SickKids®
THE HOSPITAL FOR
SICK CHILDREN
Research Ethics Board

Research Consent for Genetic Testing

(addendum)

General Section

I confirm that ______________________has explained the genetic tests that I am about to
[professional's name]

have done with respect to Autism Spectrum and Associated Neurodevelomental Disorders, and that any questions that I have asked have been answered to my satisfaction. The discomforts, consequences and possible risks associated with these tests have been explained to me. I understand that it is my choice whether or not to have this testing. Results of this test will be explained to me and I understand that this information may be shared, if necessary, with professionals involved in my medical care, including our family physician. I have been assured that records relating to me and the care that I have received will be kept confidential, and that no information will be released or printed that will reveal my identity without my permission or unless required by law.

I understand that the interpretation of the genetic information will depend in part on the family information that I have given. Differences between family information and the results of genetic tests occur when the parents of a child are different from those reported. Non paternity may be detected with this testing.

I understand that although genetic testing is usually accurate, as with all testing some inaccuracies may occur. Also genetic testing is ongoing and new research may mean that the interpretation of the test results may change over time. On occasion, in the process of testing for one genetic condition, another genetic alteration may be identified. Such findings would be reported to your health care provider to discuss with you.

I understand that it is my responsibility to notify the Genetics and Genome Biology department of any change of address, and to check with the department for updated genetics information and counseling that I feel I may need, for example in making decisions about a pregnancy.

I understand that if I apply for insurance and provide consent, information in my medical records, including the results of genetic testing will be available to the company. My sample may also be used so that other research may be done, but only after all identifying information, like my name has been removed. (see open consent only for this type of research)

Open Consent:

Open consent means that samples of tissue or DNA obtained from me may be stored indefinitely so that testing may be performed for Autism Spectrum Disorders.

Specifically:

1. Samples will be used in research relating to identification of DNA variants (Autism Spectrum Disorder); this testing will be undertaken in an accredited clinical service laboratory and/or a research laboratory.

2. I wish to be re-contacted with any new laboratory results that identify a specific genetic change in my sample of DNA;

3. Samples may be stored indefinitely;

4. Samples may be used in this laboratory or sent to other laboratories for research on other genetic conditions after all the identifying information has been removed; I understand that any sample held at SickKids or samples sent to other centres without identifying information cannot be retrieved;

5. Members of my family will be allowed access to my stored DNA or tissue only if I give my written permission or without my permission after my death.

6. On rare occasions samples obtained from me may be used to develop commercial products for which I will receive no personal recognition or payment.

Signature: ______________________ **Date:** __________________

Witness: ___________________ **Date:** ___________________