

Visiting The Rockefeller University Hospital



What does it mean to take part in genetic research?

If you have genetic testing as part of your regular medical care, that testing is intended to help improve your health or diagnose a problem, and your doctor will discuss your test results with you.

In contrast, in research, genetic testing is used to help answer a scientific question. It is not primarily intended to provide you medical care or detect health problems. When you participate in genetic research, the research team may or may not share the results of the tests with you. Depending on the research, the results of genetic research testing may or may not provide information about your own health.

What are my rights and protections?

A number of procedures are in place to help assure the rights and safety of research volunteers. 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. You are free to join the research, or to decline participation. A geneticist or genetic counselor may be available to talk with you about the pros and cons of participating.

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

The Rockefeller University's main entrance is 1230 York Avenue (at East 66th Street) on Manhattan's Upper East Side. The university shares the intersection of York Avenue and East 68th Street with Memorial Sloan Kettering Cancer Center, NewYork-Presbyterian Hospital, and Weill Cornell Medicine.

PUBLIC TRANSPORTATION

Buses: Take the M31 to 66th Street or the M66 to York Avenue. Both buses stop near our main entrance.

Subway: Take the 6 train to 68th Street/Hunter College or the F to Lexington Avenue/63rd Street. We are located a half-mile from the subway stops.

Car: Exit the FDR Drive at 61st Street (northbound) or 63rd Street (southbound).

Parking: Use Greenberg garage at NewYork-Presbyterian Hospital (entrance at 68th Street, east of York Avenue) or Quik Park at 403 East 65th Street (between York and First Avenues).

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THE ROCKEFELLER UNIVERSITY HOSPITAL

CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE

Genetic Research

at The Rockefeller University
Hospital and Center for Clinical
and Translational Science

DISCOVERIES ADVANCING MEDICINE



What is genetic research?

Genes are part of almost every cell in every person. They are made of DNA and carry instructions that tell the body how to grow and develop. Genes usually come in pairs consisting of a copy from your mother and one from your father. This is why we share some genes with our blood relatives.

In genetic research, investigators often use samples of blood, saliva, or skin to study DNA. Genetic researchers are interested in how genes affect the way our bodies work.

Researchers try to understand:

- Whether variations in 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
- How genes work in health

Who takes part in genetic research?

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

Questions to ask

1. What is the purpose of the study?
2. Why perform a genetic analysis?
3. How will you collect my genetic samples?
4. What will you look for in my genetic information?
5. What type of genetic testing will be performed?
6. Will you also want to test members of my family?
7. How reliable is the genetic testing?
8. What happens if the tests reveal a medical issue?
9. What if you find something that you did not expect?
10. Will I receive results from this study? Will anyone else?
11. Will the test results become part of my medical record?
12. How do you protect the confidentiality and security of the information in the genetic material?
13. Will test results impact my health insurance coverage in the future?
14. Will my DNA sequencing data be shared with other researchers?
15. Will my samples be used for future research? If so, will I need to give my consent?
16. What impact might my participation in the study have on my family planning and on members of my family?

What are the risks of taking part in genetic research?

The process of collecting genetic samples is 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

Ask the research team what kinds of findings will be shared with you and how this might impact you.

There is a risk that your private information could accidentally be shared with others. The Genetic Information Nondiscrimination Act of 2008 (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.



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