

SCIENCE & WELLNESS

Genetic Testing – How Much Information is Too Much Information?

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If you had access to a crystal ball, would you want to find out your child's fate from a young age? Would you rather be left in the dark or know all the details of your child's health today and potential problems in the future? A new phenomenon called "recreational genetic testing" has arrived. As parents, we will have some arduous ethical decisions to ponder.

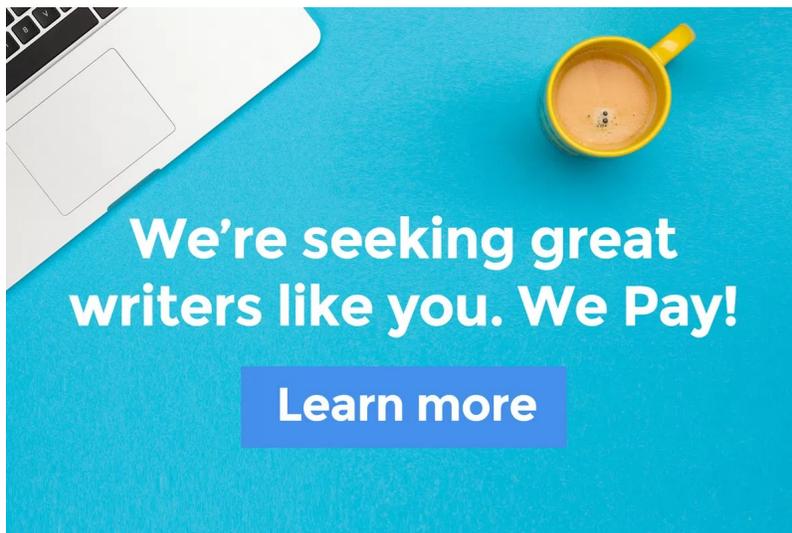
Direct-to-consumer genetic testing has arrived

The Food and Drug Administration recently approved the first home genetic test by the company 23andMe that enables people to determine if they have a genetic risk for certain diseases. This is considered recreational because you can order and take the test yourself without getting a prescription from your doctor. It's similar to the ancestry tests offered by this same company. All it takes is a simple swipe of your saliva.

This new test looks at a patient's risk for a total of 10 diseases including: Parkinson's disease, late-onset Alzheimer's disease, Celiac disease, Gaucher disease type 1, and hereditary thrombophilia and Factor XI deficiency (both blood clotting disorders). This test does not currently evaluate genes that predispose people to cancer.

This new world of genetic testing sounds intriguing because we can easily find out our future health risks in an affordable way. For a few hundred dollars we can get a report, compared to \$1,000 or more for genetic testing in a medical facility. More than a dozen companies now sell genetic tests, and they are becoming more and more popular. The global market for these tests was valued at more than \$70 million in 2015.

Having this information can shape our decisions regarding lifestyle choices like diet and exercise, and can keep us and our doctors on the lookout for signs that a disease is starting to develop. Some companies are taking advantage of this approach by selling patients diet and fitness advice that is supposedly linked to our genetics. Most companies are marketing to adults, but some offer tests for children as well. One company even promises to provide parents with information on their child's genetic predisposition for success in sports.



Flaws with the tests

With all the promises made about these genetic tests, there are several important flaws to point out before you jump into anything.

First, consumers need to understand that genetic testing is not always accurate. Our genes almost never indicate a 100 percent risk for any disease. Instead, several different genes interact with our lifestyle and other factors to trigger symptoms of disease. Experts at the National Institutes of Health state that it is unlikely that genetic testing will ever be able to predict disease with complete accuracy. In addition, some genetic mutations are inherited, some develop before birth, and some occur later in life. Because of this uncertainty, we have to be careful of putting too much faith into these results, especially for our children.

Next, a big concern with allowing individuals to take the tests and review the results in their own home is that they will not have experts to explain it to them and support them if they receive bad news. The results and their implications can be quite complicated, with even some physicians struggling to understand them fully. The tests do come, however, with a recommendation for patients to seek help from a healthcare professional or genetic counselor before getting the results of the test.

Finally, many people are alarmed by privacy issues since it is not clear what the companies will do to protect patients' results. Will they ensure that the data is safeguarded and unable to be viewed by other individuals?

Emotional fallout

Even though the FDA is requiring that customers click an acknowledgement that they understand the results could cause them anxiety, there are many concerns about the emotional fallout that these tests can cause, especially when children are involved.

For example, imagine that you had your son tested and found out he is tagged to develop a serious disease later in life. What would you do? Would you change how you treated him, the type of school you sent him to, or how often you took him to the doctor? What if you found out that your young daughter carried the BRCA gene for breast cancer? How might this change the trajectory of her life from dating to where she attends college to how early she decides to have children? Ethical experts worry that having this genetic knowledge might cause stigma or discrimination for these children. Also, learning that a child has a disease can impact other members of the family and prompt them to be concerned and to consider getting tested themselves.

Another twist to genetic testing is that people can learn information about themselves that they never expected. Sometimes when tests are taken by both parents and children they can reveal “non-paternity,” meaning that the man they thought was their dad is not actually related to them. Studies show an estimated rate of one to 10 percent that this shocking news happens. This can certainly cause intense anxiety and rip a family apart.

Finally, because of the uncertainty that the disease will actually develop, is it really worth all the stress in the current moment caused by thinking that your children will have an issue when they are older? Experts believe that the majority of genetic tests are unable to predict someone’s health future; sometimes the disease never even develops.

Recommendations

This issue is not expected to go away any time soon. In fact, more and more companies are planning to market home genetic tests and currently, major research projects are underway to explore how to gather complete genetic information when a child is born. Genetic testing for children may become the norm before we know it.

So what should parents do? Before you order the genetic test, consider these recommendations from the American Society of Human Genetics (ASHG) Workgroup on Pediatric Genetic and Genomic Testing.

- If your child is healthy, there is no need to have them undergo recreational genetic testing.
- Children are considered a vulnerable population because they are unable to make decisions for themselves regarding their own health. Parents should, in most cases, defer testing until their children are old enough to meaningfully participate in the decision.
- If your child is at imminent risk for developing a disease during childhood due to family history, such as childhood cancer or hemophilia, then genetic testing makes sense. At this point in time the home tests are too unreliable, so children should be tested within the health care setting where they can get proper counseling and support.
- In cases when a teen may benefit from genetic testing, it is best for the teen to talk directly to a trusted health care professional without parents in the room. This will provide an unbiased assessment of the benefits and risks of testing. Then the teen and parents can make the decision together.



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