

**University of North Carolina at Chapel Hill
Assent to Participate in a Research Study
Adolescent Participants age 7-14- Relatives of a Study Subject**

Consent Form Version Date: 12-04-2014
IRB Study # 11-1865

Title of Study: NCGENES: A Next-Generation Sequencing Platform for Genetic Diagnosis and Research

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Funding Source and/or Sponsor: UNC Chapel Hill, National Human Genome Research Institute at the National Institutes of Health

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What are some general things you should know about research studies?

The people named above are doing a research study.

These are some things we want you to know about research studies:

Your parent needs to give permission for you to be in this study. You do not have to be in this study if you don't want to, even if your parent has already given permission.

You may stop being in the study at any time. If you decide to stop, no one will be angry or upset with you.

Sometimes good things happen to people who take part in studies, and sometimes things we may not like happen. We will tell you more about these things below.

Why are they doing this research study?

Our bodies contain genes, which are the body's instructions for how to grow and develop. Sometimes mistakes in the genes cause health problems. Genetic tests help us look for mistakes in the genes.

Scientists have come up with a new way of doing genetic tests that is called Whole Exome Sequencing (WES). The reason for doing this research is to find out how good WES is at finding

mistakes in the genes compared to older ways of doing genetic tests.

Why are you being asked to be in this research study?

You have a relative who is part of a study at UNC called NCGENES. They had a genetic test as part of the study. Their genetic test found a change in one of their genes. We don't know enough about this change to know if it causes any health problems or not.

Sometimes testing a person's family members helps us learn if a genetic change causes health problems or not. You are being asked to be in this research study to see if you share the same genetic change as your family member. This may help us learn more about the change.

How long will your part in this study take?

Your part in this study will probably take less than one hour.

What will happen during this study?

During this study:

You will need to give a sample of your blood. We need about 2 teaspoons of blood (1 tube)

Your name will not be on the tube. Instead the tube will have a special ID number. The connection between the number and your name and birthday will be in a computer. Only a few people on the research team will be able to find out this connection.

We will use your blood sample to find out if you share the same genetic change as your relative. This is called genetic testing.

When your genetic test is done, we will tell your parent whether or not you have the genetic change..

What are the good things that might happen?

People may have good things happen to them because they are in research studies. These are called "benefits." There is a small chance you will have any benefits from being in this study.

What are the bad things that might happen?

Sometimes things happen to people in research studies that may make them feel bad. These are called "risks." These are the risks of this study:

We need a sample of your blood for the study. We will need to poke your arm with a needle to get the blood. This can make a bruise and may hurt a little for a minute.

Sometimes learning more about your health can make you sad or worry. Your genetic counselor, doctor and family will help explain what this test means for you.

Not all of these things may happen to you. None of them may happen or things may happen that the researchers don't know about. You should report any problems to the researchers.

Will you get any money or gifts for being in this research study?

You will not receive any money or gifts for being in this research study.

Who should you ask if you have any questions?

If you have questions you should ask the people listed on the first page of this form. If you have other questions, complaints or concerns about your rights while you are in this research study you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

If you sign your name below, it means that you agree to take part in this research study.

Sign your name here if you want to be in the study

Date

Print your name here if you want to be in the study

Signature of Research Team Member Obtaining Assent

Date

Printed Name of Research Team Member Obtaining Assent