

RESEARCH ASSENT FORM
For Minor Participants Ages 7-17
(Online Form)

TITLE: Global A-T Family Data Platform

PROTOCOL NO.: NB200088

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**STUDY-RELATED
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What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

Important things to know...

- You get to decide if you want to take part.
- You can say "No" or you can say "Yes."
- No one will be upset if you say "No."
- If you say "Yes," you can always say "No" later.
- You can say "No" anytime.
- Your doctor will still take good care of you no matter what you decide.

You do not have to be in the study if you don't want to.

You can ask the researcher's questions before you make up your mind. You can also talk to your mom or dad or anyone you want to about the study. You can ask to read the information the doctor gives your mom or dad about this study.

Why are we doing this research?

We are doing this research to find out more about your health issues so doctors and scientists may find ways to make medicines to treat it.

What would happen if I join this research?

If you decide to be in the research, we would ask you to do the following:

- Questions: We would ask you to read questions, then you would mark your answers on the paper.
- If you agree, your doctor could send information about your health to the people doing the research.

- Spit in a tube: If you agree, we would ask you to spit in a tube and send it to us. This may help doctors and scientists learn about why your body has specific health issues.

If you do not want to do any of these things, you can say you do not want to be in the study.

The people doing this research want to use your spit to look at your genes. Genes are things in your body that make you different from anyone else. Genes are often called “DNA.” Some genes control things like the color of your hair or eyes. Other genes might make you more likely to get certain health issues.

Some researchers want to look at your spit to learn more about your health issues. This is called a “genetics research study.”

The researchers want to know if it is okay to run some tests on the genes in your spit. The researchers might also do more testing on your genes in the future. You can say “Yes” or “No” to this.

Right now, the people doing the research cannot tell you the results of testing on your genes. But this could be possible in the future. You can say whether or not you would like to get the results in the future.

Could bad things happen if I join this research?

Some of the tests might make you uncomfortable or the questions might be hard to answer. We will try to make sure that no bad things happen.

You can say “No” to what we ask you to do for the research at any time and we will stop.

What researchers find out about your genes is private. But if the results of the gene tests got into the wrong hands, some of your privacy may be lost. Genes can tell a lot about you and your health. The people doing this study will try to make sure that only people involved with the study find out anything about your genes.

Be aware that what researchers learn about your genes may also show things about the genes of people in your family.

Could this research help me?

This research is not likely to help you. We do hope to learn something from this research though. And someday we hope it will help other kids who have health issues like you do.

What else should I know about this research?

If you don’t want to be in the study, you don’t have to be.

It is also OK to say yes and change your mind later. You can stop being in this research at any time. If you want to stop, please tell the study staff.

You will not be paid to be in this study. It will not cost you or your parents if you participate in this study.

By participating, you understand that there may be laws in your country that we do not know about, but you are volunteering to provide your information for the sake of research.

Who can I talk to about this study?

You can ask questions about this study at any time. You can call the researcher at any time. The researcher's phone number is on the first page.

If you want to ask questions about what it means to be in a research study, you or your mom or dad can email North Star Review Board at info@northstarreviewboard.org.

Is there anything else?

If you want to be in this research, please write your name below. This shows you understand what we explained about this research and that you want to take part. But remember: You don't have to be in this study if you don't want to.

You can say "Yes" or "No" to parts of this research. Please mark "Yes" or "No" below. If you say "No" to some things, you can still be in this study.

YES **NO**

☐ ☐ Study staff can contact me later with more questions or information about future research. I do not have to answer these questions or take part in future research.

☐ ☐ Study staff can do tests on the genes in my spit.

☐ ☐ Study staff may ask my doctor or hospital to share information about my health.

☐ ☐ Later, it might be possible to get the results of the tests on my genes. Please let me know if this becomes possible.

☐ ☐ If the researchers learn something about my health issues by testing my genes, please tell my doctor about this.

Name of Child (Print)

Date of Birth

Date

I attest that the participant named above had enough time to consider this information, had an opportunity to ask questions, and voluntarily agreed to be in this study.

Name of Person Explaining Assent (Print)

Date