



PARTICIPANT ASSENT FORM
(generally for children aged 7-13 years)

DIAGNOSIS OF GENETIC CONDITIONS IN INDIGENOUS FAMILIES

1. Invitation

I am being invited to take part in this research study because I have a health condition that is thought to be genetic. Genetic conditions occur in all groups of people, but only Indigenous families are being invited into this study.

This form explains the study so that I can decide if I want to take part in it. No one will make me be part of the study, and no one will get mad at me if I don't want to be in it.

2. Why are we doing this study?

The doctors invited me to be in the study because I have a health condition that the doctors don't fully understand. The point of this study is to try to find the reason for my condition. This study will check if my condition is caused by changes in genes. **Genes** are the instructions we are all born with, that tell our bodies how to work. Genes are made up of letters which make 'words' (similar to a book) that tell the body what to do. If there is a spelling mistake in a gene (called a '**gene change**'), the words in the instructions might get messed-up, and a health problem could happen.

3. What will happen to me in this study?

If I agree to take part in this study, I will be asked to do some of the steps below. Each family is a little different, so not everybody will do the exact same steps. The study doctors will let me know which steps to expect before I sign this form.

Meeting with the study genetic counsellor

The first step is meeting with the study genetic counsellor, who will explain the study to me and answer any questions I may have.

A blood test

I will be asked to give a small blood sample so that my genes can be tested. About 1 teaspoon of blood will be taken from a vein in my arm using a needle. The doctors know that this can be scary and it can feel like a prick. I can ask for a spray or cream on my skin before the test to numb the skin so it doesn't hurt.

In some cases, a saliva (spit) sample or cheek swab (wiping the inside of the mouth) may be done instead of a blood sample.

Photographs

The doctors and their team may want to take pictures of me with a camera. Sometimes it is easier to take a photo than to describe things in writing. If photos are taken of me, they will not be used for anything other than this study and will not be shared with others without my permission.

Additional tests

Sometimes the study doctors wish to collect other samples to help understand the condition. Examples include hair sample, skin sample, urine (pee), or a cheek swab (wiping the inside of the mouth). If the doctors wish to collect any of these extra samples from me, they will explain the reason for this and I will have the choice to say 'yes' or 'no'.

4. Who is doing the study?

The study doctors, **Dr. Laura Arbour and Dr. Anna Lehman**, along with other people on their research teams will be doing this study. They will answer any questions I have about the study. I can also call them if I am having any problems and I cannot talk to my parents or guardians. The person who is the main contact for me is:

Victoria site – Sarah McIntosh (genetic counsellor) and Dr. Laura Arbour (study doctor) at: 250-853-3262 or 1-888-853-8924 (toll-free); e-mail: sarahmc@uvic.ca

OR

Vancouver site – Karen Jacob (study coordinator/genetic counsellor) at: 604-875-2000 ext 5271; e-mail: karen.jacob@bcchr.ca

5. Can anything bad happen to me?

If I have a blood test, it may hurt a little, but it won't last long. Sometimes having a blood test causes a bruise on the arm.

6. What will the results of the study mean to me?

No one knows whether the results of this study will help me or my family. It is possible that I will get a better understanding of the condition that affects me. Some people find it helpful when they learn the reason for their health condition. If a genetic cause for my condition is found, it may help doctors decide the best health care for me and/or my family members. It is unlikely that this study will cure my condition.

7. Who will know that I am in this study?

Only my doctors and the research team will know I am in the study. When the study is finished, the study doctors will write a report about what was learned. This report will not say my name or that I was in the study. My parents or guardians and I do not have to tell anyone I am in the study if we don't want to. If a gene change is found in me that explains my condition or can help my doctors provide care for me, then my gene test result will not stay only in the research study, but will also become part of my medical file, and all my doctors/ healthcare team (now and in the future) will be able to look at it.

8. When do I have to decide?

I can take as much time as I want to decide about joining the study. I have also been asked to discuss my decision with my parents or guardians. If I have any questions, I should ask my family members, study doctors, or other study team members before I join the study.

If I put my name at the end of this form, it means that I agree to be in the study.

My name

My signature

Date