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## **Hereditary Breast and Ovarian Cancer Syndrome**

Hereditary Breast and Ovarian Cancer (HBOC) Syndrome is an inherited genetic condition that occurs due to a mutation in either the BRCA1 or BRCA2 gene. Normal BRCA (**BR**east **CA**ncer) genes protect against the development of certain types of cancer. If these genes mutate and do not function correctly a person's lifetime risk of developing breast and /or ovarian cancer is increased. Women who are BRCA positive (meaning that they have an inherited BRCA mutation) have up to an 85 percent lifetime risk of developing breast cancer and up to a 44 percent lifetime risk of developing ovarian cancer. Genetic testing can help to identify people with BRCA gene mutations. About 1 out of every 20 breast cancers (5%) is caused by a BRCA gene mutation and about 1 out of every 10 ovarian cancers (10%) is caused by a BRCA gene mutation.

Of importance, many BRCA-associated breast cancers occur under the age of 40 or 50, when regular screening is not being performed. Men who are BRCA positive also have up to a 6 percent lifetime risk of developing breast cancer and also an increased risk for prostate cancer. It is well established that genetic testing for hereditary cancer syndromes can improve patient outcomes by facilitating early detection of cancer, identifying effective therapies, or in some cases, preventing disease altogether through prophylactic surgery.

### **The Georgia Breast Cancer Genomics Consortium**

In 2011, the Georgia Department of Public Health was awarded funding from the Centers of Disease Control and Prevention (CDC) to target young women ages 18 to 49, at high risk for developing breast cancer, through counseling and testing for the genes that normally protect against breast and ovarian cancer. The overarching goal of the initiative is to promote the use of evidence-based guidelines to improve the identification of young women at genetic risk for breast and ovarian cancer, with the ultimate goal of reducing the cancer burden in this population and in disparate sub-populations. The three main areas of focus are ***education, surveillance, and policy.***

The Georgia Breast Cancer Genomics Consortium (Consortium) is in the third year of implementing its three-year action plan to increase understanding and utilization of appropriate genetic assessment and screening services within three targeted groups: private and public health clinicians/practitioners, payers/policy makers, and young women at risk. The Consortium is comprised of representatives the Georgia Department of Public Health, Georgia Center for Oncology Research and Education, Inc. (Georgia CORE), Emory University, Morehouse School of Medicine, and Georgia State University.

The following table is a summary of HBOC screenings facilitated by the work of the Consortium.

|  |       |
|--|-------|
| Public Health Clinics Currently Screening with B-RST Tool <sup>1</sup> | 8     |
| Clients Screened to Date (all sites)                                   | 2,602 |
| Clients Screened Positive to Date (all sites)                          | 154   |
| Clients Who Have Agreed to Follow-Up to Date (all sites)               | 143   |
| Clients Tested to Date   | 16    |
| Positive Results (to date):  |       |
| BRCA 1/2 Positive  | 1     |
| Genetic Variant of Uncertain Significance                              | 1     |
|  |       |
| Unique Visitors to BreastCancerGeneScreen.org to Date <sup>3</sup>     | 5,846 |
| Average Visitors per Day   | 40    |

<sup>1</sup> Statistics reported as of April 11, 2014

<sup>2</sup> Since May 2013

### **U.S. Preventive Services Task Force Recommendation**

In December 2013, the U.S. Preventive Services Task Force (USPSTF) released its final recommendation statement for Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer in Women. The USPSTF has designated BRCA-related genetic counseling and testing as a level B recommendation. In its statement, the USPSTF recommended that primary care providers screen women with a family history of breast or ovarian cancer for the BRCA1 or BRCA2 gene mutations via one of several screening tools. One of the tools recommended was the Referral Screening Tool (B-RST), developed by Consortium member Cecelia Bellcross. The B-RST tool was recognized as one of two screening tools found to be “the simplest and quickest to administer”. The tool is located at [BreastCancerScreenGene.org](http://BreastCancerScreenGene.org).

In addition to pointing to the efficiency of the B-RST tool, the USPSTF also cited the need for genetic counseling for women with positive screening results. Pre-and post-testing counseling are critical to the entire process as it gives patients opportunities to further understand their risk, get answers to their questions, voice concerns, and access resources that aid in making informed decisions about their follow-up care.

### **Health Plan Coverage in Georgia**

BRCA testing costs can range from \$900 to \$2900, making it financially inaccessible to some patients. Genetic counseling is critical for patients to adapt to the medical, psychological, and familial implications of disease and is essential to maximize cost-effectiveness and quality of care. Many providers are not equipped to provide thorough genetic counseling, thereby creating barriers to accessing these services. These barriers can be reduced with expertly crafted health plan genetic testing policies and by increasing members' access to trained genetics experts who can improve cost-effectiveness by ensuring BRCA testing is appropriate, the right test is ordered, and the right person in the

family is tested. With the increasing prevalence of genetic testing, and reaffirmation of its importance by the USPSTF, it is now a requirement for health plans and self-funded groups to develop policies that address genetic counseling and testing.

Prior to the release of the 2013 final recommendations; an environmental scan of the eight major health plans in Georgia revealed that most of the plans were clearly compliant with the 2005 USPSTF recommendation that women at increased risk for BRCA mutations be referred for genetic counseling and evaluation for BRCA testing<sup>1</sup>. Currently, 32 state Medicaid programs cover genetic counseling and testing for HBOC for those who qualify. To date, the Georgia Medicaid program does not cover genetic testing and counseling.

While Georgia's private health insurers have been ahead of the curve in ensuring BRCA-related genetic counseling and testing for their members, there remains a gap in access for the un- and underinsured. The Consortium is well positioned to be a resource to public and private leadership for assistance and support in understanding and complying with policy regulations to ensure that women in Georgia, especially those at high-risk for HBOC have access to the services they require – services that will ultimately save both lives and money.

DRAFT

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<sup>1</sup> The environmental scan was done in October 2013, at that time the most current USPSTF recommendation was that released in 2005. The 2013 recommendation upholds the 2005 recommendation with regard to testing and genetic counseling.