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Ask questions before buying a genetic test home kit

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The growing market for direct-to-consumer genetic testing suggests that kits may one day hit your local store shelves. Tests include a variety of medical and non-medical conditions such as baldness, paternity and ancestry, and some are just for entertainment purposes.

There is limited regulatory oversight of these direct-to-consumer testing services, warns the National Society of Genetic Counselors, so the tests may be invalid or unproven, and the results should be interpreted by a genetic counselor. But if you're contemplating using a direct-to-consumer service, the society says to consider the following:

• Are consumer-friendly materials available, developed or reviewed by health care professionals with expertise in genetics (e.g., trained genetic counselors) and suitable for individuals seeking and receiving direct-to-consumer testing services?

• Is information disclosed to potential consumers regarding test purpose, potential limitations, validity and accuracy, using language that is written for consumers?

• Will results be given in a manner understandable to the average consumer, with a clear explanation of their clinical implications, if any, and including resources providing appropriate follow-up?

• Are patients encouraged to share their medically relevant genetic test results with their health care providers and family members who may also be at risk?

• Are consumer referrals to health care professionals with expertise in genetics available, either on staff or independent of the commercial entity, before and after testing to assure appropriate medical follow-up, including psychological counseling as needed?

• Is there a process for obtaining and documenting informed consent in a manner consistent with accepted medical practices as well as state and local regulations?

• What safeguards are in place to protect the consumer/patient privacy?

• Has the company implemented policies that adhere to testing guidelines and position statements of professional organizations, including the National Society of Genetic Counselors, the American College of Medical Genetics, American Society of Human Genetics and others? These may include relevant guidelines for genetic testing of minors or other potentially vulnerable populations.

• Are the genetic tests performed by appropriately credentialed laboratories ?

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 direct-to-consumer commercial entities that have not addressed the basic issues outlined above.

Source: National Society of Genetic Counselors

COMMON CANCER MYTHS

The National Society of Genetic Counselors dispels common myths associated with breast and ovarian cancer and genetic testing:

MYTH: Breast and ovarian cancer is always hereditary.

FACT: Only 5 percent to 10 percent of breast and ovarian cancer cases are inherited.

MYTH: Anyone who wants to find out their risk of developing breast and ovarian cancer should get the BRCA1/2 genetic test.

FACT: A BRCA gene test does not test for cancer itself — only for mutations, or changes, in the BRCA1 or BRCA2 genes that may increase the chance of developing certain cancers over a lifetime. BRCA genetic testing is only for individuals whose personal and/or family history reveals red flags associated with hereditary breast and ovarian cancer. These include:

• Onset of breast cancer before age 50

• Ovarian cancer at any age

• Multiple primary tumors in the same individual

• Multiple family members with breast and/or ovarian cancer

• Cancer in both breasts or ovaries, or twice in the same one

• Presence of male breast cancer

• Ethnic background known to have a high frequency of a BRCA1/2 mutation.

MYTH: Breast and ovarian cancer can only be inherited from female family members.

FACT: About half of women who inherit a mutation, or abnormality, in the BRCA1 or BRCA2 genes receive it from their father. Genetic mutations can be inherited from either the mother's or father's side of the family.

MYTH: Men should not undergo genetic testing for breast cancer.

FACT: Men who have a BRCA1 or BRCA2 mutation are at an increased risk to develop cancer, namely breast and prostate, so knowing their genetic status will help them better manage their health. Another reason for men to undergo genetic testing for mutations in BRCA1 and BRCA2 is to determine if they have a mutation that they could pass on to their children.

MYTH: An abnormal (positive) BRCA1/2 genetic test result means breast and/or ovarian cancer will develop in the future.

FACT: A positive test result indicates a heightened risk, but does not mean a person will develop these cancers. Some individuals may inherit the risk factor, but may not develop cancer over his/her lifetime. Individuals with a positive test result should undergo regular screening and consider preventive measures to reduce the risk of developing cancer.

MYTH: A normal (negative) BRCA1/2 genetic test result means a cancer-free future.

FACT: If a person has a strong family history of breast and/or ovarian cancer, they may still have a higher risk of developing these cancers. Not all family histories of breast and/or ovarian cancer will be explained by mutations in the BRCA1 or BRCA2 genes. Other gene mutations may cause cancer and inherited cancer risk.

Source: National Society of Genetic Counselors

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