

Sponsored Genetic Testing Patient FAQs

What Do You Need to Know?

Your doctor may have recommended sponsored genetic testing, a form of genetic testing that involves a third party (usually a biopharmaceutical research company) who sponsors (ie, pays for) a patient to receive a genetic test. Unlike insurance- or patient-billed genetic testing, sponsored genetic testing is paid for by a third party biopharmaceutical research company. As you decide whether sponsored genetic testing is the best option for you, here is some general information about sponsored genetic testing followed by a checklist of questions to discuss with your doctor:

What is the Financial Cost of Sponsored Genetic Testing?

The sponsored genetic test itself has no billable costs to the patient. However, you may still be responsible for services such as the following:

- Clinical evaluation
- Genetic counseling
- Phlebotomy (blood draw)
- Specimen send out services

Who Pays for Sponsored Genetic Testing?

Typically, a third-party biopharmaceutical company (also known as the sponsor) pays for the genetic testing. However, there may be other billable expenses (see “What Is the Financial Cost of Sponsored Genetic Testing?” above).

What Sponsored Genetic Tests Are Available?

Availability of sponsored genetic tests depends on the needs of the sponsoring biopharmaceutical company. This means the genetic test your doctors feels is appropriate for you may not be available as a sponsored genetic test.

What Do the Sponsors Get from You?

Sponsors will gain access to the genetic data that result from the genetic test they sponsored. When you pay for genetic testing out-of-pocket or through insurance, you can choose to opt out of sharing certain data. However, when you choose sponsored genetic testing, you cannot opt out of data sharing. The type of genetic data, how data are shared, and with whom will vary according to the specific sponsored genetic testing program.

Why Does the Sponsor Want My Genetic Information?

Specific use of your genetic data will vary. In most cases it is unclear what the sponsoring biopharmaceutical company will be doing with the information they receive. Possible uses include research to develop therapeutics (ie, medical treatments) and identifying providers with patients in their care needing follow-up.

Will This Testing Help Other People?

Your participation in sponsored genetic testing will not directly help other patients. However, the lab or sponsor may contact you with additional research opportunities.

What Are Alternatives to Sponsored Genetic Testing?

- Laboratory assistance program: If you financially qualify, the program may provide genetic testing at reduced and sometimes no cost
- Patient Pay: You cover the entire cost of the test
- Insurance: Your insurance covers some or all of the test
- Medicare or Medicaid: Some laboratories have specific Medicare or Medicaid billing policies, which result in a reduced cost to you

Checklist of Points to Consider, Prepare for, and Discuss with Your Provider during Pre-Test Counseling

- What genes does my doctor want to test and what genes does the sponsored genetic test include?
- Will the sponsored genetic test give me results beyond the genes my doctor wants to test? If the answer is yes, what information might those extra genes tell me? Is there some information I would not want to know?
- If privacy is important to me, how will data be secured? With whom will data be shared? What data will be shared? How will data be used? Will any data be identifiable?
- If my primary care provider (instead of a geneticist or genetic counselor) is ordering the sponsored genetic test, does the sponsoring company offer pre- or post-test genetic counseling for free or at a reduced cost in case my sponsored genetic testing results need to be interpreted by a specialist?
- Do my doctor and I have a plan if the sponsored genetic test does not yield a significant finding?
- Do my doctor and I have a plan if the sponsored genetic test yields a variant of unknown significance?