

PEN's Insurance Pulse 2017

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Empower the Girl, Empower the Woman

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Q: What concerns you most about revising or repealing the ACA? What provision(s) do you think need revising?

Let's talk about your daughter and whether she might be a carrier for a genetic mutation that causes hemophilia. According to National Hemophilia Foundation's (NHF) Steps for Living, there's a chance that a woman is a carrier if she is the mom, grandmother, or sister of a biological son, grandson, or brother with hemophilia; or the aunt, cousin, or niece of a male with hemophilia related through her mother. If your daughter fits any of these scenarios, NHF's Medical and Scientific Advisory Council (MASAC) recommends that she undergo genetic testing to determine her carrier status.

What Is Genetic Testing?

Though once in the realm of sci-fi novels, genetic testing is now mainstream. Genetic testing identifies changes in the normal structures of proteins, genes, and chromosomes. An integral part of genetic testing is the counseling that goes with it. Meg Bradbury, senior genetic counselor at GeneDx, Inc., describes genetic counseling as "the process of helping patients understand and adapt to medical, psychological, and familial implications of genetics contributing to disease."

Bradbury explains that genetic counseling breaks down into three parts: "interpretation of medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources, and research; and counseling from a genetic counselor to promote informed choices and adapt to the risk or condition."¹

Does Insurance Cover Testing?

Many large health insurance plans cover genetic testing when it's recommended by a doctor. In fact, \$5 billion annually is spent on genetic testing. Within the next ten years, this number could reach \$15 billion to \$25 billion.² "Often, genetic testing for hemophilia is a covered benefit because learning hemophilia carrier status can impact medical care," says Sumedha Ghate, genetic counselor at Hemophilia Outreach Center in Wisconsin. "When you are making decisions about whether or not to pursue gene testing for carrier status and you have questions about insurance coverage, first talk to a genetic counselor. They have up-to-date information and can answer your questions."

Many insurance companies consider genetic testing medically necessary if a person is at risk for inheriting a disease or disorder. Aetna Inc., for example, offers policies that cover genetic testing for hemophilia A and B. Aetna considers genetic testing medically necessary if a patient “is at direct risk of inheriting the mutation in question and the result of the test will directly impact the treatment,” among other reasons.³

The trouble is, insurance coverage for genetic testing is inconsistent among health insurance companies, and even within a single company’s plans. For instance, Medica Health Plans covers single-gene testing for carrier status of heritable disorders when (1) testing is ordered by board-certified medical geneticist or genetic counselor; or (2) the patient has symptoms of or a family history of a genetic disorder.⁴ But while Medica covers genetic testing for hemophilia A, it doesn’t cover the same testing for hemophilia B.

The Practical Impact of Testing

Your daughter has a right under the US and state constitutions to make certain reproductive choices, including having genetic testing.⁵ But there are pros and cons to genetic testing. It’s essential to talk to your daughter about the risks of not being tested, given her chances of being a carrier, as well as the risks of being tested.

Michelle Alabek, genetic counselor at the Institute for Transfusion Medicine, advises parents and relatives of potential carriers, “Talk to your daughter or female relative about genetic testing for carrier status, share information with her, and help her understand why this could be so important.” For example, knowing carrier status before a medical procedure can help prevent bleeding complications. Equally important is testing factor levels of girls with a family history of hemophilia at as early an age as possible. “If we know someone is a carrier and at risk for bleeding with a procedure, I can develop a proactive plan with a carrier to minimize bleeding risk,” says Alabek. “Without this management plan, a female may have avoidable bleeding with or after the procedure, which can lead to negative health outcomes.”

According to MASAC, 50% of women and girls who are carriers for hemophilia also have factor levels below 50%, putting them at risk for excessive bleeding during delivery of a baby as well as during a surgery, accident, or menstruation.⁶ Carriers who plan to become pregnant need to know their factor level and create a bleed management plan for delivery. Having a plan is critical in avoiding complications for both mother and baby.

According to Bradbury, “If the genetic variant that causes bleeding is known, then you can make choices about options for genetic testing pre-conception and post-conception. An informed mom-to-be can work with her ob/gyn to create a delivery plan using MASAC guidelines. A plan may include having factor on hand, avoiding the use of assistive delivery devices, and planning for procedures, like circumcision, after a baby is born.”

It’s also important that your daughter understands the risks of being tested. These range from emotional impact to potential genetic discrimination. When a woman learns she’s a carrier, she may feel anxious, depressed, angry, or guilty. “Genetic testing can elicit a variety of emotions,” explains Alabek. “Individuals within the same family may respond differently to the same results, so having genetic

counseling ahead of time can help a woman with the psychosocial aspects of testing, promote informed decision making, and anticipate reactions to the different possible test results.”

What about the risk of genetic discrimination? After 13 years of trying, in 2009 Congress barred health insurance companies from denying coverage to people with a genetic mutation and prohibited genetic discrimination in employment by passing the Genetic Information Nondiscrimination Act (GINA).⁷ But this hard-fought win doesn’t mean that your daughter is free from genetic discrimination. GINA does not apply to employers with fewer than 15 employees who provide health insurance to their employees. GINA also does not apply to other types of insurance, such as life, disability, or long-term care insurance.⁸

Even so, Ghate stresses, “The medical benefit of genetic testing when offered by professionals with expertise far outweighs any risk of group health insurance discrimination.” She notes, “Genetic counselors can answer your questions about genetic testing and insurance discrimination. As a genetic counselor, I often address questions related to health insurance discrimination and am familiar with both federal laws and state laws, which helps me allay fears about insurance discrimination.”

The Price of Privacy

For privacy reasons, some people choose to pay out-of-pocket for genetic testing so that the testing and results do not appear in their medical record. Those costs range from \$200 to \$3,000 plus.⁹ Ghate recommends asking a genetic counselor about the actual cost of testing. “If the specific causative mutation has been identified in the affected family member, carrier testing cost is quite reasonable, with the cost varying by lab and specific mutation.” She explains, “In 2017, eligible potential carriers can seek carrier testing at no cost through the My Life Our Future program at qualified hemophilia treatment centers.” If you do not receive care at a hemophilia treatment center (HTC), Bradbury recommends that you visit the National Society for Genetic Counselors website (www.nsgc.org) to find a genetic counselor. For more on My Life Our Future and a list of HTCs participating in the genetic testing program, visit www.mylifeourfuture.org.

Experts agree that it can be empowering to know if you’re a carrier of a genetic mutation that causes hemophilia. “A woman who knows her risk of passing a bleeding disorder on to her child can better advocate for herself,” Bradbury believes. It’s your turn to talk to your daughter about genetic testing to determine if she’s a carrier. Empower the girl, empower the woman. It could save a life.

1. Hemophilia Federation of America, <https://www.youtube.com/user/VoicesHFA> (accessed May 17, 2017).

2. Christina Farr, “If You Want Life Insurance, Think Twice Before Getting a Genetic Test,” <https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing> (April 6, 2016, accessed May 3, 2017).

3. “Genetic Testing,” Aetna, http://www.aetna.com/cpb/medical/data/100_199/0140.html (accessed May 3, 2017).

4. Medica Coverage Policy, Genetic and Pharmacogenetic Testing (policy name), https://www.medica.com/-/media/documents/provider/coverage-policies/genetic_and_pharmacogenetic_testing_cp.pdf?la=en (accessed May 31, 2017).

5. Institute of Medicine (US) Committee on Assessing Genetic Risks, Lori B. Andrews et al., eds., "Social, Legal, and Ethical Implications of Genetic Testing" (Washington, DC: National Academies Press, 1994), <https://www.ncbi.nlm.nih.gov/books/NBK236044/> (accessed May 31, 2017).
6. "MASAC Recommendations Regarding Girls and Women with Inherited Bleeding Disorders," <https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASACRecommendations/MASAC-Recommendations-Regarding-Girls-and-Women-with-Inherited-Bleeding-Disorders> (Nov. 16, 2016, accessed May 3, 2017).
7. Farr, "If You Want Life Insurance, Think Twice Before Getting a Genetic Test."
8. "What Is Genetic Discrimination?" Genetics Home Reference, US National Library of Medicine, National Institutes of Health, <https://ghr.nlm.nih.gov/primer/testing/discrimination> (accessed May 3, 2017).
9. "Frequently Asked Questions About Genetic Testing," <https://www.genome.gov/19516567/#al-4> (accessed May 3, 2017).