



Assent to Participate in a Research Study Genetic Analysis

Study Title:

Molecular and Genomic Analysis of Autism Spectrum Disorder and Related Conditions

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Study Sponsor or Funder:

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What is a research study?

A research study is a way to find out new information about something. You do not need to be in a research study if you don't want to.

Why am I being asked to be a part of this research study?

You are being asked to take part in this research study because we are trying to learn more about autism and similar conditions. We are trying to find out why some children have autism and some children do not. We are looking for differences in the genes of children who have autism to see if these differences could be causing autism. We know that autism may be passed down in some families. We are asking you to be in the study because you or someone in your family has autism or a similar condition.

If I join the study what will happen?

If you decide to be in the study

- We will use a needle to take some blood from your arm one time.
- We will collect some information about you. For example, we will get information about your health, your family and your development by asking your mother/ father/ guardian to fill out some forms or by looking at your medical file at SickKids and other hospitals.
- We may do some tests that will help us to understand how you communicate and learn.

Will any part of the study hurt?

When we take blood from your arm, it may hurt a little bit, but it will not last long. If you would like, we do have some cream that you can put on that will help you not feel the needle. There may be a small bruise afterwards, but it will disappear in a few days.

Will the study help me?

We don't know if being in this study will help you. We may learn why you or someone in your family has autism or a similar condition. This may help doctors know how to take care of you better.

Will the study help other people?

This study might find out things that will help other children with autism or similar conditions someday.

Do I have to be in the study?

You do not have to be in the study. It's up to you. No one will be angry or upset if you don't want to do this study. If you join the study, you can change your mind and stop being part of it at any time. All you have to do is tell us, nobody will be upset.

Do my parents/guardian know about this study?

This study was explained to your parents/guardian and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about me?

The information collected about you during this study will be kept safely locked up. The study information about you will be given to your parents. Nobody else will know it except the people doing the research. The researchers will not tell your friends or anyone else.

What if I have questions?

You can ask any questions you want about the study. If you think of a question later, you can call or have your parents call Barbara Kellam at 416-813-7654 x301289.

Assent (for the study team to complete):

I have discussed this research study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assent to participate in this study.

Person obtaining assent

Signature

Date (DD/MMM/YYYY)