What is the ClinSeq study about?

The main goal of ClinSeq is to learn how to do genome sequencing in a clinical research setting. Genome sequencing is a research test that allows us to analyze many genes from a person. By doing this test, we may find changes in a gene that cause or contribute to disease. So people who decide to participate in this study may learn about changes in a gene that have already caused them to have signs and symptoms of a disease. They may also learn about changes in a gene that may cause them to have signs and symptoms of a disease in the future. For example, we may find a change in a gene that predisposes a person to have high cholesterol.

In the beginning of the study, we will focus on heart disease. So we will be analyzing some genes that we know are involved in heart disease, and some genes that we think are involved in heart disease. Later in the study, we hope to expand our focus to other conditions and genes. It is important for you to know that we are looking for participants who are willing to interact with us over a period of years.

ClinSeq™

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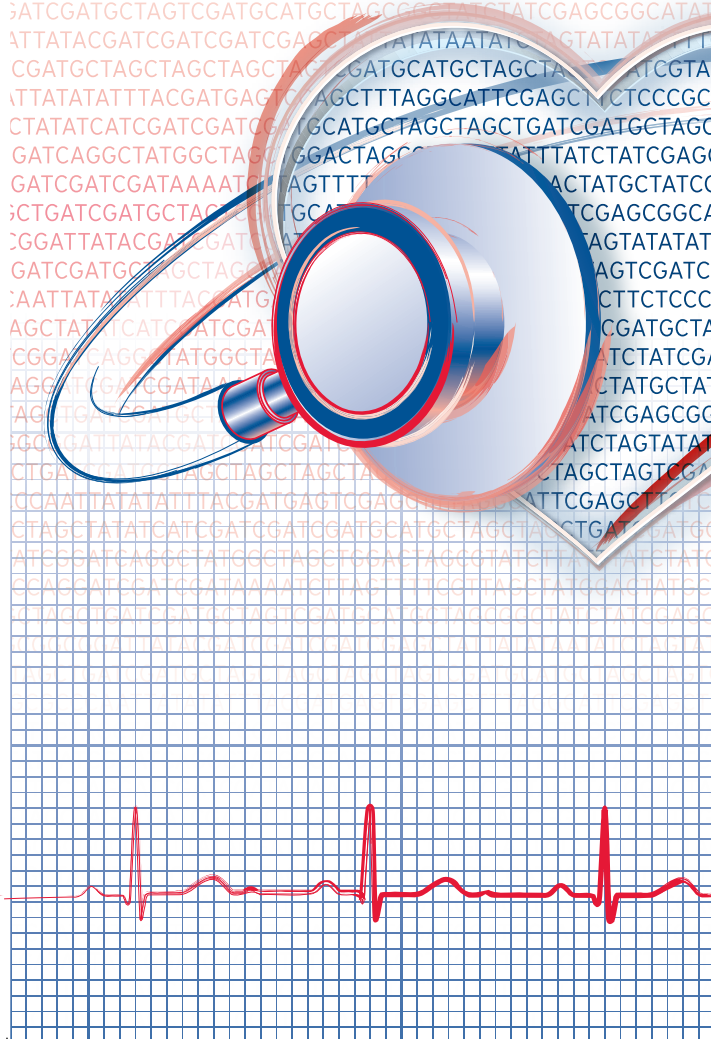
ClinSeq is a collaborative NIH study supported by the National Human Genome Research Institute, the NIH Intramural Sequencing Center, the National Heart, Lung, and Blood Institute, and the NIH Clinical Research Center

Thank you very much for your time and interest!

The ClinSeq Research Team

ClinSeq™

Large-Scale Medical Sequencing Research Study



Can I participate?

If you are between 45 and 65 years old…
AND have NOT smoked regularly in the past year…
AND have a primary care physician…

…You may be eligible to participate in the study.

What is involved in the study?

Participation in ClinSeq will involve an initial visit to the National Institutes of Health in Bethesda, Maryland. During this visit, you will learn more about the study and sign a consent form if you decide to participate. You will undergo a series of tests and evaluations, including blood tests, urine tests, blood pressure measurements, an echocardiogram, and an EKG. During this visit or at a later visit, you may also have a CAT scan of your coronary artery. After these visits, you will receive a letter summarizing the results of all these tests.

Then, over the course of the coming years, we may ask you to return for follow-up visits for different reasons. For example, if we find a change in a gene that we think may cause or contribute to a disease, we will ask you to return in case you want to learn about that change and what it means for your health. Another example is if we decide to do other clinical tests to understand gene changes we find in a group of participants.

What are the possible benefits of joining the study?

- Free clinical testing, such as testing for cholesterol and diabetes;
- Free CAT scan to detect coronary artery disease;
- Finding gene change(s) that are important to your health and/or the health of your relatives.

What are the possible risks of joining the study?

- Physical risks, such as pain or bruising as a result of the blood draw and radiation exposure during the CAT scan. These risks tend to be very rare or minor.
- Emotional and psychological risks, such as becoming upset when learning that one has a gene variation that may cause or contribute to a disease.

What is the cost of the study?

The visits and all tests are free of charge. There is no cost to you or your health insurance company for this study.

Will I get paid for joining the study?

No, you will not be paid for participating in the study.

How can I learn more about the study?

You can learn more about the study by reading the information on the following website http://www.genome.gov/ClinSeq. You may also call the ClinSeq research study assistant at (301) 443-6160 to ask questions about it.

How do I enroll?

You can call the ClinSeq research study assistant at (301) 443-6160. She or he will make sure you are eligible, tell you more information about the initial visit, and help you get your initial visit scheduled for a day that is convenient for you.

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