

# Sponsored Genetic Testing Provider FAQs

## What Do Patients Need to Know?

Sponsored Genetic Testing is 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.

## What Is the Financial Cost of Sponsored Genetic Testing?

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

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

## Who Pays 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 you feel is appropriate for the patient may not be available as a sponsored genetic test.

## What Do the Sponsors Get from Your Patient?

Sponsors will gain access to the genetic data that result from the genetic test they sponsored. When a patient pays for genetic testing out-of-pocket or through insurance, they can choose to opt out of sharing certain data. However, when a patient chooses sponsored genetic testing, they 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.

## How Does Ordering Sponsored Genetic Testing Impact Providers?

The lab and sponsor may gather your contact information and seek your assistance in recruiting patients to participate in a registry or clinical trial. This may require you to obtain institutional review board approval if you accept a formal recruiting role in the research.

## Why Does the Sponsor Want My Patient’s Genetic Information?

Specific use of your patient’s 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 interesting patients in their care for future follow-up.

## **Will This Testing Help Other People?**

Your patient's participation in sponsored genetic testing will not directly help other patients. However, the lab or sponsor may contact you with additional research opportunities that you can share with your patient(s).

## **What Are Alternatives to Sponsored Genetic Testing?**

- Laboratory assistance program: If a patient financially qualifies, the program may provide genetic testing at reduced and sometimes no cost
- Patient Pay: The patient covers the entire cost of the test
- Insurance: The patient's 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 the patient

## **Checklist of Points Providers Should Think About, Prepare for, and Discuss with Patients in Pre-Test Counseling Before Ordering Sponsored Genetic Testing**

- Data privacy: 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?
- What genes you want to test and what genes the sponsored genetic test includes
- The sponsored genetic test may yield results in genes beyond the genes you are concerned about
- Does the sponsoring company offer pre- or post-test genetic counseling for free or at a reduced cost
- Plan for arranging testing other clinically relevant genes should the sponsored genetic test yield nothing significant
- Plan for next step in management should the sponsored genetic test yield a significant finding
- Plan next steps in management should the sponsored genetic test yield a variant of unknown significance