

Participant name:

DOB:

HSC#:

ASSENT FORM

Genetic diagnosis associated with an increased risk for autism

Title of Study

Molecular and Genomic Analysis of Autism Spectrum and Associated Neurodevelopmental Disorders

Investigator(s)

STEVE SCHERER; (416) 813-7613
JOHN VINCENT; (416) 535-8501 X6487
WENDY ROBERTS; (416) 813-8748
JESSICA BRIAN; (416) 813-8748
PETER SZATMARI; (905) 521- 2100 X77367
BRIDGET FERNANDEZ; (709) 777-4363
ROSANNA WEKSBERG; (416) 813-6386
ANDREW PATERSON; (416) 813-6994
ERIC FOMBONNE; (514) 412-4400 X22174
LONNIE ZWAIGENBAUM; (780) 735-8280
EVDOKIA ANAGNOSTOU; (416) 753-6005
PAUL ARNOLD; (416) 813-2483
RUSSELL SCHACHAR; (416) 813-6564
ANNE BASSETT; (416) 535-8501 X2732
IRENE DRMIC; (416) 813-8748
CHERYL CYTRYNBAUM; (416) 813-5334
MARC WOODBURY-SMITH; (905) 521-2100 X73504
WILLIAM MAHONEY; (905) 521-2100 X77605
ROB NICOLSON; (519) 685-8427

Why are we doing this study?

Right now we don't know why some children have autism spectrum and/or associated neurodevelopmental disorders. We think that autism spectrum and/or associated neurodevelopmental disorders may be passed down in some families. We are asking you to participate in our research on autism, even though you don't have a diagnosis of autism. By studying children with autism spectrum and/or associated neurodevelopmental disorders and their families, we hope we can find out what the causes are. This will help us better understand autism spectrum disorders and how to treat it.

What will happen during the study?

1. We will go to the hospital or ask you to go to a clinic where there will be a needle prick that might hurt a little bit. 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.

2. You will talk with doctors and people working at the Autism Research Unit about you and your family. You may do some tests that will help us to understand how you communicate and learn.

Are there good things and bad things about this study?

We think the study will help doctors understand people with autism spectrum disorders. This will help with knowing how to treat it better. We do not think that there are any bad things. If there are possible worries for you about anything we find out, we will explain these carefully to you and your family and help you avoid any problems as much as possible.

Who will know what I did in the study?

Your name and address will not be given to anyone. This form will be in your hospital chart. Important results will be put in the chart. Doctors looking after you would then know that you were in the study. This will be important if they need to know something that will help you.

If we feel your health may be in danger, we may have to report your results to your doctor.

Can I decide if I want to be in the study?

If you do not want to be a part of the study, that is okay. Nobody will be angry or upset if you do not want to be in the study. We are talking to your parent/legal guardians about the study and you should talk to them about it too. Ask them any questions if you do not understand what you have read or heard. They will also help you to understand. If you say yes now but change your mind later, you can say no to the doctor or nurse, and that will be okay. Please ask the doctor or nurse any questions you may have. They will also help you to understand.

Assent:

I was present when _____ read this form (or had it read to him/her) and gave his/her verbal assent.

Name of person who obtained assent

Signature

Date