



8/20/09
For immediate release:



Genetics Health Professionals Uniquely Trained to Coordinate Genetic Testing

Direct-to-consumer (DTC) marketing of genetic tests has been increasing considerably over the past few years. DTC genetic marketing presents both opportunities and challenges. It increases the awareness of the public regarding their risks for hereditary conditions and risk reducing options such as screening and lifestyle modifications, while at the same time it may generate confusion and anxiety, or even false reassurance. There is also the potential for results of such testing to be misinterpreted or misused. This is especially true when testing does not involve the expertise of a health care professional. Geneticists and genetic counselors are uniquely trained to identify those who would benefit from genetic testing, educate those who undergo genetic testing and help prepare individuals for what they might learn from testing. Additionally, they can interpret complicated genetic test results with regard to their clinical implications.

Myriad Genetics Laboratories, Inc. is currently running a DTC marketing campaign in Indiana and the surrounding states. Myriad is the only laboratory in the United States that offers BRCA1 and BRCA2 gene analysis. Mutations in these two genes are associated with an increased risk for breast, ovarian, and other cancers. It is estimated that only 5-10% of breast cancer is due to a mutation in one of these two genes. Similar marketing in other regions of the U.S. has drastically increased the demand for this type of genetic testing. It is therefore likely that primary health care providers will be approached with questions regarding testing for hereditary cancer and many of them will not have the knowledge and background to handle these inquiries. Additionally, many of those concerned about their risks will actually have a low likelihood for hereditary cancer and may not be appropriate candidates for genetic testing.

Professional organizations including the American Society of Clinical Oncology (ASCO), the National Comprehensive Cancer Network (NCCN), the Society of Gynecologic Oncologists (SGO), the National Society of Genetic Counselors (NSGC) and the Oncology Nursing Society (ONS) recommend pre- and post-test genetic counseling. This is an essential component to the process of genetic testing for hereditary cancer so that individuals may fully understand the benefits, limitations, and cancer risk reduction options. In addition, because family history can be complex and hereditary breast cancer may be caused by mutations in a gene other than BRCA1 and BRCA2, there are many situations where genetic risk evaluation and testing is complex. Finally, pre- and post-test genetic counseling is important to convey to the individual being tested that results from genetic tests have implications for the entire family, not just the person who is being tested.

Geneticists, genetic counselors and other health care professionals trained in genetics are available to answer questions regarding genetic testing and to accept referrals for hereditary risk assessment and patient education regarding the benefits and limitations of genetic testing. For additional information regarding DTC genetic testing or to locate a genetics-trained health care professional near you, please refer to the following resources.

Genetics testing and health care provider resources:

Policy statements:

- American Medical Association (AMA) statement on genetic testing: <http://www.ama-assn.org/ama/pub/physician-resources/medical-science/genetics-molecular-medicine/related-policy-topics/genetic-testing.shtml>
- American College of Obstetrics and Gynecology (ACOG) press release on testing for BRCA1/2: http://www.acog.org/from_home/publications/press_releases/nr03-20-09.cfm
- National Society of Genetic Counselors (NSGC) position statement on DTC: <http://www.nsgc.org/about/position.cfm#DTC>
- American College of Medical Genetics (ACMG) position statement on DTC: http://www.acmg.net/AM/Template.cfm?Section=Policy_Statements&Template=/CM/ContentDisplay.cfm&ContentID=2975
- American Society of Human Genetics (ASHG) statement on DTC: http://www.ashg.org/pdf/dtc_statement.pdf

To locate a Genetics Health-care professional:

- National Society of Genetic Counselors www.nsgc.org/
- Indiana Network of Genetic Counselors www.ingc.info/
- Indiana State Department of Health <http://www.in.gov/isdh/20478.htm>
- International Society of Nurses in Genetics www.isong.org/
- National Cancer Institute Cancer Information Service http://www.cancer.gov/search/genetics_services/ or 1-800-4-CANCER

About the INGC:

The Indiana Network of Genetic Counselors (INGC) represents genetic counselors from across the state. The mission of the INGC is to encourage professional growth, provide support for its members, and promote the genetic counseling profession. The INGC works to achieve these goals by maintaining a system of communication among genetic counselors, acting as a resource to the community and mentoring genetic counseling students.

www.ingc.info/

Contact: Stephanie A. Cohen, MS, CGC
(317) 415-6676
sacohen@stvincent.org

About the IGAC:

The Indiana Genetics Advisory Committee (IGAC) was created in 2000 to advise ISDH Maternal and Children's Special Health Care Services in the development of programs and policies that aid in preserving the rights, health, and well-being of the citizens of Indiana. These rights include: proper genetic evaluation, counseling, and treatment; the right of privacy; and the freedom from discrimination and undue anxiety. IGAC also advises the ISDH Genomics Program with regards to public health genetic issues, particularly as these issues relate to assessment, policy development, and assurance.

<http://www.in.gov/isdh/20578.htm>

Contact: Janice Zunich, MD
(219) 980-6560
jzunich@iun.edu