

What is genetic research?

Genes are part of every cell in every person. Genes come in pairs and are made of DNA. Genes carry instructions that tell the body how to grow and develop. We share some genes with our blood relatives.

Genetic researchers often use blood or saliva samples to look at DNA. Genetic researchers are interested in how genes affect the way our bodies work.

Researchers try to understand:

- If our genes make us more or less likely to get a certain disease or condition
- How to prevent or treat a disease or condition
- How genes affect a body's response to drugs or treatments

Who takes part in genetic research?

- Adults and children
- People with a disease or condition
- Family members
- Healthy volunteers

This brochure contains general information for educational purposes and is not intended to provide medical advice. Talk with your doctor or research team before acting on any information contained herein for advice specific to your situation.

Questions to ask

1. What is the purpose of the study?
2. How will you collect my genetic sample?
3. Will I, or anyone else, receive results from this study?
4. What happens if the tests reveal a medical issue?
5. Will the test results become part of my medical record?
6. Will the genetic testing impact my family?
7. Will test results impact my health insurance coverage in the future?
8. Will my samples or genetic information be used for future research? If so, will I need to give my consent?
9. Will my samples or genetic information be shared with any other researchers?
10. If I choose not to take part in future studies, can I be a part of the current study?



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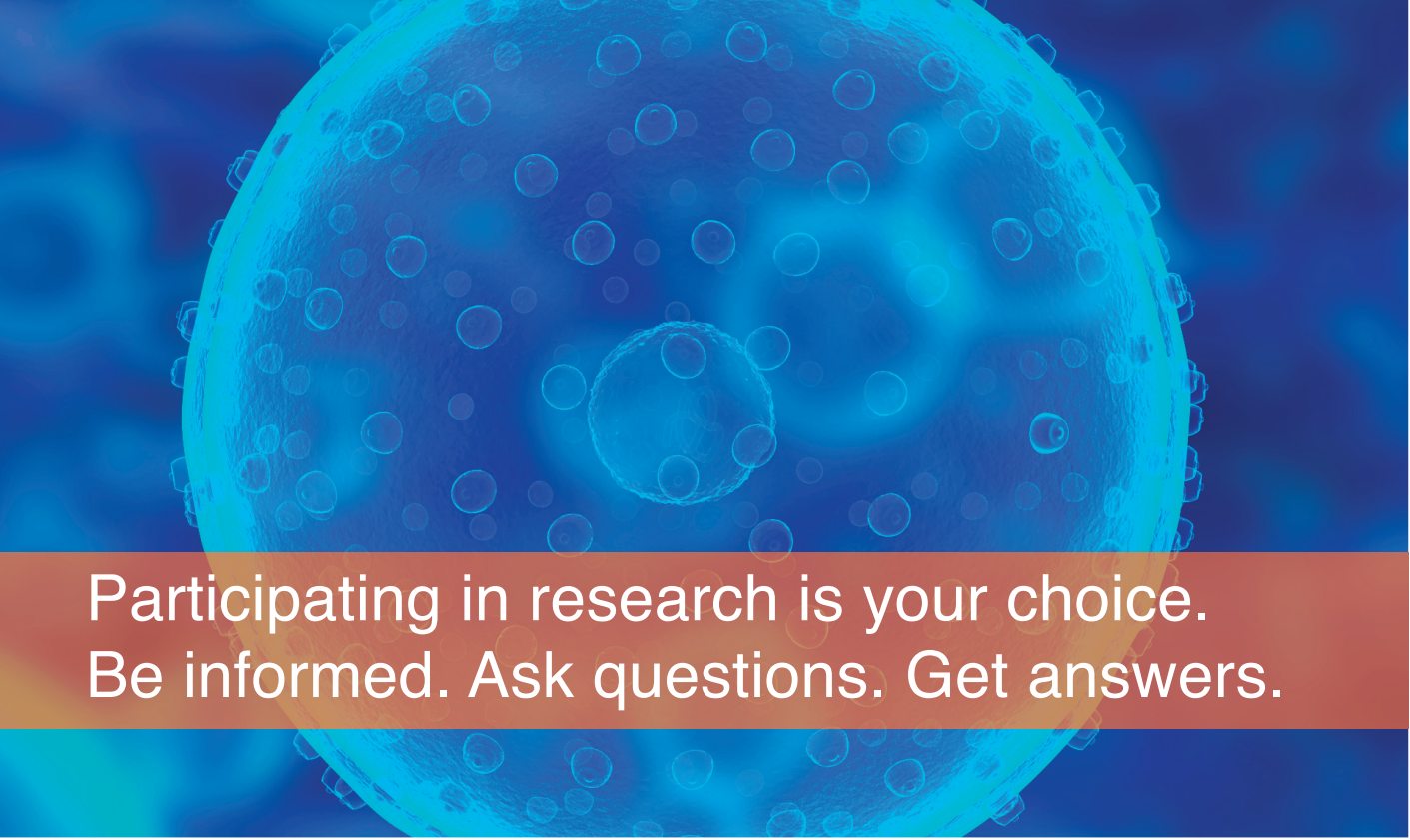
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More questions?

Call:



Genetic Research



**Participating in research is your choice.
Be informed. Ask questions. Get answers.**

What does it mean to take part in genetic research?

If you have genetic testing as part of your regular medical care, your doctor is usually trying to check your health or diagnose a problem. In this case, you and your doctor would discuss your test results together.

In research, genetic testing is used to help answer a scientific question. It is not intended to provide you medical care or detect health problems.

When you participate in genetic research, the research team might not share the results of your tests with you. Depending on the research, the results of genetic research testing may or may not provide information about your overall health.

What are my rights and protections?

Protections are in place to help assure the safety of research volunteers (also called “research subjects”) and ensure volunteers are treated with respect.

The research team will go over an Informed Consent Form with you. They will explain the study’s goals, procedures, and possible risks and benefits. A geneticist or genetic counselor may be available to talk with you about the pros and cons.

Ask for help if you don’t understand something. You should never feel rushed or pressured.

What are the risks of taking part in genetic research?

The process of collecting genetic samples is considered to be safe and relatively painless. However, deciding whether to participate in a genetic research study is a personal decision.

Receiving your test results may be stressful or upsetting to you or your family. For example, tests might reveal:

- You have, or may develop, a certain disease or an untreatable condition
- Unexpected information about your family’s genes
- That your family members may be at risk of a particular disease or condition

A researcher may notice something that he or she was not looking for—this is called an incidental finding. Ask the research team what kinds of findings will be shared with you and how this might impact you.

There is a risk your private information could accidentally be shared with others. The Genetic Information Nondiscrimination Act (GINA) protects you from unfair treatment by health insurers or employers because of differences in your DNA that may affect your health. However, the law does not cover all types of insurance.

Specific risks will be described in the Informed Consent Form. Make sure you understand the risks before agreeing to participate in a study.