

# **Consumer Federation of America**

# 9 Questions and Answers about DTC Genetic Testing

Would you like to learn more about where your ancestors came from? Find long-lost relatives? Know whether you're likely to develop certain health problems? This is the kind of information that direct-to-consumer (DTC) genetic testing companies promise. You can buy a test kit online or in a store, without a doctor's orders. Just follow the directions to swab the inside of your cheek or spit into a tube and send in your sample as instructed, and within a couple of weeks you'll get the results. If you're thinking about taking one of these tests or giving a kit to someone else, it's important to understand what the tests reveal, how your personal information is handled, and how the test results could affect you and your family.

## 1. What do you get when you take a DTC genetic test?

Your genes are the DNA instructions you inherit from your mother and father. They are a large part of what makes you "you." DTC genetic tests for ancestry look for your genetic links to certain geographic areas – the parts of the world your ancestors likely came from, and perhaps even more specifically the countries and areas within them. You may also get information about Jewish origins. Some DTC genetic testing companies also provide DNA matches – people who may be related to you. Health-related DTC genetic tests may provide helpful information about nutrition, skincare, and weight based on your genetic make-up. Some tests predict the risks of developing specific health conditions or diseases.

#### 2. How accurate is this information?

The information a DTC genetic testing company provides is an *estimate* based on comparing your data to that of other customers in its database. Predictions about DNA matches are generally more accurate for close family members than for distant ones. When the company adds more customers and collects more data, your test results may change. With health tests, new scientific research may also change the results. Since DTC genetic testing companies don't all have the same customers and don't use the same formulas to produce their ancestry and health reports, one may provide you with different information than another.

# 3. Could DTC genetic tests produce unexpected results?

The information you receive as a result of genetic tests may be welcome, but it could also be upsetting. You may be excited to discover unknown relatives, but that could create family stress and financial issues. You could also learn that your origins are not what you thought, or that you are not biologically related to someone you thought you were, or that you're at risk of a serious health problem. Some DTC genetic testing companies offer advice about unexpected results, but not all do. You can find organizations online that provide suggestions for handling these situations.

#### 4. Will you get historical information about your ancestors?

Based on some ads for DTC genetic testing services, you may assume that you'll be able to learn where your ancestors lived, their occupations, and other details about their lives. Access to census records, birth and death records, immigration records, newspaper articles, military records and other historical information is not included in the basic ancestry services, however. If the company offers this information, it is an upgrade or a separate service, for an extra charge. You may have access to additional information about your ancestors posted by other people. But you may have to go to more expense, and do a lot more work yourself, to get a more complete picture of your ancestors.

#### 5. What action should you take based on the results of health-related DTC genetic tests?

These tests are *not* intended to diagnose or treat health conditions. The information they produce is an *estimate* based on the data the company has about how your genes link to health conditions. It's also important to know that these tests can produce false positives or false negatives, and they can't predict health risks with absolute certainty because your environment and lifestyle can also affect your health. Always check with your doctor before taking any action based on DTC genetic health tests.

## 6. What should you do if the testing company asks you to participate in research?

DTC genetic testing companies may conduct their own research or work with research partners for scientific or historical purposes. Research provides the companies with more data to work with, which can make the information they provide to customers more accurate, and they may also make money from research projects. Participation is strictly voluntary and you'll be asked to sign a separate agreement for it. While research may benefit you and others, there are risks, including data breaches, being identified even if you are "anonymous," and receiving results that may be unexpected or uncomfortable.

# 7. Will the company try to sell you other products or services?

Once you become a customer, you'll likely receive offers from the company for expanded ancestry services, information about personal "traits," health-related tests, access to historical records, personalized books, and even genetic tests for pets. Some offers may be for "free trials" – for instance, to access historical information for a certain period of time at no charge. Before you sign up, look for details about how much the service will cost if you continue to use it after the trial period ends and when you must let the company know if you don't plan to continue to avoid being charged. Offers may come by email or phone, or pop up in your portal on the company's website. You may have controls in your settings to control emails, and by law you always have the right to stop receiving marketing emails and calls.

# 8. Will the company share your personal information with others?

The company may use your personal information for its own marketing and share it with other companies. It may ask for your consent to use or share particularly sensitive data, such as your genetic information. Law enforcement may be able to get your data, including genetic information, from the company under certain circumstances. The company may also allow invisible trackers on its website to collect information about what you do there and elsewhere on the internet (though they can't see the information in your password-protected portal) for advertising and other purposes. Check with your state oi local consumer agency about any privacy rights that apply, and read DTC testing genetic companies' privacy policies carefully before buying their services.

# 9. What other privacy issues should you consider with DTC genetic testing?

You can control what other customers can see about you and how they can communicate with you on the company's website. If you use social media in connection with the service, be sure your settings on the social media platform don't allow the genetic testing company to collect your personal information. Take care if you post or share information with others, or upload your genetic data to another website, since once it's out there you may not be able to retrieve it. Be aware that if you close your genetic testing account, you may need to take a separate step to request that your genetic sample be destroyed, and the company may still keep some information about you if necessary for legal purposes.