



#### **MOLECULAR DIAGNOSTIC LABORATORY**

Montreal Heart Institute 5000, rue Bélanger East, C-1760 Montréal (Québec) H1T 1C8 Telephone : 514 376-3330 ext 3712 Fax: 514 593-2577

# Consent Form for Genetic Testing

 Name, first name :

 Date of birth :

 ICM file number :

 RAMQ number :

 Mother's name :

 Father's name :

 Family number :

## Patient under 14 years of age

The purpose of genetic testing is to identify genetic variations, also known as variants or mutations, which are associated with certain heart conditions and may have health implications for you and your family members.

If a patient is under 14 years of age or is otherwise unable to give consent, a parent or other legally authorized person should sign on the patient's behalf. The results will be communicated to the parent or the legally authorized person.

#### By signing this form, I understand that:

- 1. I am giving permission for my sample (blood, DNA or another type of sample) to be tested and this test is not mandatory.
- 2. The Montreal Heart Institute may request my physician to send information regarding my medical records, such as the results of certain investigations and/or my familial history, which could help for my result's interpretation. Our knowledge regarding hereditary cardiovascular conditions is evolving; it is possible that this information may be requested in the next 25 years. It is recommended that my family (and I) maintain contact with the MHI's Molecular Diagnostic Laboratory, as well as specialized centres.
- 3. While genetic testing is a valuable tool, it may not always provide a definite answer about my genetic status. Therefore, the results of this test are not intended to be used as single information for diagnosis or management decisions.
- 4. The purposes, limits, risks and benefits of genetic testing have been explained to me prior to proceeding with genetic testing. I had the opportunity to obtain answers to all my questions.
- 5. Genetic testing is expected to take several months and my physician or I will be contacted to receive these results. Because of the complexity of genetic results interpretation, as well as implications for other family members, genetic counselling may be recommended.
- 6. In the interest of scientific knowledge advancement of these heart conditions, summary results may be presented, for example at scientific meetings or in publications. However, key efforts will be made to preserve confidentiality in this information sharing process.
- 7. My genetic testing results will be conserved at the MHI's Molecular Diagnostic Laboratory and be kept in my medical file at my physician's clinical centre. Any information communicated to another physician or a third party, such as an insurer, can only be sent following my written request, unless required by law.
- 8. The results of this test may be used to help interpreting results of other family members. (Please check below to indicate your choice)

I allow 🗌 I do not allow 🗌

MHI physician or genetic counsellor to communicate, in the future, my genetic results to other health professionals, if this will help with the diagnostic of similar conditions in other family members.

9. I may choose at any time to withdraw this consent and / or opt to never receive the results of this genetic testing by contacting the MHI's Molecular Diagnostic Laboratory at 514-376-3330 extension 3712 or by email (Idm@icm-mhi.org). This decision will not affect current or future medical follow-up. If I do withdraw, appropriate steps will be undertaken to have my sample destroyed if desired. Furthermore, if a genetic or biomarker testing has already been done on the sample, results obtained prior to my withdrawal will not be sent to my medical file.

## Laboratory testing

10. While genetic testing may provide valuable information, it may not be 100 % accurate. In rare circumstances, the laboratory may request a second sample due to difficulties regarding the analysis of my sample.

## Future use of samples

11. After the requested testing is completed, the DNA sample will be stored in the MHI's Molecular Diagnosis Laboratory. In case of scientific knowledge advancement in the cardiovascular genetic field, for example identification of new genes or new technologies, additional testing can be recommended. To facilitate these supplementary testing, DNA sample will be kept for up to 50 years. The aim of these further analyses is for clinical goals and not for research. (Please check below to indicate your choice. <u>One choice accepted</u>).

I accept that the sample may be used for these purposes and would like to be informed if any findings relevant to my own health or the health of my family are found.

I accept that the sample may be used for these purposes, but do not want to be informed of any findings.

I do not accept that the sample may be used for these purposes and want my sample to be destroyed after the requested tests have been done.

If I have any further questions or concerns, now or in the future, I can contact the MHI's Molecular Diagnostic Laboratory at 514-376-3330 extension 3712.

I understand the information included in this document and have had the opportunity to obtain answers to my questions surrounding genetic testing. I consent to the use indicated in this document.

Patient's signature
Legal representativ

Date

Legal representative of the patient under 14 years of age

Legally authorized person for an adult

Name (please print) of the signatory

I have explained the genetic analysis to the person who has consented and I have answered all questions.

Verbal consent obtained

Signature of the Health Care Professional

Date