

Hereditary Breast and Ovarian Cancer Syndrome

Hereditary Breast and Ovarian Cancer syndrome (HBOC) is the most common type of breast cancer that runs in families. It is caused by problems in the *BRCA1* and *BRCA2* genes. Changes in these genes can increase a woman's risk for breast cancer, ovarian cancer, pancreatic cancer and melanoma. Changes in these genes can also increase a man's risk for prostate cancer, male breast cancer, pancreatic cancer and melanoma. People who have changes in these genes should follow the National Comprehensive Cancer Network (NCCN) Guidelines.

NCCN Guidelines for Women

- Self-breast exams starting at age 18. It is important for you to know what your normal breasts look and feel like.
- Breast exams done by your provider every 6 to 12 months beginning at age 25.
- Yearly breast MRI with contrast beginning at age 25-29. May be done sooner if someone in the family has breast cancer before age 30.
- Yearly breast MRI with contrast **and** mammograms between the ages 30-75. Consider having a 3-D mammogram (tomosynthesis).
- Screening after age 75 should be considered on an individual basis.
- If you have had both breasts removed, you do not need the yearly MRI and mammogram.
- Screening should continue, even after a diagnosis of breast cancer.
- You should have your ovaries and tubes removed between the ages of 35 to 40 years or when you are done having children. *BRCA2* carriers may wait until they are 40-45 years old.
- You can use hormone replacement to manage symptoms of menopause after your ovaries are removed.

Some women may also consider:

- The removal of the breast tissue (bilateral mastectomies) with or without reconstruction.
- Taking medicine such as:
 - birth control pills (which reduces the chance for ovarian cancer).
 - tamoxifen or raloxifene (which reduces the chance for breast cancer).
- Some doctors may want to screen for ovarian cancer. If you decide to do this, you should know it does not find ovarian cancer early or improve survival rates. Screening can include ultrasound of the ovaries and a blood test (CA-125) starting at age 30-35. This can be done until your ovaries are removed.
- *BRCA1* carriers may have a slight increased risk of uterine cancer. You may want to have your uterus removed when you have your ovaries and tubes removed.

NCCN Guidelines for Men

- Men should start doing self-breast exams by age 35.
- Breast exams done by your provider every 12 months beginning at age 35.
- Yearly prostate screening starting at age 40 (suggested for *BRCA2* carriers, an option for *BRCA1* carriers).

NCCN Guidelines for Men and Women

- A yearly full-body skin exam. You should protect your skin from the sun. Don't use tanning booths or beds.
- If a relative has pancreatic cancer consider pancreatic cancer screening. This can be done with a special type of MRI or endoscopic ultrasound beginning at age 50. It may be done earlier if your family member was diagnosed before age 60. It is best to do this at a hospital that has done a lot of these screens.
- You should tell your family members that you carry the gene. They can get more information and decide if they want to do testing. Share a copy of your testing results with any of your family members who want to be tested. This will help their provider know what to test.

Reproductive Options

- There are a few options to prevent passing the *BRCA1* or *BRCA2* gene to your children. Some people choose:
 - Adoption.
 - To use a donor egg or sperm.
 - To use IVF and test the cells of the embryo to ensure the gene is not present.
- For *BRCA2* carriers, you may want to have your partner tested to see if they carry the gene too. If both of you carry *BRCA2*, there is a 25% chance you will have a child with Fanconi anemia (a syndrome that includes birth defects and a high risk for childhood cancers).

Support Groups/Resources

- FORCE: (www.facingourrisk.org) a support network for HBOC families.
- Bright Pink: (www.brightpink.org) a support network for young women with breast cancer or in high risk families.
- BRCAn't Stop Me (brcantstopme.wix.com/brcantstopme) A student support group started at Grand Valley State University.
- HIS (www.hisbreastcancer.org) A support site for men with or at risk for breast cancer.
- Kintalk: (<https://kintalk.org/>) A secure social media-style network to aid in the sharing of genetic information to other family members at risk (HIPPA-compliant).

Books

- "Previvors: Facing the Breast Cancer Gene and Making Life-Changing Decisions" by Dina Roth Port: Personal stories of young women in families with HBOC syndrome and interviews with experts.
- "Confronting Hereditary Breast and Ovarian Cancer" by Sue Friedman, DVM, Rebecca Sutphen, MD, and Kathy Steligo: A guide book for Previvors, Survivors and family members covering basic information to help people make decisions about genetic testing, family planning, cancer screening, surgical options and beyond.

If you have questions, or would like to review this information in more detail, please contact our office to schedule an appointment. Our number is 269-286-7195.