



**INSTITUT DE
CARDIOLOGIE
DE MONTRÉAL**



Name, first name : _____

Date of birth : _____

ICM file number : _____

RAMQ number : _____

Mother's name : _____

Father's name : _____

Family number : _____

Adressograph

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

Child under 14 years

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 age of 14 years 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 the genetic testing. I had the opportunity to obtain answers to all my questions.
5. It is expected that the genetic testing will take several months and my physician or I will be contacted to receive these results. Because of the complexity involved in the interpretation of genetic results, 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. The result of my genetic testing 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

the physician or genetic counsellor at the MHI 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.

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9. I may choose at any time to withdraw this consent and / or opt to never receive the results of this genetic testing; 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. 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 is not 100 % accurate and may include possible sources of error which are not limited to misidentification and sample contamination. 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 Molecular Diagnosis Laboratory at the MHI. In case of advancement in scientific knowledge in the cardiovascular genetic fields, for example identification of new genes or new technologies, supplementary testing can be recommended. To facilitate these supplementary testing, the 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. **One choice accepted**).

- 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 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.

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- Patient signature (adult)
- Legally authorized person / parent of the child
- Legally authorized person for an adult

Date

Name (please print) by the signatory

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

Signature of the Health Care Professional

Date