment?
  - Do I need to know my BRCA mutation status to be prescribed a maintenance treatment?
- 

Who can I reach out to for extra support during this time?



### About Our Way Forward

*Our Way Forward* is a call-to-action that encourages women living with ovarian cancer, their loved ones and healthcare providers to rethink how they talk about advanced ovarian cancer. The program provides ways to partner together and navigate the physical and emotional challenges that the disease brings. For more information, visit [ourwayforward.com](http://ourwayforward.com), and follow us on Instagram ([@ourwayforward\\_gsk](https://www.instagram.com/ourwayforward_gsk)).

### If you have recurred:

What are my treatment options now that my cancer has returned?

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Now that my cancer has returned, is there a recurrence pattern that I can expect?

## AFTER YOUR APPOINTMENT

Even with the best preparation, you may think of new or different questions following your appointments. Remember to write in your journal any thoughts, questions or concerns to ensure you ask at your next appointment. Or, if your oncology team offers an online communication system, secure the contact information and/or email addresses in order to reach out between visits.

### Notes:

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# Living With Metastatic Breast Cancer



## Resources/info for patients living with metastatic breast cancer

Over the next weeks and months, you'll have many choices to make. We hope the information and resources provided in this booklet will help you make decisions about your care.



Content is consistent with the Oncology Nursing Society Standards and Guidelines. The ONS Seal of Approval does not constitute medical advice, and does not imply product endorsement by ONS. Healthcare providers should exercise their own independent medical judgment. Website content or other resources referenced in these materials have not been reviewed for the ONS Seal of Approval.

# Living With Metastatic Breast Cancer

## Emotional well-being

Having cancer can trigger many emotions, such as shock, disbelief, and fear. These emotions are normal. If you're feeling stressed or anxious, talk with your health care team. Seek counseling or try support groups.



Do you have “scanxiety”? Anxiety about having a medical procedure or an imaging test is completely normal. However, if these emotions become overwhelming, talk to your health care team about coping strategies.



People with cancer who have a strong support network tend to feel less anxious and report a better quality of life.

## Nutrition and exercise

Proper nutrition is important for building strength during treatment. That means consuming:

- Small snacks throughout the day if you are unable to eat normal meals
- Plenty of water and other liquids
- Protein-rich foods
- 2 cups of colorful fruits and 2.5 cups of colorful vegetables a day

If treatment side effects make it difficult for you to eat well, ask your health care team about ways to help manage these side effects.

**Exercise, including yoga,** is a great way to boost energy and may help decrease stress, depression, nausea, and constipation.

Talk to your doctor before starting/changing any exercise.

# Understanding Metastatic Breast Cancer

## Metastatic breast cancer (MBC)

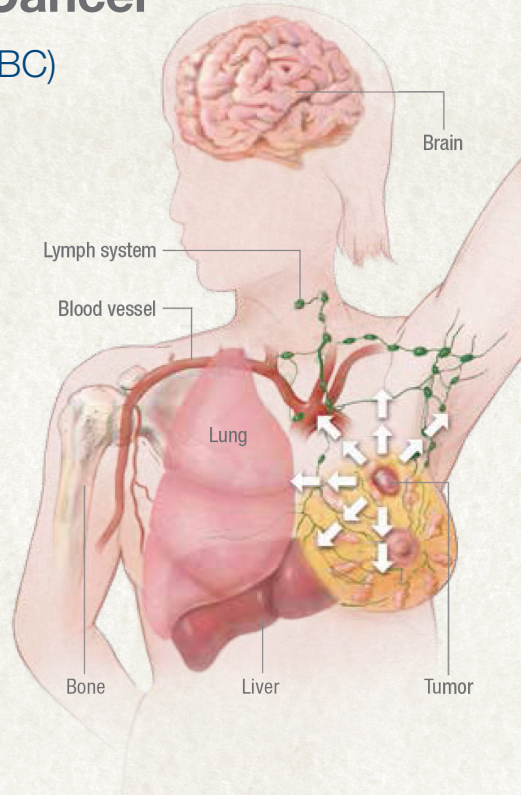
MBC, also called advanced breast cancer, is cancer that starts in the breast tissue and then spreads to other parts of the body. Cancer cells break away from the breast tumor and travel through the lymph system or blood vessels to another site (usually the bones, lungs, liver, or brain). No matter where the new cancer develops, it's still considered breast cancer.

## Types of breast cancer

Some of the most common forms of breast cancer are classified by the cancer subtype. Testing for the cancer subtype is important because the results help you and your health care team decide the best treatment for you.

The subtypes of breast cancer are based on whether your cancer has receptors for certain hormones in your body. These hormone receptors, which can tell your cancer to grow, include estrogen receptors and progesterone receptors.

It's important to know that disease subtypes in advanced breast cancer may not be the same as in early stages of the disease.



## You are not alone

As of 2021, more than  
**3.8 million women**  
in the United States have been  
diagnosed with breast cancer\*



The number of women  
diagnosed with or living with  
MBC is not currently measured.

\*Includes women who are currently being treated for breast cancer and women who have been treated in the past.

# Finding Treatment Options

## Talking to your health care team about your treatment options

It's important to talk to your health care providers about your diagnosis and treatment plan. Your treatment will depend on many different factors, including:

- The pathology report
- Where the cancer has spread
- Your type of breast cancer
- Treatments you have previously received
- Your current symptoms

**A pathology report** is the document that provides a diagnosis based on examination of your blood and tissue under a microscope. For information on how to read your pathology report, visit the College of American Pathologists online at [www.yourpathologist.org](http://www.yourpathologist.org). Watch the video and download the infographic to learn more.

## Systemic treatment overview

There are many different treatment options available. Treatment decisions are made based on specific disease characteristics, including MBC subtypes. Treatment options include:

- Hormone therapy
- Chemotherapy
- Targeted therapy

Some people find that complementary and alternative therapies can help promote healing of the mind, spirit, and body through acupuncture, massage, meditation, yoga, and other methods.



Talk to your health care team before taking any complementary medicines.



# Reach Out to Others for Help

## Get the support you need

To fight metastatic breast cancer, you'll need to stay strong physically and emotionally. Surround yourself with people who care about you and will help you maintain a positive attitude.

Since talking about your diagnosis and treatment can be emotionally draining, don't hesitate to refer others to outside resources for more information.

In addition, you may find it helpful to connect with others going through similar experiences. Support groups for people living with MBC can help answer your questions and offer advice and encouragement.



## Additional support

If you need more day-to-day help, there are additional resources available. You can connect with others through certain websites and organizations designed to help patients and caregivers. Find more information and create your own account on these websites: [www.mealtrain.com](http://www.mealtrain.com) and [www.mylifeline.org](http://www.mylifeline.org).



[MyLifeLine.org](http://MyLifeLine.org)  
connect. inspire. heal.

For more information, visit the

**mbc**info center<sup>SM</sup>

Go to [www.MBCInfoCenter.com](http://www.MBCInfoCenter.com) to find helpful resources for MBC. MBCInfoCenter lets you access many resources in one convenient place to make it fast and easy to search for MBC information.

**EXPLORE**



resources to learn about metastatic or advanced breast cancer

**DISCOVER**



information on MBC treatments

**GET TIPS**



on healthy living with MBC

**JOIN**



communities and support groups

**FIND**



practical information on insurance coverage and financial assistance

**LEARN**



about providing support for loved ones with MBC

**Be sure to check out the featured organizations for additional resources!**

[www.mbcinfocenter.com/mbc-community-groups-list](http://www.mbcinfocenter.com/mbc-community-groups-list)



Remember, your family, friends, and health care team are there to support you.



MBCInfoCenter<sup>SM</sup> is a service mark of Eisai Inc.  
The bird and tree designs are registered trademarks of Eisai Inc.  
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The logo for Seagen, featuring a stylized 'S' icon in green and black, followed by the word 'Seagen' in a bold, sans-serif font. The 'S' icon consists of a black circle with a green arrow-like shape pointing upwards and to the right. The word 'Seagen' is in black, with a registered trademark symbol (®) to its upper right.

**Seagen**<sup>®</sup>



## 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

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

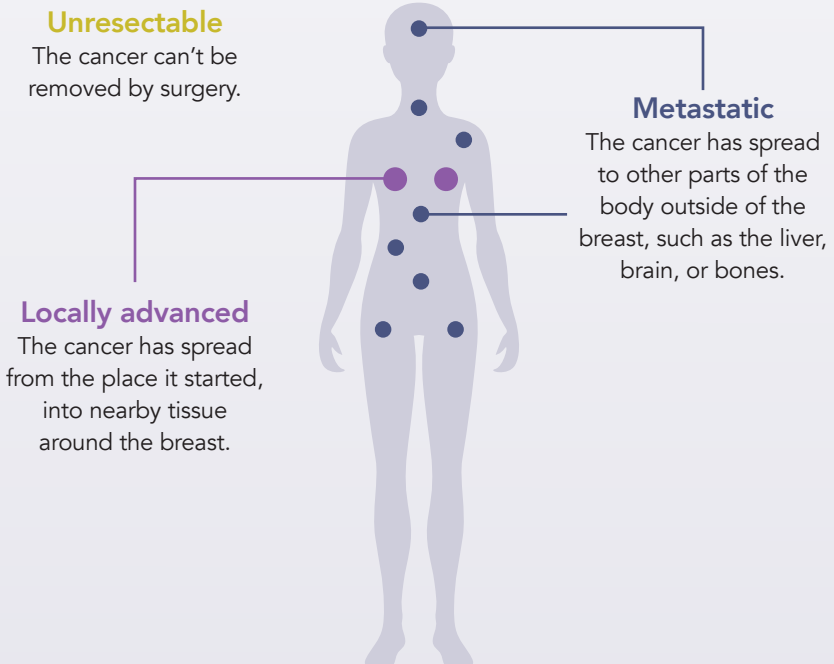
## What is HER2-positive breast cancer?

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.



# 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

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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:



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HER2CLIMB-05 Patient Information Brochure\_v1.0 [30Mar2022] US [EN]







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



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## GET INSPIRED

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## AS WE AGE

*Tools and resources for older adults*

Did you know that about 54% of cancers occur in people over the age of 65? "As We Age" was created to meet the unique needs and challenges of older adults and empower them to take control of their health.



## ENCOURAGEMENT

Hear inspirational patient stories



## EDUCATION

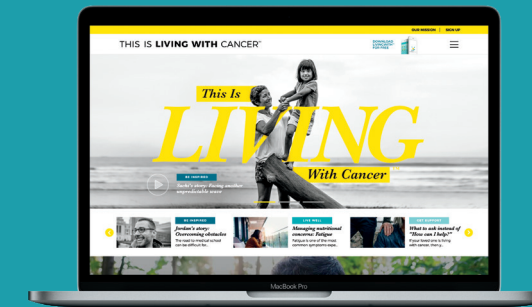
Navigate common challenges and learn about healthy living



## TOOLS

Download guides and journals to build healthy habits, track activities and manage daily life

## RESOURCES TO HELP YOU LIVE LIFE BEYOND YOUR DIAGNOSIS



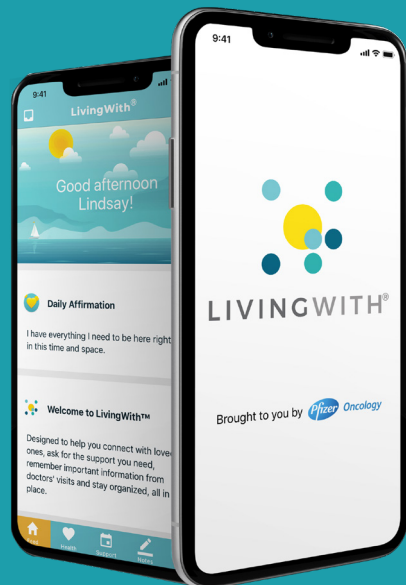
### This Is Living With Cancer™

is a program developed by Pfizer Oncology that includes resources designed for all people living with cancer.

This program is **available to anyone in the United States**, whether you're currently on a Pfizer treatment or not.



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Asking for help can be difficult. LivingWith makes it easy to send requests for help with daily tasks, such as meals or rides to doctors' appointments. You can also find support groups and local events in your community.



Scan this code with your phone's camera to learn about other app features or visit [ThisIsLivingWithCancer.com/Living-With-App](https://www.thisislivingwithcancer.com/Living-With-App)



### TRACK YOUR HEALTH

How you're feeling may change day by day, so it's helpful to look for patterns. With LivingWith, you can track mood and pain patterns and sync sleep and steps with wearable fitness trackers like Fitbit™, Apple® Health or Google Fit™.

### STAY ORGANIZED

Being prepared leads to better conversations with your doctor. LivingWith helps you keep track of questions, record audio notes and remember important information from doctors' visits.

### ASSIGN A PROXY

If managing the app is too much, you can assign someone to send requests for help or update friends or family on your behalf.

### STAY CONNECTED

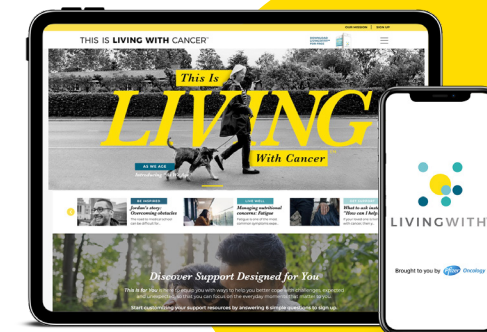
Connecting with friends and loved ones is important. LivingWith lets you invite friends and family to join your private circle of support, send or receive requests for help and share how you're feeling on a daily basis.

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August 2020





Daiichi-Sankyo

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**cancer**enterprise

# METASTATIC BREAST CANCER WITH LOW LEVELS OF HER2 CONVERSATION STARTER

## Using the Conversation Starter

Learning more about your metastatic breast cancer (mBC) will help you with the road ahead. Knowing your HER2 status is especially important for your conversations with your healthcare team.

Review the information in this Conversation Starter and bring it with you to appointments. These questions can help you learn more about mBC with low levels of HER2 and also help you get the most out of your time with your healthcare team.

## Understanding mBC with low levels of HER2

60%

It has been recently discovered that having breast cancer with low levels of HER2 is common. **About 60% of people** diagnosed with HER2-negative breast cancer **actually have low levels of HER2**



**HER2 is a protein** that tells cells to grow. When cells produce too much HER2, they can become cancerous

LOW  
HER2

Until recently, healthcare providers diagnosed breast cancer as either HER2-positive or HER2-negative. Now, they can diagnose a new status: breast cancer with low levels of HER2. **Having low HER2 means that there is a low level of HER2 on the cancer cells but not enough HER2 to be considered HER2-positive**

HR  
+

**HER2 status is different than hormone receptor (HR) status. People with low levels of HER2 can be either HR+ (hormone receptor-positive) or HR- (hormone receptor-negative)**

- HR status is also referred to as ER+ or ER- (estrogen receptor-positive/negative) and/or PR+ or PR- (progesterone receptor-positive/negative)
- If a person was previously told they were HR- HER2-negative, this might have been referred to as triple-negative breast cancer (TNBC). TNBC refers to tumors that don't have a large amount of HER2 or hormone (estrogen/progesterone) proteins



**If your healthcare provider told you that you have HER2-negative mBC, ask if you could be one of the many people living with low levels of HER2**



**If you do have mBC with low levels of HER2, there may be treatment options that are right for you**

HER2, human epidermal growth factor receptor 2.

Sign up to learn more about mBC with low levels of HER2—visit [InfoOnLow.com](http://InfoOnLow.com) or scan the QR code



## Questions

**Q** How are low levels of HER2 different from other HER2 statuses?

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**Q** Can someone with HR+ HER2-negative or triple-negative mBC also have low levels of HER2?

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**Q** Does having low levels of HER2 give me additional treatment options?

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**Q** **Already diagnosed with low levels of HER2:** How did you know that I have low levels of HER2 and why did my diagnosis change from HER2-negative?

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**Q** **Currently diagnosed with HER2-negative mBC:** Is it possible that I have low levels of HER2? How will you know?

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**References:** **1.** Tarantino P, Hamilton E, Tolaney SM, et al. HER2-low breast cancer: pathological and clinical landscape. *J Clin Oncol*. 2020;38(17):1951-1962. doi:10.1200/JCO.19.02488 **2.** National Cancer Institute. NCI Dictionary of Cancer Terms. Accessed June 16, 2022. <https://www.cancer.gov/publications/dictionaries/cancer-terms/search/HER2/?searchMode=Begin> **3.** Schettini F, Chic N, Brasó-Maristany F, et al. Clinical, pathological, and PAM50 gene expression features of HER2-low breast cancer. *NPJ Breast Cancer*. 2021;7(1):1-13. doi:10.1038/s41523-020-00208-2 **4.** National Cancer Institute. NCI Dictionary of Cancer Terms. Accessed July 27, 2022. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/hormone-receptor-positive> **5.** American Cancer Society. Understanding a breast cancer diagnosis. Accessed July 29, 2022. <https://www.cancer.org/cancer/breast-cancer/understanding-a-breast-cancer-diagnosis/breast-cancer-hormone-receptor-status.html> **6.** National Cancer Institute. NCI Dictionary of Cancer Terms. Accessed June 16, 2022. <https://www.cancer.gov/publications/dictionaries/genetics-dictionary/def/triple-negative-breast-cancer>



FLORENCE AND JOSEPH APPLEMAN  
EDUCATIONAL BOOKLET SERIES

# Your Jewish Genes

Hereditary Breast Cancer and Ovarian Cancer



 SHARSHERET®

**FUNDING AND SUPPORT PROVIDED BY**

**The Cooperative Agreement DP14-1408 from  
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**The Marcus Foundation**

# 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.

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

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

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

## OUR PROGRAMS

### The Link Program®

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

### Education and Outreach Programs

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

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

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

In this booklet you will find some frequently asked questions about breast cancer and ovarian cancer and

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

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

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

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

# QUESTIONS AND ANSWERS ABOUT HEREDITARY CANCER AND BRCA GENES

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

## **How common are hereditary breast cancer and hereditary ovarian cancer?**

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

## **What are BRCA1 and BRCA2 genes?**

BRCA1 and BRCA2 are genes found in both men and women. While both men and women can carry an altered BRCA1 or BRCA2 gene, inherited alterations in these two genes make female carriers more susceptible to developing breast cancer and ovarian cancer, accounting for up to 5-10% of all breast cancer and ovarian cancer cases.<sup>1</sup> However, these may not be 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 multi-gene panel testing can still produce negative results for already known genetic mutations and therefore, researchers continue to search for other genes that may also increase cancer risk. Talk to a certified genetic counselor or healthcare provider to find out more about multi-gene testing.

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

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

### **What is the difference between genetics and genomic testing?**

Cancer genetic testing usually refers to testing in a single gene or a selected group of genes. Genetic testing is usually targeted to a specific concern, even when testing includes a large panel of genes. Genomics, on the other hand, is the study of all of the inherited traits in an organism. Genomic testing includes most or all of the genes. This is done when there is no specific target in mind.

### **What is the difference between somatic and germline testing?**

Somatic testing looks at genetic mutations that happen in body cells. Somatic changes are not inherited, but can accumulate slowly over time, gradually changing normal cells into cancer cells. Physicians are better able to treat cancer if they know the specific mutations that have accumulated to cause it. Germline testing is done on normal tissue, usually blood or saliva, to identify changes that were present prior to the development of cancer in order to find an inherited cause for the development of cancer.

### **How do alterations in BRCA1 and BRCA2 affect the risk of breast cancer and ovarian cancer in a woman of Jewish descent?**

A woman's lifetime risk of developing breast cancer or ovarian cancer is greatly increased if she inherits an altered BRCA1 or BRCA2 gene. Recent studies suggest that for those carrying mutations, the risk for breast cancer may be as high as 50% to 80%, and for ovarian cancer, it may be as high as 44%.<sup>2</sup> This is in comparison to the average woman's lifetime risk for breast cancer of approximately 12% and ovarian cancer of 1-2%.<sup>3</sup> 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 500 individuals in the general population.<sup>4</sup> Among alterations in the BRCA1 or BRCA2 genes, three in particular have been found to be most common in the Ashkenazi Jewish population—two in the BRCA1 gene and one in the BRCA2 gene. While there is still debate as to whether breast cancer and ovarian cancer rates are higher in women of Jewish descent as compared to the general population, the proportion of hereditary breast cancer and ovarian cancer is higher in women of Ashkenazi descent. Because of this risk, a woman of Ashkenazi descent with breast cancer or ovarian cancer, and men and women with a family history of these cancers, may want to consider genetic counseling and testing. BRCA gene mutations that are most common in Ashkenazi Jews have also been found in Jews of Sephardi (Spanish, Middle Eastern, or North African) descent<sup>5</sup>. If you are of Sephardi Jewish descent, and have a family history of cancer, you may want to consider genetic counseling to discuss your risk of hereditary cancer and whether genetic testing is appropriate for you and your family.



### **How are BRCA1 or BRCA2 mutations inherited?**

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

### **Are there other cancers associated with BRCA1 and BRCA2 mutations?**

The principal cancers associated with the BRCA mutations are breast cancer and ovarian cancer. However, depending on which gene is involved, there are small associated risks for melanoma, pancreatic cancer, prostate cancer, and male breast cancer (especially in BRCA2 mutation carriers). Screening for these associated risks should be discussed with a certified genetic counselor or health care provider.

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

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

### **What is breast cancer and ovarian cancer genetic testing?**

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

### **Where can I get more information about genetic testing for breast cancer and ovarian cancer risk?**

If you are considering genetic testing, you should speak with a health care professional who is trained and certified as a genetic counselor before making a decision. Genetic counseling can help you identify and understand what particular traits you may have inherited and your options following testing.

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

#### **What can I do to prepare for my genetic counseling appointment?**

Prepare for your genetic counseling appointment by collecting information about your family history ahead of time and bringing it to your appointment, including information about family members who have had cancer, ages of diagnoses, types of cancer, any previous genetic testing reports in the family, and pathology reports/medical records regarding any cancer in family members. Visit [www.sharsheret.org](http://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 21 of this booklet, and share your results with your clinician to help determine if further genetic evaluation is right for you.

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

#### **How do I determine what type of genetic testing may be right for me?**

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

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

Effective in 2009, Congress passed the Genetic Nondiscrimination Information Act (GINA) into law. This law provides protection against discrimination in health insurance coverage and employment settings based on an individual's genetic information. GINA prohibits employers from firing, refusing to hire, or otherwise discriminating against employees with respect to compensation, terms, conditions, or privileges of

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

### **What are my options if I test positive for a BRCA1 or BRCA2 mutation?**

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

### **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](http://www.cancer.gov).



### **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.

### **Do I require further genetic testing if I test negative for a BRCA1 or BRCA2 mutation?**

If you test 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 are 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) that predispose to breast, ovarian, and other types of cancer. A certified genetic counselor can advise which testing is recommended based on your personal and family history of cancer. He/she may also be able to help identify testing that is covered by your insurance.

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

If you test negative for a BRCA1 or BRCA2 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 BRCA1 or BRCA2 mutation, a strong family history of cancer should not be ignored, as researchers have not yet identified all of the genes involved in hereditary cancer.

### **What impact will genetic counseling or testing have on the other members of my family?**

The genetic information you receive can influence your family members' health care decisions. A certified genetic counselor can help you determine the ways in which your family may be affected by counseling or testing and how health information can be shared responsibly.

### **What are my options if I choose not to be tested?**

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

### **Are there any issues of Jewish law related to hereditary breast cancer and ovarian cancer or genetic counseling and testing?**

Questions of Jewish law may arise with regard to surgery and treatment decisions. If this issue is of concern to you, questions are best addressed by a Rabbi or spiritual leader who can answer them with sensitivity to your unique medical situation.

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

# STORIES FROM YOUR SHARSHERET COMMUNITY

## Leah's Story

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

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

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

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

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

## Rachel's Story

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

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

*“When the genetic counselor called to tell me I had tested negative...”*

I chose to be tested because, at the time, I was struggling to decide whether to opt for a lumpectomy or a mastectomy. Raising young children, and terrified of the prospect

of developing breast cancer a second time, I was prepared to have a bilateral mastectomy if I tested positive as a carrier. However, if I tested negative, I was comfortable with my doctor's recommendation to have a lumpectomy.

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

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

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

## Sara's Story

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

Once I was diagnosed with breast cancer, I chose to have a bilateral mastectomy and an 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 wasn't ready to take the risk. Finally, on an emotional level, I needed to cling to the hope that maybe, just maybe, my breast cancer was simply the result of bad luck and that I was not at greater risk than anyone else.

*“Nevertheless,  
I chose not to be tested...”*

I do worry about the possibility of passing a genetic predisposition for

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

## Rebecca's Story

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



face her own fight against breast cancer.

*“Prophylactic surgery may significantly decrease the risk...”*

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

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

## Beth’s Story

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

When my sister’s oncologist suggested that she undergo genetic testing, it suddenly occurred to us that perhaps I, and my two other sisters, could also be at risk. We made an appointment with a genetic counselor who explained that Sharon’s young age at diagnosis, coupled with our Ashkenazi background, suggested that there may be a genetic predisposition in our family, not only to breast cancer but also to ovarian cancer. She told us that if Sharon was found to carry a BRCA



mutation, the rest of us could then test to find out if we also carried the mutation. If Sharon tested negative, however, we were not home free, as a negative result is not 100% definitive because there may be mutations in other genes that cannot be detected yet. We agreed that the testing had to be done. Sharon had her blood drawn and we held our collective breath while we waited for the results.

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

*“We all made an appointment with a genetic counselor...”*

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

We are blessed to live during a time when we have the opportunity to learn about our health history and therefore

can find tremendous relief or take advantage of options to try to avoid cancer. We now realize that Sharon’s cancer and genetic results led us to a different understanding of ourselves.

## Steve’s Story

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

*“We both tested positive for a BRCA1 mutation...”*

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

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

## Eve's Story

When I was eight years old, my mother died of “female problems”, as they were called in my family. My father and I were devastated, but it never occurred to either of us that I had anything to worry about. The “problem” didn't even have a name. It

wasn't until years later that I realized that “female problems” was the term used years ago when the word “cancer” was taboo and that all the information about hereditary breast cancer also applied to hereditary ovarian cancer. This realization and information inspired me to begin to question my own family history.

*“Knowing your family history can guide you to making decisions that could save your life...”*

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

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

## 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 was not interested in further genetic testing. The thought of finding out "too much information" was frightening. But my quest for an answer to our family history prevailed and finally my mother agreed to multi-gene sequencing.

My mother's results came back positive for a mutation called CHEK2. It's responsible for 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.



## HOW CAN SHARSHERET HELP ME?

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

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

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

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

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

# RESOURCE DIRECTORY

## **Sharsheret**

866.474.2774

[www.sharsheret.org](http://www.sharsheret.org)

[info@sharsheret.org](mailto:info@sharsheret.org)

## **Organizations Addressing Cancer Genetics**

### **Basser Center for BRCA - Education and Outreach**

215.662.2748

[www.basser.org](http://www.basser.org)

### **Bright Pink**

312.787.4412

[www.brightpink.org](http://www.brightpink.org)

### **Center for Jewish Genetics**

312.357.4718

[www.jewishgenetics.org](http://www.jewishgenetics.org)

### **FORCE: Facing Our Risk of Cancer Empowered**

866.288.7475 (Helpline)

[www.facingourrisk.org](http://www.facingourrisk.org)

### **National Society of Genetic Counselors**

312.321.6834

[www.nsgc.org](http://www.nsgc.org)

### **NCI Cancer Genetics Services Directory**

800.4.CANCER

[www.cancer.gov/cancertopics/genetics/directory](http://www.cancer.gov/cancertopics/genetics/directory)

## **Breast Cancer Organizations**

### **Breastcancer.org**

[www.breastcancer.org](http://www.breastcancer.org)

### **Dr. Susan Love Research Foundation**

866.569.0388

[www.dsrlf.org](http://www.dsrlf.org)

### **Living Beyond Breast Cancer**

855.807.6386

888.753.5222 (Helpline)

[www.lbbc.org](http://www.lbbc.org)

### **National Breast Cancer Coalition**

800.622.2838

[www.natlbcc.org](http://www.natlbcc.org)

### **National Breast Cancer Foundation**

[www.nationalbreastcancer.org](http://www.nationalbreastcancer.org)

### **SHARE (Self-Help for Women with Breast or Ovarian Cancer)**

866.891.2392

[www.sharecancersupport.org](http://www.sharecancersupport.org)

### **Susan G. Komen for the Cure**

877.465.6636

[www.komen.org](http://www.komen.org)

### **Young Survival Coalition**

877.972.1011

[www.youngsurvival.org](http://www.youngsurvival.org)

## Ovarian Cancer Organizations

### **Foundation for Women's Cancer**

312.578.1439  
800.444.4441 (Hotline)  
[www.foundationforwomenscancer.org](http://www.foundationforwomenscancer.org)

### **Gilda Radner Familial Ovarian Cancer Registry**

800.682.7426  
[www.ovariancancer.com](http://www.ovariancancer.com)

### **HERA Women's Cancer Foundation**

972.948.7360  
[www.herafoundation.org](http://www.herafoundation.org)

### **National Ovarian Cancer Coalition**

888.682.7426  
[www.ovarian.org](http://www.ovarian.org)

### **Ovarian Cancer National Alliance**

202.331.1332  
866.399.6262  
[www.ovariancancer.org](http://www.ovariancancer.org)

### **Ovarian Cancer Research Fund**

212.268.1002  
[www.ocrf.org](http://www.ocrf.org)

## Survivorship

### **American Cancer Society Survivors Network**

[www.csn.cancer.org](http://www.csn.cancer.org)

### **LIVESTRONG Foundation**

855.220.7777  
[www.livestrong.org](http://www.livestrong.org)

### **National Coalition for Cancer Survivorship**

877.622.7937  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

### **Thriving Again® (A Sharsheret Program)**

866.474.2774  
[www.sharsheret.org](http://www.sharsheret.org)

Please visit Sharsheret's website at [www.sharsheret.org](http://www.sharsheret.org) for a continuously updated online resource directory.

The information contained in this booklet is intended to provide broad knowledge and available resources and should not be construed as professional advice or an endorsement of any health care professional, organization, or program mentioned in the Resource Directory. All medical information should be discussed with a health care professional. To the extent permissible under applicable laws, Sharsheret and NSGC disclaim responsibility for any injury and/or damage to persons or property as a result of any actual or alleged infringement of intellectual property or other proprietary or privacy rights, or from use or operation of any ideas, instructions, procedures, products or methods contained in the material therein.

# 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

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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

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

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

P 866.474.2774  
E [info@sharsheret.org](mailto:info@sharsheret.org)  
[www.sharsheret.org](http://www.sharsheret.org)



**SHARSHERET®**  
The Jewish Breast & Ovarian Cancer Community