

national society  
of genetic  
counselors, inc.



**Media Contact:**  
Lindsay Kahn or  
Shauna Sheffer  
312-558-1770  
[lkahn@pciipr.com](mailto:lkahn@pciipr.com)  
[ssheffer@pciipr.com](mailto:ssheffer@pciipr.com)

**FOR IMMEDIATE RELEASE**

## **Consumers Should Be Mindful of DTC Genetic Testing: Don't Bypass Genetic Counselors, Medical Geneticists or Other Healthcare Providers**

CHICAGO – Feb 4, 2010 – As attention to new direct-to-consumer (DTC) genetic screening tests increases, so does the risk that test results may be misinterpreted, according to the National Society of Genetic Counselors (NSGC). This is especially the case with companies that do not include a genetic counselor or clinical geneticist in their testing and reporting process.

“Genetic testing can be very helpful in determining a person’s chance to develop or pass on hereditary diseases to their offspring. However, the most important first step is to understand what can or cannot be learned from a test,” said Elizabeth Kearney, President of NSGC. “DTC genetic tests can deliver powerful information. A trained genetic counselor can help prepare you for what you might learn and be there for you to interpret results. They can also help you decide if having a genetic test is a good choice.”

All genetic tests can reveal life-changing information, both positive and negative. When test results indicate a lower risk for certain conditions, some people will be falsely reassured because the test may only detect some of the individuals at risk. Consumers need to be aware of these possibilities, Kearney said.

The NSGC recommends that anyone considering undergoing genetic testing ask the following questions:

1. Is a genetics professional or a knowledgeable healthcare provider involved in the process of ordering or interpreting a genetic test?
2. Is the consumer provided with comprehensive information regarding what the test can and cannot say about his or her health or chances to pass on a hereditary condition?
3. Will results be given in a manner understandable to the average consumer, with a clear explanation of their clinical implications if any?
4. Does communication of results include referrals to appropriate resources or recommendations for follow-up?
5. Is the scientific evidence on which a test is based clearly stated?
6. Is the clinical testing laboratory accredited by CLIA, the State and/or other applicable accrediting agencies?

7. Are privacy concerns addressed?

The NSGC supports consumers' right to access high-quality genetic services, strongly encourages the involvement of appropriately trained clinical genetics professionals in the genetic testing process, and cautions against using DTC commercial entities that have not addressed these basic issues.

**About the National Society of Genetic Counselors**

NSGC is the leading voice, authority and advocate for the genetic counseling profession. The Society represents more than 2,500 health professionals, most of whom provide direct patient care (totaling more than one million visits per year). Members are employed in a wide range of clinical care, academic, research and biotechnology settings, and are located in every state of the U.S. and internationally. The organization is committed to ensuring that the public has access to genetic counseling and genetic testing. For more information, visit [www.nsgc.org](http://www.nsgc.org).