

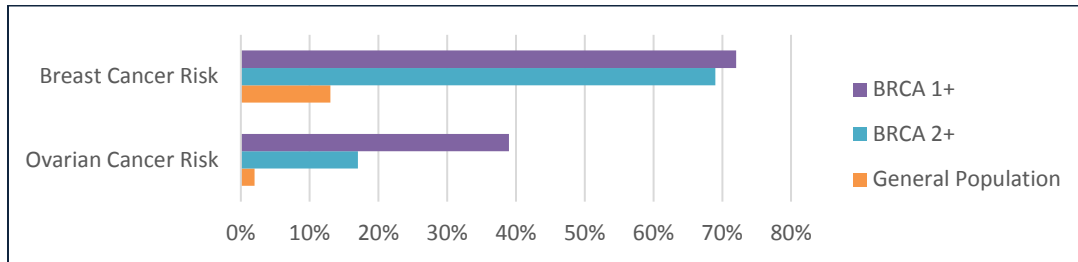
## BRCA DECISION AID (for unaffected BRCA+ women)

**GENERAL INFORMATION:** This decision aid is based on internationally accepted guidelines for management of hereditary breast and ovarian cancer (HBOC).

**The aid is designed to help you evaluate your options as a healthy woman with a BRCA mutation and prepare for a discussion with your health care provider.**

There may be no easy answers, but this is designed to help you sort out your choices.

**The following is general information about women’s cancer risks associated with BRCA mutations:**



The figure above shows BRCA+ women’s cumulative risks of breast and ovarian cancer to age 80 compared to the general population average risks. Risks for breast cancer: 72% for those who are BRCA 1+, 69% for BRCA 2+, 13% for the general population. Risks for ovarian cancer: 44% for BRCA1+, 17% for BRCA 2+, and <2% for the general population. Your age, family history and the location of your mutation affects your risk.

**DIRECTIONS:** Please provide below as much information about yourself and your family as you can.

### INFORMATION ABOUT YOURSELF:

Age \_\_\_\_\_

BRCA 1 Mutation \_\_\_\_\_ BRCA 2 Mutation \_\_\_\_\_

Premenopausal \_\_\_\_\_ Postmenopausal \_\_\_\_\_

Want to have children \_\_\_\_\_ Do not intend to have children \_\_\_\_\_

Already have children \_\_\_\_\_ Number of children \_\_\_\_\_ Finished having children \_\_\_\_\_

**(Discussion of risks, benefits and limitations of reproductive options is recommended)**

### INFORMATION ABOUT CANCER IN YOUR FAMILY:

Family Member Relationship / Type of Cancer(s)    Age at Cancer Diagnosis    Please Circle    Age at Death

\_\_\_\_\_    \_\_\_\_\_    Living    Deceased    \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_    Living    Deceased    \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_    Living    Deceased    \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_    Living    Deceased    \_\_\_\_\_

\_\_\_\_\_    \_\_\_\_\_    Living    Deceased    \_\_\_\_\_

**In the next section, review guidelines for each of the options for cancer risk management.**

**Rate the advantages and disadvantages and write in your own values and concerns in the space provided.**

**Your risk management plan may incorporate a combination of options and your choices may change over time.**

**Your provider will assist you in developing a plan that incorporates options appropriate for you.**

## 1<sup>st</sup> OPTION: Intensive Surveillance (Screening for Cancer)

### Breast cancer screening recommendations:

- \*Monthly breast awareness / self-exam (done at the end of your period if premenopausal) starting at age 18 with report of changes in your breasts to your provider.
- \*Clinical breast exam by a health care provider every 6-12 months starting at age 25.
- \*Age 25-29, Annual breast magnetic resonance imaging (MRI) with contrast (preferred) or mammogram (with tomosynthesis [digital, 3-dimensional]). (Screening may begin earlier if there is a breast cancer diagnosis  $\leq$  age 30 in the family).
- \*Age 30-75, Annual mammogram (with tomosynthesis) **and** breast MRI with contrast.
- \*Age > 75, Breast screening should be considered on an individual basis.

### Ovarian cancer screening recommendations:

- \* Recommend Salpingo-oophorectomy (removal of ovaries and fallopian tubes) when childbearing is complete, between ages 35-40 (for BRCA1) and by age 40-45 (for BRCA2). Transvaginal Ultrasound and CA-125 antigen blood tests may be considered starting at age 30-35.

Rate each Advantage or Disadvantage listed below with a number 1-3 with 1-not important, 2-important, 3-very important	
<p style="text-align: center;"><u>Advantages</u></p> <p>___ If breast cancer is detected, survival is 93% or higher.</p> <p>___ Keep breasts and ovaries.</p> <p>___ Remain fertile (premenopausal women).</p>	<p style="text-align: center;"><u>Disadvantages</u></p> <p>___ Risk for getting cancer is not reduced.</p> <p>___ Possible cancer worry.</p> <p>___ Does not improve ovarian cancer survival.</p> <p>___ Possible false negative/positive screening results.</p> <p>___ MRI may not be tolerated in those with claustrophobia, metal implants, or kidney problems.</p>
Personal Values and Other Concerns I Have:	

## 2<sup>nd</sup> OPTION: Prophylactic Mastectomy (Removal of Breasts)

- \*Recommend discussion of risk reducing mastectomy with your provider, including reconstruction options.

Rate each Advantage or Disadvantage with a number 1-3 with 1-not important, 2-important, 3-very important	
<p style="text-align: center;"><u>Advantages</u></p> <p>___ Risk for breast cancer decreases by at least 90%.</p> <p>___ May lessen anxiety related to breast cancer risk.</p> <p>___ May have breast reconstruction (immediately or delayed).</p>	<p style="text-align: center;"><u>Disadvantages</u></p> <p>___ Change in body image (how you feel about your body) and sexuality.</p> <p>___ Unable to breast feed.</p> <p>___ May have surgical complications: bleeding, infection, collection of fluid under the wound after surgery, or problems related to anesthesia.</p> <p>___ Up to 6 weeks recovery time after surgery.</p> <p>___ May have surgical complications related to breast reconstruction.</p>
Personal Values and Other Concerns I Have:	

### 3rd OPTION: Prophylactic Oophorectomy (Removal of Ovaries and Fallopian Tubes)

\*Recommend risk reducing bilateral salpingo-oophorectomy (removal of both ovaries and fallopian tubes) when childbearing is complete: between the ages of 35-40 for women with BRCA 1 mutations; and between the ages of 40-45 for women with BRCA 2 mutations; consider age of diagnosis in family members.

Rate each Advantage or Disadvantage with a number 1-3 with 1-not important, 2-important, 3-very important	
<p style="text-align: center;"><u>Advantages</u></p> <p>___ Risk for ovarian cancer decreases by at least 80%.</p> <p>___ Less anxiety related to ovarian cancer risk.</p> <p>___ For premenopausal women, risk for breast cancer decreases by 50% and anxiety related to breast cancer risk may lessen.</p> <p>___ For premenopausal women, menopausal symptoms and risk for osteoporosis may be lessened with short term hormonal replacement therapy until the natural age of menopause.</p>	<p style="text-align: center;"><u>Disadvantages</u></p> <p>___ Unable to become pregnant.</p> <p>___ Results in early menopause (natural menopause occurs at about age 50).</p> <p>___ Long term risks of early menopause are cardiovascular disease and osteoporosis.</p> <p>___ Menopausal symptoms may include night sweats, hot flashes, sexual discomfort, and a decline in sexual activity, desire and pleasure.</p> <p>___ May have surgical complications: bleeding, infection, pain, or problems related to anesthesia.</p> <p>___ Up to 2 weeks recovery time.</p>
<p>Personal Values and Other Concerns I Have:</p>	

### 4th OPTION: Chemoprevention (Use of Medication to Reduce the Risk for Developing Cancer)

\*Consider risk reduction agents as options for breast and ovarian cancer;

Rate each Advantage or Disadvantage with a number 1-3 with 1-not important, 2-important, 3-very important	
<p style="text-align: center;"><u>Advantages</u></p> <p><u>Tamoxifen or Raloxifene:</u></p> <p>___ Reduce risk for invasive breast cancer in high risk women with unknown BRCA mutation status by about 50%.</p>	<p style="text-align: center;"><u>Disadvantages</u></p> <p>___ These drugs have not been fully evaluated in BRCA+ women.</p> <p>___ Cannot be taken while pregnant.</p> <p>___ Serious side effects may include blood clots, strokes, uterine cancer, and cataracts.</p> <p>___ Other side effects may include hot flashes, vaginal dryness, joint pain and leg cramps.</p>
<p><u>Oral Contraceptives:</u></p> <p>___ Reduce ovarian cancer risk by 33-80% when taken for more than 1year.</p>	<p>___ If trying to get pregnant, will prevent pregnancy.</p> <p>___ Side effects may include blood clots, heart attack and stroke (these risks increase in smokers).</p>
<p>Personal Values and Other Concerns I Have:</p>	

## RESOURCES

### **FORCE (Facing our Risk of Cancer Empowered)**

<http://www.facingourrisk.org>

FORCE is a national nonprofit organization devoted to hereditary breast and ovarian cancer. Their mission includes support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. Their programs serve anyone with a BRCA mutation or a family history of cancer.

### **Be Bright Pink**

<http://www.brightpink.org>

Bright Pink is a national non-profit organization focusing on the prevention and early detection of breast and ovarian cancer in young women, while providing support for high-risk individuals.

### **National Cancer Institute**

#### **BRCA1 and BRCA2: Cancer Risk and Genetic Testing Fact Sheet**

<http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>

#### **Genetic Testing for Hereditary Cancer Syndromes Fact Sheet**

<http://www.cancer.gov/cancertopics/factsheet/Risk/genetic-testing>

The National Cancer Institute (NCI) is part of the National Institutes of Health (NIH), which is one of 11 agencies that compose the Department of Health and Human Services (HHS). The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

### **National Comprehensive Cancer Network**

<http://www.nccn.org>

The National Comprehensive Cancer Network is an alliance of leading cancer centers dedicated to patient care, research, and education, to improve the quality, effectiveness, and efficiency of cancer care so that patients can live better lives.