Patient

BRCA Testing for Twenty- and Thirty- Somethings: The questions, the issues, and the options.

Young men and women who are at-risk to inherit a familial BRCA mutation, or already know that they carry a BRCA mutation, are in a unique position to learn about their risks for cancer and take action in managing their risks before a cancer diagnosis. However, along with this opportunity come unique questions and concerns for this age group regarding genetic testing, hereditary cancer risk, and the implications of testing for themselves and their offspring. Individuals in their 20s and 30s should know that they are not alone and that many of their peers have the same questions and concerns.

Young BRCA mutation carriers may have specific questions and concerns regarding relationships (i.e. when and how to share genetic test results with a date), sexual self-image and functioning, (i.e. feelings about breasts in general, possible sexual side-effects from prophylactic surgeries) and about possible comments and reactions from their peers, family members, and even healthcare professionals.

Here we highlight some of the most common questions and concerns asked by men and women in their 20s and 30s who are contemplating or have had BRCA testing.

In review, the available data suggest that women who carry mutations in the BRCA genes have a 55-85% risk to develop breast cancer and as great as a 15-60% risk to develop ovarian cancer (this includes cancer of the fallopian tubes) in their lifetime. These figures are significantly higher than the general population lifetime risks of 12-13% for breast cancer and 1-2% for ovarian cancer. Carriers also have a greater chance of developing second primary breast cancers. Males who carry mutations in either BRCA gene have a slightly increased lifetime risk to develop prostate cancer. Individuals who carry BRCA2 mutations are at increased risk to develop male breast cancer and have an increased risk to develop pancreatic cancer and perhaps melanoma.

Q: When should I be tested for the BRCA mutation in my family?
A: It is recommended that young women seriously consider testing by age 25, but usually not before age 18. Screening for breast cancer in BRCA positive women generally begins at age 25.

Men at risk for a BRCA mutation should seriously consider testing by age 40, but usually not before age 18. Men may wish to be tested earlier than age 40 if there is a family history of early-onset prostate cancer or if they wish to use the information for family planning.

Q: Will insurance or my employer discriminate against me if I have genetic testing?
A: A federal law, known as GINA (Genetic Information Nondiscrimination Act), provides broad protection against genetic discrimination in group and individual health insurance and employment. GINA specifically prohibits issuers of health insurance (including group, individual and Medicare supplement policies) from using genetic information to:

- establish eligibility, contribution amounts and premium fees;
- specify the conditions of the policy;
- impose a preexisting condition exclusion.

GINA specifically prohibits employers, labor organizations, employment agencies and joint labor-management committees from using genetic information to:

- fire or refuse to hire an employee;
- discriminate against an employee with respect to compensation, promotions, or terms, conditions or privileges of employment;
- treat employees differently in admission to apprenticeships, training or retraining programs.

GINA also specifically prohibits employers and health insurers from requesting, requiring, disclosing or purchasing the results of a genetic test or genetic information.

GINA, however, does not apply to members of the US military, veterans obtaining healthcare through Veterans Administration, or the Indian Health Service. It also does not address life insurance, disability insurance, or long-term-care insurance.

Q: What are my options for cancer surveillance and risk reduction if I test BRCA positive?
A: The answers to this question will vary depending on your age and family history. However, in general, young women who are known to carry a BRCA mutation may opt for breast cancer surveillance to increase early detection of a cancer or preventative surgery to reduce the risk to develop breast cancer. Once a woman completes childbearing, she may wish to discuss with her doctor or a breast specialist the use of medications (e.g. tamoxifen) to reduce her breast cancer risk. In regards to ovarian cancer risk, young women who are not finished childbearing may opt for ovarian cancer surveillance and/or the use of birth control pills to reduce risk. After childbearing or by age 40, she should discuss with her doctors the timing of removing her ovaries and fallopian tubes to reduce her ovarian and fallopian tube cancer risk.

It is currently recommended that young men who carry a BRCA mutation begin screening for prostate cancer at age 40, or younger if there is a family history of early-onset prostate cancer. Screening for breast cancer, especially in a male BRCA2 mutation carrier, should include a monthly self-exam, a yearly clinical breast exam with a clinician and discussion of the pros and cons of mammography. Men should also be counseled regarding symptoms of breast cancer.

Q: Do I have to rush to...get married? have children?
A: It is common for young BRCA mutation carriers to express concerns about how and when to share their genetic test results with someone they are dating. You may sometimes feel like you have to “find the right person, get married, and have kids….pronto”. We have also, unfortunately, heard that some young BRCA mutation carriers are being ill advised by healthcare providers to rush into these lifecycle events. This often does not lead to healthy decision-making. We recommend speaking with a genetic counselor regarding your personal and family history, developing a personalized medical management plan, and discussing how often this plan should be re-assessed over the coming years.

Q: Can I still have children if I carry a BRCA mutation?
A: Yes! There are a multitude of options available to BRCA mutation carriers who wish to have children. Each child of a BRCA mutation carrier has a 50% chance to inherit the mutation, regardless of whether the child is male or female. However, for those who are interested, there are options to reduce the likelihood of the mutation being passed to the next generation (e.g. Preimplantation Genetic Diagnosis [PGD]) and options for determining if a fetus carries the mutation (e.g. Chorionic Villus Sampling [CVS] or amniocentesis). Women diagnosed with breast cancer who will need to have chemotherapy treatment may choose to freeze embryos or their eggs before beginning treatment to preserve fertility. These options and others have been described in more detail in our Spring 2006 and Fall 2006 newsletters. These editions can be found on our website www.yalecancercenter.org/genetics.

Q: Where can I go for more information?
A: There are national organizations such as Facing Our Risk of Cancer Empowered (FORCE) (www.facingourrisk.org) and Bright Pink (www.brightpink.org) that offer specific resources to women in their 20s and 30s, such as on-line resources and peer-to-peer support. FORCE also has resources for male BRCA mutation carriers. Fertile Hope (www.fertilehope.org) is an organization specifically for men and women diagnosed with cancer who are interested in learning about their fertility preservation options. Additionally, our program offers a listserv for female BRCA mutation carriers that have been seen for genetic counseling through our program. The genetic counselors at our program would also be happy to sit-down with you to discuss your history and review the recommendations available based on your personal and family history and age. Others have found therapy with a clinical psychologist or licensed social worker beneficial in addressing their concerns, fears, and overall well-being.