

# CARTaGENE PROJECT

## CONSENT FORM

**CARTaGENE investigators :** Bartha Maria Knoppers, Ph.D., (Law Professor, Université de Montréal), Claude Laberge, M.D., Ph.D., (Doctor-Geneticist, Professor, Laval University and Université de Montréal), Daniel Gaudet, M.D., Ph.D., (Doctor, Université de Montréal), Béatrice Godard, Ph.D., (Sociologist and Bioethicist, Université de Montréal), Isabel Fortier, Ph.D., (epidemiologist, Université de Montréal).

**CARTaGENE funding resources:** Genome Canada and Genome Québec.

CARTaGENE's goal is to establish a database and a biobank of biological samples for the use of researchers in health and genomics. Your participation in CARTaGENE may help in the advancement of knowledge in genomics and contribute in the long term to better prevention, diagnosis and treatment of disease. *Thank you for reading the information brochure and for asking all the questions you may have about the project.*

By signing this consent form, I agree to participate in CARTaGENE and I declare that:

- I have read and understood the information brochure and it was explained to me verbally to my satisfaction. I had the opportunity to ask all the questions I had to help me clarify this information and received satisfactory answers. I was given sufficient time to think about this and make an informed decision regarding my participation.
- I agree to meet with a nurse or an interviewer to answer a detailed questionnaire regarding my health and lifestyle, to allow the nurse to take certain basic clinical measurements and to take a sample of my blood and urine.
- I agree that a representative of CARTaGENE may be present occasionally during this appointment to verify the quality of the work done by the nurse or interviewer.
- I agree that my blood and urine sample be analysed by the laboratory designated by CARTaGENE and that the results of the analyses coded be transmitted to CARTaGENE.
- I understand that the results of the physical measures that the nurse will transmit to me at the end of my interview will be the only results that will be given to me and that I will never have access to my data and samples stored in CARTaGENE.
- I accept that the data and blood and urine samples collected during the appointment be transmitted, in coded form, to CARTaGENE and to the *Biobanque Génome Québec-Centre hospitalier affilié universitaire régional de Chicoutimi* (the Biobank GQ-CAUR).
- I accept that personal information about me and contained in government databases be transmitted to CARTaGENE, in coded form and confidentially, when needed for research in health and genomics. This information may cover the period from January 1<sup>st</sup> 1998 to the end of CARTaGENE.

- I agree that the data and samples stored by CARTaGENE be destroyed at the end of its activities on December 31<sup>st</sup> 2058 or if its funding ends prematurely, unless otherwise specified by the body responsible for ethics review and monitoring.
- I accept that my data and samples, once coded, be used by researchers of Quebec, Canada or other countries with in the framework of biomedical studies that have received the necessary approvals from a scientific committee and a research ethic committee.
- I understand that I will receive no personal financial benefit from any possible commercialization of any test or product developed by using the data and samples from CARTaGENE.
- I understand that my participation is completely voluntary and that I can withdraw at any moment without giving a specific reason by calling 1-800-XXX-XXXX. I authorize the CaG-RAMQ Service to inform CARTaGENE of the end my participation if I should withdraw.

**Option : Check your answer with an X.**

- Do you accept to be contacted by the CaG-RAMQ Service or any other instance acting on CARTaGENE's behalf in the future for new questionnaires, physical measures and/or sample collection? If so, you also agree that the CaG-RAMQ Service or any other instance acting on CARTaGENE's behalf obtain confidentially your information in order to be able to contact you.

I accept

I refuse

**Contact personnel**

For further information about this form, you can:

-Visit CARTaGENE's website at [www.cartagene.qc.ca](http://www.cartagene.qc.ca)

Call the CaG-RAMQ Service toll-free at 1-800-XXX-XXXX; operators will be available to answer your questions Monday through Friday from 8:30 a.m. to 8:00 p.m. and Saturday from 9:00 a.m. to 5:00 p.m.

- Write to: the CaG-RAMQ Service at \_\_\_\_\_

- Or send an e-mail to: \_\_\_\_\_

Any complaint regarding your participation in this research project can be addressed to the Université de Montréal's Ombudsman at (514) 343-2100 or by e-mail at [ombudsman@umontreal.ca](mailto:ombudsman@umontreal.ca). (The Ombudsman accepts collect calls).

**Participant**

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**SIGNATURE**

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**LAST NAME**

**FIRST NAME**

**DATE**

**Representative from the healthcare facility**

I have explained the present consent form to the participant and indicated that he/she is free to withdraw from CARTaGENE at any moment. I gave a signed copy of the present form to the participant.

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**SIGNATURE**

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**LAST NAME**

**FIRST NAME**

**DATE**

**A signed copy of the present form must be given to the participant.**