

## Participating in research is a choice

Joining a research study is an important personal decision. Before you join, researchers will talk with you about the goals of the study and possible risks and benefits. They will also explain the rules they follow to protect your safety and privacy. Ask for help if you don't understand something or have questions.

You should never feel rushed or pressured to make a decision. Being part of a research study is completely voluntary - it's your choice.

After you understand the study, if you decide to take part you will be asked to sign a document called an "informed consent form." You can change your mind at any time, for any reason, even after you sign.

### Questions to ask

You have a right to ask questions about genetic research before you decide whether to take part in a research study.

You may want to ask the following questions:

- > What is the purpose of the study?
- > How will you collect my genetic sample(s)?
- > Will I receive results from this study?
- > What happens if the tests reveal a medical issue?
- > Will the test results become part of my medical record?
- > Will the genetic testing impact my family?
- > Will test results impact my health insurance coverage in the future?
- > Will my samples or genetic information be used for future research? If so, will I need to give my consent?
- > Will my samples or genetic information be shared with any other researchers?

## GENETIC RESEARCH



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

Genes are part of every cell; they are made of DNA and come in pairs. Genetic researchers often use blood or saliva samples to look at DNA, and they are interested in how genes affect the way our bodies work.



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Questions? Call us at



## What is genetic research?

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

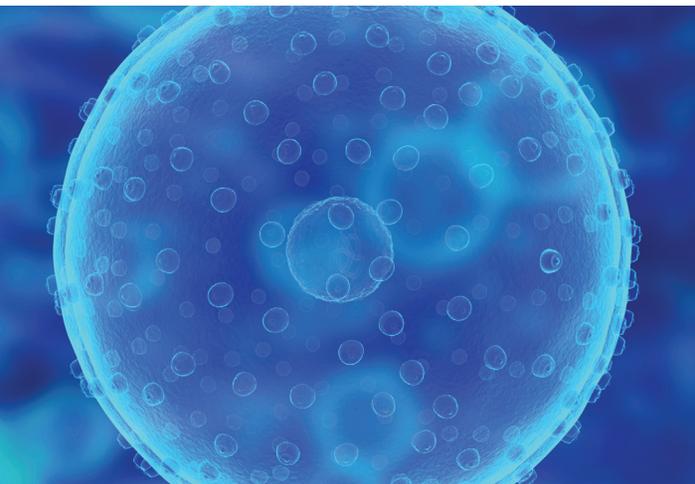
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## Researchers try to understand:

- > If our genes make us more or less likely to have 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



## 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 the 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 participants”) and ensure volunteers are treated with respect. The research team will go over a document called 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 of participating in genetic research.

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

- > You have, or may develop, a certain disease or an untreatable condition
- > Unexpected information about your family’s genes
- > That you 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.

The informed consent form for your study will describe any specific risks. Make sure you understand these risks before you agree to take part.