Huntington Disease BioBank at the University of British Columbia

SUBJECT ASSENT FORM
(for those unable to give legal consent)

Invitation
I am being invited to be part of a research study on Huntington Disease. A research study helps doctors learn more about a disease. It is up to me if I want to be in this study. I have as much time as I want to decide. No one will make me be part of the study. Even if I agree now to be part of the study, I can change my mind later. No one will be mad at me if I choose not to be part of this study.

Why are they doing this research study?
I might have Huntington Disease or something that is like Huntington Disease. The doctors would like to study my blood to help them learn more about the disease in my family.

What will happen in this study?
If I decide to be in this study, they will collect blood from my arm with a needle. I will feel a tiny prick when they put in the needle, but it only lasts a second. Sometimes afterwards my arm might bleed a little bit or feel bruised or sore. My blood will be stored in a locked freezer called a “BioBank” where researchers at UBC and around the world can use it for only for Huntington Disease research and keep it for as long as they need to until they find a treatment or cure for the disease.

Who is doing this study?
Dr. Michael Hayden and other doctors and researchers from UBC will be doing this study. I can call them at 604-875-3999 and they will answer any questions I have about being a part of the DNA Bank.

Who will know I am in the study?
Only my doctors and people who are involved in the study will know I am in it. When the researchers write reports about what was learned they will not say my name or that I was in the study. The researchers will try their best to keep all information about me and my family private, but there is a small risk that people outside my family and doctors may find out.

Do I want to do this research study?
If I write my name just below, it means that I agree to be in the study.

Name (printed) ___________________ Signature ___________________ Date ___________________