CONSENT – Genetic Testing
Pediatric/Adult

I consent to genetic testing for (condition/name of test(s)) _____ to identify the genetic cause(s) potentially related to my/my child's condition. This consent is not a substitute for genetic counselling, which will be provided to me by a healthcare professional. Some of the following information may not apply to my situation. The healthcare professional who obtains my consent will specify this to me (box will be checked off, as shown, when the situation is applicable: ☒).

I understand the following:

- The test(s) will be performed on a biological sample.

- The healthcare professionals involved in performing the test(s) may use medical information provided by the prescribing doctor from my/my child's medical record (including family history) and/or my/my child's Québec Health Record to help interpret the results.

- I will be informed of the results regarding my/my child's health, and they will be recorded in my/my child's medical record. If trio analysis (e.g., family analysis including the patient and biological parents) is recommended, no individual report will be produced for either parent.

- The test(s) may yield several types of results:
  - ☐ No genetic changes related to my/my child's condition. This does not completely eliminate the possibility of a genetic cause, as it may not be detectable by the method used.
  - ☐ Presence of one or more genetic changes explaining my/my child's condition.
  - ☐ Presence of one or more genetic changes of uncertain significance. It may still be difficult to determine the implications of the test results for my/my child's health.

- ☐ Some results may indicate present/future risks to my/my child's health. The *Genetic Non-Discrimination Act* (S.C. 2017, c. 3) is a Canadian law that governs the use of genetic results in contracts (e.g., employment, insurance, etc.). This law prohibits anyone from accessing or requesting genetic test results before such contracts are drawn up. Other medical record information, including family history, is confidential but not specifically protected by this law.

- This test or these tests may, in rare cases, detect the absence of a genetic link between me/my child and some members of my family. Such results may be discussed with me only if they impact my/my child's care or the care of my family members. They will never be specifically mentioned in the report issued by the laboratory.

- Once testing has been completed, the sample will be kept at the Québec medical laboratory that performed the testing, for the period determined by the current guidelines.

- If I am unable to receive my/my child's results (e.g., death, disability):

☐ I would like them to be given to (e.g., family member):

Name:_____ Relationship:_____ Telephone/Email:_____

☐ I do not want them shared with anyone else.

- If members of my/my child's biological family are tested for the same condition (e.g., family screening), the results of the test(s) and/or associated medical information may be used to help interpret their results.
  ☐ Yes, I agree. ☐ No, I decline.

☐ **Communication of incidental findings**

In rare cases, the test(s) may unexpectedly identify genetic changes that are unrelated to the condition being tested for, but could impact my or my child's health (incidental findings). The lab will not actively search for these genetic changes. This means that even if no incidental findings are reported with the results, it is still possible that I or my child may have an unidentified genetic condition.

ADULTS AND MINORS 14 YEARS OLD OR OLDER

If my test(s) reveal an incidental finding that has a potential impact on my health and for which treatment or preventive monitoring is currently available, I have the option to agree or decline that this information be included in the test results and communicated to me by my healthcare professional.

☐ Yes, I agree. ☐ No, I decline.

CHILDREN UNDER 14

Parents of a child under 14 will automatically receive the results of incidental findings that have a known impact on the child's health during childhood or adolescence, for which treatment or prevention exists **and** is currently available during childhood or adolescence. Incidental findings with implications only in adulthood will not be disclosed.

Data sharing for quality assurance and improvement

Sharing coded data: The results of the genetic test(s), the diagnosis, and other medical information (your "clinical data") will be shared within the databases of the Québec Molecular Diagnostic Network and an equivalent Canadian network, in a coded form that does not identify you/your child. These databases meet strict security and confidentiality standards. Data sharing is intended to help doctors and laboratories interpret genetic test results and carry out quality assurance and improvement activities. Only the professionals in the laboratory where the analysis was performed will be able to link the patient to the code assigned to their data.

Sharing anonymized data: For the same reasons as described above, your clinical data will also be anonymized (i.e., information that directly identifies you will be permanently deleted) before being submitted to national or international public databases.

Contact for research purposes

I may be invited to participate in research projects approved by a research ethics board in relation to the test(s) mentioned above and for which I/my child may be eligible.

☐ Yes, I agree. ☐ No, I decline.

I confirm that the healthcare professional has provided the necessary explanations and has answered my questions so that I can give informed consent.

Name: _____

Signature (including a minor 14 years old and over, or a legal representative): _____

Relationship (if applicable): Mother ☐ Father ☐ Legal representative ☐

Date (YYYY/MM/DD): _____

Name of person obtaining consent: _____

Signature of person obtaining consent: _____

Date (YYYY/MM/DD): _____

FOR TRIO ANALYSIS ONLY:

Name: _____
Signature: _____
Date (YYYY/MM/DD): _____
Biological relationship: Mother ☐ Father ☐
Other, please specify ☐: _____
Health insurance number (RAMQ):_____
If an incidental finding is identified in the patient under evaluation,

☐ I agree to be informed of the presence or absence of the incidental finding for myself.
☐ I decline to be informed of the presence or absence of the incidental finding for myself.

Name: _____
Signature: _____
Date (YYYY/MM/DD): _____
Biological relationship: Mother ☐ Father ☐
Other, please specify ☐: _____
Health insurance number (RAMQ): _____
If an incidental finding is identified in the patient under evaluation,

☐ I agree to be informed of the presence or absence of the incidental finding for myself.
☐ I decline to be informed of the presence or absence of the incidental finding for myself.