

Participant name:

DOB:

HSC #:

## Assent Form (Child)

- Title of Study

Analysis of Candidate Genes on Chromosome 7 in Infantile Spasm and Seizure Disorders

- Investigator(s)

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You are being asked to take part in a research study. This form may contain words that you do not understand. Please ask the staff or your parents or guardian to explain any words or information that you do not clearly understand.

In order to be part of this study, you and your parent (or legal guardian) must listen to someone explain the information about this study, and you should ask any questions that you have. Then, in order for you to start the study, your parent or legal guardian must agree, in writing, that you will take part. Also, we are asking you to agree to take part, and you can do this by signing this form at the end of these sheets. If you decide to take part in this study and then change your mind later on, you may choose to stop at any time.

- Why are we doing this study?

We hope to use this study to find genes on chromosome 7 that cause infantile spasms or seizure disorders. We have narrowed such a gene to a small region on the seventh chromosome, and now we will search for changes in genes from within this region, in children who have experienced spasms or seizures. We hope to identify a gene that is causing the seizures. If we do find the gene, it may give us new information about why seizures happen which, in the coming years, may help with both early identification of babies with infantile spasms and the design of new kinds of treatments.

- What will happen during the study?

You will come to SickKids hospital with your parents for your usual visit to the Neurology clinic. You may already have a stored genetic sample (DNA) at SickKids. If you do, we can use this sample for the study.

If you do not already have a genetic sample stored at SickKids, then we will ask you to give a small blood sample (1-2 tablespoons) the next time you are having blood taken for medical reasons. The blood will be taken from you by a trained person during a usual visit to the clinic.

Your blood sample or DNA sample will be used to look at genes on the seventh chromosome.

• Are there good things and bad things about the study?

You may feel discomfort during the blood drawing, but the doctor will try to minimize it using a numbing cream. Sometimes a small amount of bruising occurs around the area where the needle went in, and very rarely you can have some swelling and pain around this area.

• Who will know about what I did in the study?

If you are part of this study, your name and address will not be given to anyone. Only your parents and the people who are directly involved with the study will know that you took part. 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?

It is up to you to decide if you want to be in the study. You do not have to be part of this study. Nobody will be angry or upset if you do not want to be in the study. Your mother or father is also reading some information about the study. They will talk to you about it. Ask them questions if you do not understand what you have heard or read and they will help you understand. You can also ask the people who work in the study any questions that you might have. We will also help you to understand.

**Assent:**

"I was present when \_\_\_\_\_ read this form and said that he or she agreed, or assented, to take part in this study".

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Printed Name of person who obtained assent

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Signature & Date