SickKids®
THE HOSPITAL FOR SICK CHILDREN
Research Ethics Board

Research Consent for Genetic Testing
Parent/Guardian Consenting on Behalf of Child
(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 Neurodevelopmental 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/my child's medical care, including our family physician. I have been
assured that records relating to me or my child and the care that we received will be kept
confidential, and that no information will be released or printed that will reveal my or my child's
identity without my permission or unless required by law.

I understand that when my child has the maturity to understand these tests he/she may request the
information and it will be made available to him/her.

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/my child's sample
may also be used so that other research may be done, but only after all identifying information,
like my and my child's 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 or my child 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 a 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/my child's 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. I will continue to have access to my child's DNA even in the event of my child's death or until such time that my child has the maturity to make his or her own decisions relating to the stored genetic material.

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

Signature: _____   **Date:** _____

Witness: _____   **Date:** _____