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# Dumont UHC Biobank, Neurodegenerative Diseases Registry

Invitation to participate | Information on a patient's participation and rights

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## Please take the time to read this brochure.

Feel free to contact us if you have any questions.

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### 1. What is the Dumont UHC Neurodegenerative Diseases Biobank?

A biobank is a type of library for researchers that contains a collection of biological samples and related information (diagnosis, treatment, etc.).

The Dumont UHC Neurodegenerative Diseases Biobank stores blood, spinal fluid and tissue samples from patients with neurodegenerative diseases. The Biobank helps our local research teams expand their knowledge of neurodegenerative diseases. Thanks to the Biobank and to research, patients could benefit from:

- Better early screening tools;
- More precise diagnoses;
- Targeted treatments.

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### 2. How to participate

A patient who agrees to participate allows the Biobank team to collect **biological samples** and **health information**.

**The samples** in question are collected in the course of the patient's care (diagnosis and treatment). These samples are no longer needed for treatment, and could consist of:

- A small portion of the tissue from a biopsy, if applicable;
- One or more blood samples (up to 30 mL, or 6 teaspoons);
- Body fluid samples involving spinal fluid (up to 20 mL if applicable, or 4 teaspoons), saliva, urine or bronchial washing (if applicable and performed by your physician for your care).

**Information:** By signing this document, a patient also authorizes the Dumont UHC Biobank to access their health record for the purposes of collecting demographic information as well as information on their general health history and neurodegenerative disease-related medical history.

Participation is **voluntary**. You have the right to agree or refuse to participate.

Furthermore, even if you agree to participate, you may withdraw at any time without having to justify your decision and with no repercussions on the quality of the care that you receive.

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### 3. What benefits come with participating?

No direct benefits come with participating in the Dumont UHC Biobank. Participants receive no financial compensation for their participation in the Dumont UHC Biobank or for future discoveries.

However, your participation in this project could expand our knowledge of various types of neurodegenerative diseases and help discover new treatments.

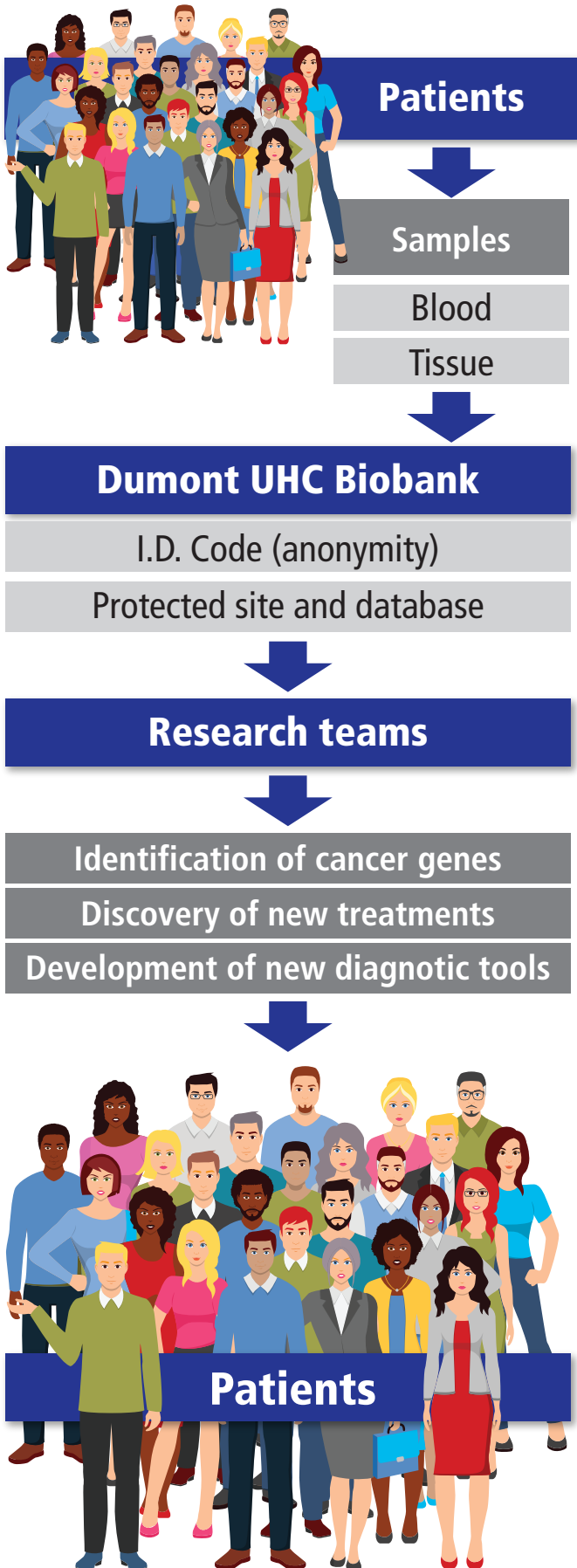
Your participation will not affect your treatments.

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### 4. Do any risks come with participating?

No risks come with participating in the Dumont UHC Biobank except for the usual discomfort associated with having blood samples taken (i.e. risk of bruising and, in rare cases, of fainting or of contracting an infection).

Only excess tissue from a biopsy or diagnostic surgical procedure is collected.



## 5. What is done with the samples?

The samples and data are stored at the Dr. Georges-L.-Dumont University Hospital Centre until they are used for research projects. If the Biobank were to close, unused samples could be transferred to another biobank or destroyed. Any transfer or destruction of unused samples must be approved beforehand by the Research Ethics Board of Vitalité Health Network.

## 6. How is confidentiality respected?

The samples and data are identified by a code when they are entered into the database. They are stored anonymously and securely within the walls of the Dr. Georges-L.-Dumont University Hospital Centre. No information identifies a specific patient.

Ethics laws governing confidentiality are strictly observed.

## 7. How to withdraw from the Biobank

You are free to withdraw from the Biobank at any time by contacting us at **506-862-4221** or by e-mail at **CHUDumontBiobanque@vitalitenb.ca**.

When a patient withdraws:

- Their samples and data that have already been distributed for research purposes are retained and used to protect the scientific integrity of the research underway;
- Any other samples and data are destroyed. They are no longer used from the moment you advise us of your withdrawal.

# Dumont UHC Biobank Informed Consent Form

You may discuss your future participation with your doctor, family and friends.

## Understanding of my participation and consent

I have read and understood the information provided.

I understand that I may refuse to participate or may change my mind and decide to withdraw at any time with no repercussions on my health care.

I have had the opportunity to ask questions, which were answered to my satisfaction.

I will receive a copy of this document, which I will keep so that I can contact the staff of the Dumont UHC Biobank if I have questions in future.

I understand that no information identifying me will be given to researchers and that all samples will be anonymized and coded.

## I have read and understood this consent form and wish to participate in the Dumont UHC Biobank.

### Check the appropriate box:

Yes

No

Family name, first name:

Date of birth \_\_\_\_\_ (DD/MM/YYYY)

Medicare number: \_\_\_\_\_

or medical record number: \_\_\_\_\_

Patient signature: \_\_\_\_\_

Patient name: \_\_\_\_\_

Date: \_\_\_\_\_ (DD/MM/YYYY)

Or

If it is required to have a legal representative sign or to have an impartial witness attend (if the participant cannot read the document), please check the appropriate box and write in their name and their relationship to the participant.

### Check the appropriate box:

A legal representative is required

\_\_\_\_\_  
Name of legal representative

\_\_\_\_\_  
Legal representative's relationship to patient

\_\_\_\_\_  
Signature of legal representative

An impartial witness is required

\_\_\_\_\_  
Name of impartial witness

\_\_\_\_\_  
Impartial witness's relationship to patient

\_\_\_\_\_  
Signature of impartial witness

### Signature of person responsible for the consent

\_\_\_\_\_

### Name of person responsible for the consent

\_\_\_\_\_

Date: \_\_\_\_\_ (DD/MM/YYYY)

## Compensation in case of harm

If you were to suffer harm by participating in the Biobank (when blood samples are taken), necessary medical treatment will be available to you. By signing this consent form, you do not waive your legal rights and do not release the members of this institution from their professional and legal responsibilities. This consent form does not affect your right to claim damages.

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### Please answer the following questions:

1. My relevant and anonymized biological sample(s) and/or health information may be used in future research to increase knowledge and prevent or treat neurodegenerative diseases.

#### Check the appropriate box:

- Yes  
 No

2. I agree to be recontacted about giving, if necessary, body fluid samples involving saliva, urine or bronchial washing (if applicable and performed by your physician for your care). I understand that giving permission to be contacted in no way obliges me to supply these samples.

#### Check the appropriate box:

- Yes  
 No

3. I agree to be recontacted for five years for research projects I could be eligible for. I understand that giving permission to be contacted in no way obliges me to supply these samples.

#### Check the appropriate box:

- Yes  
 No

4. My relevant and anonymized biological sample(s) and/or health information may be used in the neurodegenerative disease research field by authorized researchers from the local university and industrial sectors.

#### Check the appropriate box:

- Yes  
 No

### Signature of participant

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### Name of participant

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**Date:** \_\_\_\_\_ (DD/MM/YYYY)

### Signature of person responsible for the consent

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### Name of participant

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**Date:** \_\_\_\_\_ (DD/MM/YYYY)

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### Contact us

Dumont UHC Biobank - Research Support Office  
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CHUDumontBiobanque@vitalitenb.ca  
**(506) 862-4221**