

Cardiovascular Genetic Centre

Montreal Heart Institute

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Montréal, QC

H1T 1C8

Téléphone: 514-593-2498



Name of child:

Child's date of birth:

Consent Form for Genetic Testing

Genetic testing is done for the purpose of identifying genetic changes, known as variants or mutations, which may be associated with certain heart conditions and which may have implications for your own health, as well as for the health of other persons in your family.

By signing this form, I understand that:

GENETIC RESULTS

- 1) I am giving permission for the sample of my child _____ (blood, DNA or another type of sample) to be tested; this test is not mandatory.
- 2) The physician may be requested to send information to the MHI from their medical records, (such as the results of certain investigations and the family history) in order to help in the interpretation of the test.
- 3) While genetic testing is a valuable tool, it may not always provide a definite answer. The results of this test are therefore not intended to be used as the sole information on which to base 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 analyses.
- 5) It is expected that genetic testing will take several months and my physician or I will be contacted to receive these results. Because the complexity involved in the interpretation of genetic results, as well as implications for other family members, genetic counselling is recommended.
- 6) In the interest of advancing the understanding 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.
- 7) The results of this genetic testing will be conserved in the medical file at the medical centre of my referring physician. Any information communicated to another physician or to a third party, such as an insurer, can only be sent following my written request, unless otherwise required by law.
- 8) The results of this test may be used for the interpretation of testing for other members of my family.
I allow / I do not allow

The health professionals at the MHI to communicate my results, in the future, to other health professionals, if this will help in the testing of similar conditions in other family members.

(please initial above to indicate your choice)

9) In rare situations, when testing is performed on multiple family members, the results may suggest previously unrecognized family relationships, such as adoption or non-paternity.

10) I may choose at any time to withdraw this consent and/or to opt to not know the results of this genetic testing; this decision will not affect current or future medical follow-up. If I do withdraw, steps will be undertaken to have the sample destroyed. However, if genetic or biomarker testing has already been done on the sample, results obtained before this withdrawal will not be destroyed, however all identification linked to the sample will be permanently removed.

LABORATORY TESTING

11) While genetic testing may provide valuable information, no test is 100% accurate and possible sources of error include, but are not limited to, sample misidentification and sample contamination. In rare circumstances, the laboratory may have difficulties analyzing the sample and a second sample may be requested.

12) The sample will be stored in the clinical cardiovascular genetic laboratory of the ICM, in case knowledge in this field expands such that further clinical testing is considered warranted.

FUTURE USE OF SAMPLES

13) The sample will be stored in the laboratory, after the requested testing is complete, for the purpose of identifying new genes, testing new technologies and validating laboratory procedures regarding cardiovascular conditions, however my permission is required (please initial below to indicate your choice):

I accept that the sample of my child 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.

OR

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

OR

I do not accept that the sample of my child be used for these purposes.

If I have any further questions or concerns, I can contact the Cardiovascular Genetic Centre at (514) 593-2498.

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

_____ (parent) (Print full name)

Parent's signature

Date

If a patient is a minor or is otherwise unable to give consent, a parent or other legally authorized person should sign on the patient's