

SOIGNER.  
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*Douglas*  
INSTITUT MENTAL HEALTH  
UNIVERSITAIRE EN UNIVERSITY  
SANTÉ MENTALE INSTITUTE

CARING.  
DISCOVERING.  
TEACHING.

## *Banque de cerveaux Douglas - Bell Canada Brain Bank*

### **To the Quebec Parkinson Network (QPN) participants**

Madam, Sir:

Thank you for your interest in the Douglas - Bell Canada Brain Bank. Brain donations really help us further advance the research in the areas of Movement Disorders, such as Parkinson's Disease, or other diseases of the nervous system. Our purpose is to discover ways to make life easier for those who suffer. Your contribution would be invaluable.

You will find enclosed the information about the Brain Bank. The brochure contains all the consent forms necessary for one donor. To bequeath a brain, it is very important to discuss the decision with your relatives, and make them aware of your intent to donate because at the time of death, they are the persons who will have to contact the Brain Bank quite rapidly. Please note that the original forms "Brain Bank's copies" (**pages 9 to 12**) should be handed to a representative of the Quebec Parkinson Network (QPN). The "Pathologist's Copy", pages 13 and 14, should be kept with personal papers or be placed in the medical file if the donor lives in a nursing home and should be easily and rapidly accessible at the time of death. Finally, page 15 and 16 should be kept by a next-of-kin who knows the donor's wish to donate.

We hope that this information will be useful. If we can help in any other way, please do not hesitate to call us at (514) 761-6131 (and ask for the Brain Bank).

With our deepest gratitude for your interest in neurological and psychiatric research, please accept my best regards.

Sincerely,



Dominique Mirault  
Research Assistant  
Douglas – Bell Canada Brain Bank  
Douglas Institute Research Centre  
Montreal West Island IUHSSC



## *Banque de cerveaux Douglas - Bell Canada Brain Bank*

### **Important - General Notices**

Since the printing of the attached information and consent brochure, the name of the Douglas Hospital Research Center Brain Bank has changed and became “The Douglas - Bell Canada Brain Bank”. Another important change is that **the coverage 24 hours a day, 7 days a week is no longer in effect**. A representative of the Brain Bank can be reached from Monday to Friday between 9:00am and 5:00pm, except during statutory holidays. It should be noted, however, that a voicemail system has been set up in order to be able to transmit certain instructions for deaths that occur during the evening, night, weekend or statutory holidays. This voicemail is available outside working hours by calling (514) 761-6131, dialing 0, asking for the Brain Bank and mentioning that it is urgent; please browse through the different menus.

### **Modification in page 6 February 2012**

In page 6 of the document titled *The Hows and Whys of Using Human Tissue for Research*, section « **Will the donor’s family receive a copy of the brain autopsy report?** » was written as follows:

A donor who signs his own brain donation consent form can also authorize that the brain autopsy report – the neuropathological report – be sent to his family. If a representative signed the consent on behalf of the donor, he will receive a copy of the neuropathological report. **Please note that it usually takes about two years to produce a neuropathological report, but it can sometimes take a little longer.** Also, the tissue can usually be used for research only after the Brain Bank has received the diagnosis.

#### **THIS SECTION SHOULD NOW BE READ LIKE THIS:**

#### **Will the donor’s family receive a copy of the brain autopsy report?**

A donor who signs his own brain donation consent form can also authorize that the brain autopsy report – the neuropathological report – be sent to his family. If a representative signed the consent on behalf of the donor, he will receive a copy of the neuropathological report. **Please note that it will take several years to produce this report. Contact the Brain Bank for more details.** Also, the tissue can usually be used for research only after the Brain Bank has received the diagnosis.

#### **Explanation**

The diagnostic evaluation of brain tissue from a donor is carried out by specialists, neuropathologists, who collaborate with the Brain Bank. These specialists also receive consultation requests from all hospitals in Quebec. Unfortunately, they are very few and their workload has increased steadily in recent years. Moreover, priority is given to the results concerning living patients waiting for diagnosis and treatment over results for deceased persons (autopsies). The direct consequence is that the delay to produce the neuropathological report has considerably increased and this regrettable situation is totally beyond the control of the Brain Bank.



# THE BRAIN BANK:

*The Hows and Whys of Using*

# *Human Tissue for Research*



*Information preceding consent  
for brain donation to the  
Douglas Hospital Research Centre  
Brain Bank for diagnostic and  
research purposes*



#### **THE BRAIN BANK**

Douglas Hospital Research Centre  
6875 LaSalle Blvd.  
Borough of Verdun  
Montreal, Quebec H4H 1R3

Tel.: (514) 761-6131, then dial 0

Fax: (514) 762-3033

E-mail: [brain.bank@douglas.mcgill.ca](mailto:brain.bank@douglas.mcgill.ca)

[www.douglas.qc.ca](http://www.douglas.qc.ca)

## *Why use human tissue samples and from where do they come?*

In biomedical research, any fragment of an organ is called "tissue". Cerebral tissue comes from the brain. The use of tissue in research can help us better understand the causes of illnesses; it can also help us to predict illnesses, and to find treatments and cures. The availability of cerebral tissue in research has played a very important role in the understanding of certain neurological and mental illnesses in the last few decades. This has greatly contributed to the development of new treatments that have had a major impact on the quality of life for people suffering from these illnesses. But much work is still to be done. Unfortunately, when it comes to treating diseases of the brain, the animal model is not always relevant—only human tissue can truly reveal the secrets of certain human mental disorders. For researchers in neurology and psychiatry, access to a resource like the Brain Bank is essential. The use of human brains in research can also help us better understand the effects of other diseases (like diabetes, cancer, and vascular diseases) on the brain.

In certain cases, tissue from biopsies or from surgery (taken from living donors) can also be used in part for research, provided the donor has been fully informed and has given his consent. Anyone can consent to having one or several of his organs or tissues removed after his death and to having them preserved for research purposes. If a potential donor is not legally competent to consent, his legal representative (a person legally approved by a court of law, such as a tutor, a curator or a mandatary) or, by default, his marital spouse or even his closest relative (if there is no marital spouse) can consent in his place. The availability of these tissues, be they pathological or not, is of prime importance to the advancement of biomedical learning. Any individual, regardless of his mental and physical health, can donate his brain when he dies, as long as a consent form has been signed. Another important point: brain donation is not one of the options on the back of the Quebec Health Insurance Card.

## *Where will the donor's tissue be kept?*

### **BRAIN BANK**

Brain tissue is preserved in the Douglas Hospital Research Centre Brain Bank, which has been created to promote neurological and psychiatric illness studies. Here, tissue is collected, stored and distributed to researchers, who request these specimens as an invaluable part of their work. Established in 1980, it was the first brain tissue bank in Canada. Its creation is due to a major investment, financed almost entirely by the Douglas Hospital Foundation. Today, its main support comes from the Quebec Mental Health and Neuroscience Network (QMHNN) of the Fonds de la recherche en santé du Québec (FRSQ). The Bank is administered by the director, who develops the rules of operation and the financial methods inherent in specimen preservation, in collaboration with the Brain Bank Management Committee, the Douglas Hospital Research Centre and Douglas Hospital administration, and with the approval of the Douglas Hospital Research Ethics Board.

The Douglas Hospital and its Research Centre are affiliated with McGill University and the World Health Organization. The Brain Bank also works directly with neuropathologists at Hôpital Sainte-Justine and the Montreal Neurological Institute.

### **COLLECTION**

Brain tissue comes from donors, who have made the donation themselves, or from a family who has done so in their name. Removals take place at the hospital closest to the place of death and according to an established protocol. Samples are collected by a Brain Bank employee and the tissue transport fees are paid by the Bank.

### **STORAGE**

Once sent to our laboratories, part of the brain is rapidly frozen, according to a specific protocol, and stored at -80°C in a special freezer linked to a central surveillance system. Treated and stored in this way, the human brain tissue tends to retain the characteristics necessary for research. Another part of the brain is set in formaline and is used for the brain autopsy to establish the neuropathological diagnosis of the donor. The results of this exam take the form of a report, which is sent to the donor's family, if the donor has so consented. This neuropathological exam is part of the Bank's diagnostic arm and not the research arm.

### **DISTRIBUTION**

After the neuropathological diagnosis has been completed, the remaining stored samples are distributed to the researchers who have requested brain tissue. The quality of tissue that comes from the Bank has enabled many scientists throughout the world to discover new data that has helped improve the prevention and treatment of various neurodegenerative diseases. The more access researchers have to human cerebral tissue, the more major discoveries may be made that could have an impact on the sufferer's quality of life.

## **BANK STAFF**

The Bank employs personnel who are qualified to handle human tissue samples, protect the rights of donors, and ensure that the Bank's operations uphold the highest possible standards. The director can put one or several people in charge of the Bank, and keeps abreast of how they exercise their responsibility. The person in charge of the Bank, where the tissues are kept, is the Brain Bank coordinator. Outside regular business hours—be it evenings or weekends—a Brain Bank representative is always available. You can reach a Bank employee any time by calling (514) 761-6131, dialing 0, and then asking for the Brain Bank. Quebec hospital pathologists do not work for the Brain Bank, but they will agree to remove a deceased person's brain if specific consent has been given and if there is an agreement between their institution and the Brain Bank. If you have questions concerning the rights of research subjects (donors), you may contact the Douglas Hospital Ombudsman at (514) 761-6131, ext. 3287.

## *Freedom to participate*

The donor's participation is completely voluntary, and will not be remunerated financially in any way. If a donor agrees, the removed tissue and samples will be used by researchers whose research projects have been approved by their respective institutions' Research Ethics Boards. If consent to remove the tissues was given by a donor's legal representative and/or his closest relative, this person can change his mind at any time. If he no longer wants the tissues to be used for research purposes, he can call the Brain Bank coordinator at (514) 761-6131, dial 0, then ask for the Brain Bank. The tissue and all information related to the donor will then be destroyed.

## *What are the advantages and potential risks of donating a brain?*

Brain donation helps researchers gain a better understanding of the causes of neurological, psychiatric and other illnesses, and find ways to prevent, treat and cure them. In the future, this research may help many more people suffering from these illnesses. Moreover, the neuropathological diagnosis can confirm or invalidate a clinical diagnosis, which can be very useful for the donor's family.

The greatest potential risk is linked to confidentiality and the dissemination of information from the deceased donor's medical file (information on following pages).

## *How will the donor's tissue be used?*

### **WHAT KINDS OF RESEARCH WILL BE CONDUCTED WITH THE TISSUE?**

Many types of research can be conducted on human tissue. Some researchers study cells and their proteins in the hopes of finding the causes and characteristics of illnesses, while others may choose to focus on finding new ways to treat and even cure illness. In the future, some research may lead to the development of new products, like detection tests or new medications. Researchers may be interested in testing whether some modifications in certain genes can be associated with—or even be the cause of—selected illnesses. Genes are molecules that contain all transmissible information that directs the body's cellular activities. They determine a person's hereditary traits such as eye color or blood type.

To understand particular illnesses, researchers must have access to tissue samples from people who were afflicted with those illnesses. But they also must compare these pathological samples with those of a healthy person. For every pathological case studied, scientists must have access to a normal case to use as a control. Finally, researchers must also verify the specifics of their discoveries by comparing different illnesses and disorders.

### **COULD FAMILIAL GENETIC RESEARCH BE A POSSIBLE OPTION?**

In exceptional cases, researchers may conduct other studies to look at how genes may transmit some illnesses within families. This research is extremely sensitive, and can have serious repercussions for the whole family—that is why these studies are always very well supervised. They also require direct contact between the research team and the family members who are participating in the study. Researchers conducting this type of study may potentially ask the Brain Bank to contact families who may be interested in participating. These familial genetic studies, however, cannot be conducted without the donor's general consent and his representative's express permission. The representative will have to consent to the specific project, which has been approved and well supervised by the Douglas Hospital Research Ethics Board. Moreover, any preliminary contact the Brain Bank staff may have with the researchers must not reveal the identity of the donor, his representative, or other members of the donor's family, until having received their express consent. Families interested in learning more about the option of familial genetic research should contact the Brain Bank Office. Consent forms specific to this purpose will then be sent to family members for their consideration.

### **WHO WILL HAVE ACCESS TO THE TISSUE?**

The Brain Bank was created specifically to provide precious brain tissue samples to the international scientific community. Historically, Quebec researchers have benefited most from this resource because of their proximity to the Bank. Any qualified researcher from the public sector, however, can get tissue, on the condition that his research protocol is approved by his institution's Research Ethics Board. As for private sector research centres, the Douglas Hospital Research Ethics Board must specifically approve requests before any tissue is sent.

### **HOW LONG WILL THE TISSUE BE STORED?**

The sample will be stored in the Bank as long as the Douglas Hospital Research Ethics Board feels that the sample's scientific value is justified. Meanwhile, the general mode of operation will be evaluated by the same committee at one-year intervals, to ensure that the Bank's management continues to conform to the latest standards. When the Bank decides to stop storing the tissue, the tissue will be incinerated by a company that specializes in eliminating biomedical material.

### **HOW ARE THE RESEARCH RESULTS, INVOLVING DONATED TISSUE, DISTRIBUTED?**

It goes without saying that the results obtained will be treated with the utmost confidentiality. The results will be used to write articles for peer review before going on to be published in scientific journals. The donors' identities will never be revealed, and the articles will not contain any information that can be used to identify or trace the donors.

## *Can the tissue be used commercially?*

The tissue cannot be sold, and will be used solely for research purposes. However, some of the research conducted with the tissue may contribute to the development of new products in the future. If these products are patented, it is possible that the researcher or his institution may profit. This profit may be divided between the researcher (and/or his institution) and the Brain Bank, according to the agreement protocol between the parties. Any profit following such an agreement by the institution that manages the Bank will be reinvested in the administrative costs of the Bank. Moreover, a researcher who uses tissue must disclose if a company is financing his project, and if so, if he has a financial interest in that company. The Research Ethics Board must then determine if this poses a conflict of interest for the researcher.

## *How does the Bank protect the identity of its donors?*

### **WHY DOES THE BANK NEED INFORMATION FROM THE DONOR'S MEDICAL FILE?**

Researchers may sometimes need information about the donor in order to conduct research on the tissue. Information that may be shared includes age, sex, race, diagnosis, health, family history, treatments received and the response to them. This helps researchers find the cause of illnesses, and the Bank deals with this information in a confidential manner.

### **WHAT PRECAUTIONS DOES THE BRAIN BANK TAKE?**

It goes without saying that the Bank protects personal information, so that donors' names, or any other information that may help identify donors, are treated with the utmost confidentiality and conform with the provincial laws in effect. Research results will not be put in the donor's medical file and no information will be transmitted to the researcher that could in any way disclose the identity of the donor. With these precautions, it will be very hard to link the research results to the donor (or his family). Moreover, the information and results will be used exclusively for scientific purposes. These results will be known only by the researchers, and they will be shared only for scientific purposes, without ever identifying who donated the tissue.

### **WILL THE DONOR'S FAMILY RECEIVE A COPY OF THE BRAIN AUTOPSY REPORT?**

A donor who signs his own brain donation consent form can also authorize that the brain autopsy report—the neuropathological report—be sent to his family. If a representative signed the consent on behalf of the donor, he will receive a copy of the neuropathological report. Please note that it usually takes about two years to produce a neuropathological report, but it can sometimes take a little longer. Also, the tissue can usually be used for research only after the Brain Bank has received the diagnosis.

## **WILL THE DONOR'S FAMILY RECEIVE A COPY OF THE RESEARCH RESULTS FROM THE STUDIES IN WHICH THE DONOR'S TISSUE WAS USED?**

The results of the research conducted with the tissue will not be sent to the donor's family. The reason for this is that research can take a long time, sometimes years, and many other donors' samples are used to get results. The research results cannot be given to the Brain Bank either, since the researchers won't know the tissue donors. With the exception of the brain autopsy results (neuropathological diagnosis), no research results can be shared with members of the donor's family—not for insurance, employment or legal purposes.

## *Brain removal and general autopsy*

When it comes to research into the human brain, a brain autopsy is invaluable to establish or confirm the clinical diagnosis; that is why it is mandatory. However, a general autopsy is not mandatory. The Brain Bank assumes the costs related to brain removal and brain autopsy, but it cannot be accountable for costs related to the general autopsy if the treating physician or a family member has requested it. However, the Brain Bank staff can arrange for the brain removal and general autopsy to occur in the same place.

It is important to mention that removing the brain does not interfere in any way with the funeral service. There are usually no visible scars and a donor can have an open casket visitation if he or the family so chooses. A 24-hour delay, however, should be foreseen.

## **WHERE AND WHEN DOES THE REMOVAL TAKE PLACE?**

Brain removal must take place as soon as possible—ideally within 24 hours of death. The quality of the research depends on having as short a delay as possible.

The removal location will be chosen shortly after death, by the Brain Bank staff. Generally, if a death occurs in a hospital, removal is done there. For a death occurring elsewhere (a private home or a nursing home), the body must be transported to a hospital close to the place of death as quickly as possible. Transport will take place by the funeral home chosen by the family. If the family or the legal representative cannot assume the additional cost of transporting the deceased for brain removal, the costs may be defrayed by the Brain Bank (maximum distance: 75 km).

## *What has to be done to bequeath a brain?*

The donor must discuss the decision with his relatives, and make them aware of his intent to donate. He must also sign the brain donation consent forms, which are included at the end of this document.

## Who can sign the consent forms?

**The donor**, if he is 14 years old or over and if he is legally competent to make the decision

**or his legal representative** (*approved by a court of law, such as a tutor, curator or mandatary*)

**or his marital spouse** (*if the donor is not legally represented*)

**or his common-law spouse, close relative or friend** (*if the donor is not married and not represented*)

### and a witness

The person who can legally sign may differ, according to the situation. For more information, please contact the Brain Bank Office.

## What has to be done at the time of death?

If the donor dies in his home, call 911 to report the death. An Urgences-santé doctor will go to the location and give notice of the death. For a death occurring in a nursing home or hospital, the staff will contact a doctor.

Then, without delay, you must call the Douglas Hospital at (514) 761-6131, dial (0) and ask the operator to contact the Brain Bank representative. This Brain Bank employee will take charge of the donation process, answer all your questions and ensure that this ultimate gift is treated with respect and efficiency. A Brain Bank representative is always available—24 hours a day, 7 days a week.

## Forms

The following pages contain various forms to be completed.

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### Brain Bank's copies

- Brain Donation Consent Form
- Neuropathological Report Transmission Authorization
- Donor Response Form

*To be returned to the Brain Bank Office.*

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### Pathologist's copy

*To be put in the medical file (if the donor lives in a nursing home), or with the donor's personal papers.*

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### Legal representative's or closest relative's copy

*To be kept by the legal representative, the marital spouse, the common-law spouse, a close relative, or a friend of the donor.*

Please Note: Families interested in learning more about the option of familial genetic research should contact the Brain Bank Office. Consent forms specific to this purpose will then be sent to family members for their consideration.

## CONSENT FOR BRAIN REMOVAL, AUTOPSY AND DONATION FOR DIAGNOSTIC AND RESEARCH PURPOSES

### INTRODUCTION

You're aware of the importance of mental health research. Maybe you, or someone close to you, have been directly affected or maybe you've heard about diseases of the brain in general. To help scientists find the causes of neurological and mental illnesses, as well as discover new treatments, we request your permission to remove your, or a close relative's, brain at the time of death, and allow its use for research purposes. This donation would be extremely valuable to the advancement of medical and scientific learning. We ask that you read the enclosed brochure, entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, to learn about the use of tissue—specifically, brain tissue—in research and how the Douglas Hospital Research Centre Brain Bank functions.

### CONSENT

I have read this consent form (as well as the brochure entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, (hereafter called "the enclosed brochure"). I understand the contents of these documents, I've had the opportunity to ask any questions I may have had about the research, and I am satisfied with the answers provided. I understand that my participation is on a purely voluntary basis, and that I remain free to withdraw at any time without prejudice. Therefore:

I, **THE UNDERSIGNED**, \_\_\_\_\_  
PLEASE PRINT YOUR NAME

**DONOR**       **LEGAL REPRESENTATIVE**       **CLOSEST RELATIVE**  
APPROVED BY A COURT OF LAW  
(TUTOR/CURATOR/MANDATARY)

In the name of:  
**DONOR NAME** \_\_\_\_\_  
PLEASE PRINT THE DONOR'S NAME

**HEREBY ACCEPT**, (place a check mark and your initials below, where appropriate):

**1** Brain removal and autopsy **2** Access to all of the donor's confidential medical files for diagnosis and research and **3** That the donor's brain be preserved and used for the research purposes described in this consent form (and the enclosed brochure) in order to better understand, prevent, treat and cure neurological and mental illnesses:

**YES**    
INITIALS

### Research into other diseases

That the donor's brain be preserved and used for research purposes into diseases other than neurological and mental illnesses (i.e. diabetes, cancer, vascular diseases):

**YES**    
INITIALS

**NO**    
INITIALS

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE DONOR OR THE LEGAL REPRESENTATIVE

**ADDRESS** \_\_\_\_\_

**CITY/PROVINCE** \_\_\_\_\_ **POSTAL CODE** \_\_\_\_\_

**TELEPHONE** (      ) \_\_\_\_\_ **E-MAIL** \_\_\_\_\_

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE WITNESS

## AUTHORIZATION TO TRANSMIT A NEUROPATHOLOGICAL REPORT

If the donor has signed his consent form for brain donation, he may also decide to give authorization to the Brain Bank in order to transmit the results of the brain autopsy to another party (relative, doctor, friend, etc.) by completing and signing this consent form.

In the event that a legal representative has given consent for a brain donation on behalf of someone unable to consent, he/she will receive the donor's brain autopsy report. To transmit the neuropathological report to another party (relative, doctor, friend, etc.) the legal representative must complete and sign this consent form.

**I, THE UNDERSIGNED,** \_\_\_\_\_  
PLEASE PRINT YOUR NAME

**DONOR**       **LEGAL REPRESENTATIVE**       **CLOSEST RELATIVE**  
APPROVED BY A COURT OF LAW  
(TUTOR / CURATOR / MANDATARY)

*In the name of:*  
**DONOR NAME** \_\_\_\_\_  
PLEASE PRINT THE DONOR'S NAME

### HEREBY ACCEPT

*(place a check mark and your initials below, where appropriate):*

That the brain autopsy report be transmitted to the person(s) or institution(s) named below. Moreover, these persons have agreed to receive it:

**YES**  \_\_\_\_\_ **INITIALS**      **NO**  \_\_\_\_\_ **INITIALS**

### NAME OF THE PERSON(S) OR INSTITUTION(S) THAT SHOULD RECEIVE THE REPORT FROM THE BRAIN BANK

**NAME** \_\_\_\_\_  
PLEASE PRINT THE NAME OF THE PERSON OR INSTITUTION

**ADDRESS** \_\_\_\_\_

**CITY/PROVINCE** \_\_\_\_\_ **POSTAL CODE** \_\_\_\_\_

**TELEPHONE (      )** \_\_\_\_\_ **E-MAIL** \_\_\_\_\_

**NAME** Quebec Parkinson Network  
PLEASE PRINT THE NAME OF THE PERSON OR INSTITUTION

**ADDRESS** 3801, rue University

**CITY/PROVINCE** Montreal, Quebec **POSTAL CODE** H3A 2B4

**TELEPHONE (      )** (514) 398-7174 **E-MAIL** \_\_\_\_\_

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE DONOR OR THE LEGAL REPRESENTATIVE

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE WITNESS

## DONOR RESPONSE FORM

Please complete this form and return it to the Brain Bank.

### 1. DONOR INFORMATION

FRENCH  ENGLISH

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

HOME TELEPHONE (        ) \_\_\_\_\_

OFFICE TELEPHONE (        ) \_\_\_\_\_

DATE OF BIRTH DAY \_\_\_\_\_ MONTH \_\_\_\_\_ YEAR \_\_\_\_\_

HEALTH INSURANCE CARD NUMBER (RAMQ) \_\_\_\_\_

PLACE OF BIRTH \_\_\_\_\_

NATURE OF ILLNESS (IF APPLICABLE) \_\_\_\_\_

LENGTH OF ILLNESS (IF APPLICABLE) \_\_\_\_\_

### 2. RELATIVE AND/OR LEGAL REPRESENTATIVE

FRENCH  ENGLISH

NAME \_\_\_\_\_

CLOSEST RELATIVE      AND/OR       LEGAL REPRESENTATIVE      AND/OR       EXECUTOR OF THE WILL  
APPROVED BY A COURT OF LAW  
(TUTOR/CURATOR/MANDATARY)

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

HOME TELEPHONE (        ) \_\_\_\_\_

OFFICE TELEPHONE (        ) \_\_\_\_\_

RELATIONSHIP \_\_\_\_\_

### 3. OTHER PERSON WHO MAY BE RESPONSIBLE AT THE TIME OF DEATH

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

HOME TELEPHONE (        ) \_\_\_\_\_

OFFICE TELEPHONE (        ) \_\_\_\_\_

RELATIONSHIP \_\_\_\_\_

## DONOR RESPONSE FORM (continued)

### 4. FUNERAL HOME (IF ALREADY CHOSEN)

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

TELEPHONE (        ) \_\_\_\_\_

FAX        (        ) \_\_\_\_\_

### 5. DOCTOR, NEUROLOGIST OR PSYCHIATRIST

(who diagnosed the neurological or mental illness)

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

TELEPHONE (        ) \_\_\_\_\_

FAX        (        ) \_\_\_\_\_

### 6. HOSPITAL OR NURSING HOME

(CHSLD, if applicable)

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/PROVINCE \_\_\_\_\_ POSTAL CODE \_\_\_\_\_

TELEPHONE (        ) \_\_\_\_\_

FAX        (        ) \_\_\_\_\_

### 7. OTHER MEDICAL FILES

(Please specify the name of the institution where the files are located.)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### 8. QUESTIONS, RESTRICTIONS OR COMMENTS

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

## CONSENT FOR BRAIN REMOVAL, AUTOPSY AND DONATION FOR DIAGNOSTIC AND RESEARCH PURPOSES

### INTRODUCTION

You're aware of the importance of mental health research. Maybe you, or someone close to you, have been directly affected or maybe you've heard about diseases of the brain in general. To help scientists find the causes of neurological and mental illnesses, as well as discover new treatments, we request your permission to remove your, or a close relative's, brain at the time of death, and allow its use for research purposes. This donation would be extremely valuable to the advancement of medical and scientific learning. We ask that you read the enclosed brochure, entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, to learn about the use of tissue—specifically, brain tissue—in research and how the Douglas Hospital Research Centre Brain Bank functions.

### CONSENT

I have read this consent form (as well as the brochure entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, (hereafter called "the enclosed brochure"). I understand the contents of these documents, I've had the opportunity to ask any questions I may have had about the research, and I am satisfied with the answers provided. I understand that my participation is on a purely voluntary basis, and that I remain free to withdraw at any time without prejudice. Therefore:

I, **THE UNDERSIGNED**, \_\_\_\_\_  
PLEASE PRINT YOUR NAME

**DONOR**                     
  **LEGAL REPRESENTATIVE**                     
  **CLOSEST RELATIVE**  
APPROVED BY A COURT OF LAW  
 (TUTOR/CURATOR/MANDATARY)

In the name of:  
**DONOR NAME** \_\_\_\_\_  
PLEASE PRINT THE DONOR'S NAME

**HEREBY ACCEPT**, (place a check mark and your initials below, where appropriate):

**1** Brain removal and autopsy **2** Access to all of the donor's confidential medical files for diagnosis and research and **3** That the donor's brain be preserved and used for the research purposes described in this consent form (and the enclosed brochure) in order to better understand, prevent, treat and cure neurological and mental illnesses:

**YES**    
INITIALS

#### Research into other diseases

That the donor's brain be preserved and used for research purposes into diseases other than neurological and mental illnesses (i.e. diabetes, cancer, vascular diseases):

**YES**    
INITIALS

**NO**    
INITIALS

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE DONOR OR THE LEGAL REPRESENTATIVE

**ADDRESS** \_\_\_\_\_

**CITY/PROVINCE** \_\_\_\_\_ **POSTAL CODE** \_\_\_\_\_

**TELEPHONE** (        ) \_\_\_\_\_ **E-MAIL** \_\_\_\_\_

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE WITNESS

## DOCUMENTS TO BE TRANSMITTED TO THE PATHOLOGIST

It is very important to note that some documents must absolutely accompany the body; otherwise, the brain removal will be refused. The Brain Bank representative, who will have to be contacted at the time of death, will work with you and/or the medical staff to gather together the necessary documents. The Brain Bank representative can be reached by calling the Douglas Hospital at (514) 761-6131, dialing 0, and asking for the Brain Bank. This Brain Bank representative will coordinate every step of the brain donation, will be able to answer all questions or concerns, and will make sure that this ultimate gift will be treated with respect and will be dealt with very efficiently in order to maximize its potential. A Brain Bank representative is always available, 24 hours a day, 7 days a week.

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### The documents that **MUST** accompany the body are:

- 1** The signed consent form  
*(pathologist's copy, please see other side of this page);*
- 2** At least 4 out of 5 copies of the death notice  
*(which is also called an SP3);*
- 3** The donor's clinical summary  
*(which should be as detailed as possible).*

Please Note: If the donor lives in a nursing home, this copy of the consent form (to be transmitted to the pathologist) may be put in the medical file of the donor. If the donor does not live in a nursing home, simply place the pathologist's copy with the personal papers of the donor. However, this consent form should be rapidly accessible at the time of death.

## CONSENT FOR BRAIN REMOVAL, AUTOPSY AND DONATION FOR DIAGNOSTIC AND RESEARCH PURPOSES

### INTRODUCTION

You're aware of the importance of mental health research. Maybe you, or someone close to you, have been directly affected or maybe you've heard about diseases of the brain in general. To help scientists find the causes of neurological and mental illnesses, as well as discover new treatments, we request your permission to remove your, or a close relative's, brain at the time of death, and allow its use for research purposes. This donation would be extremely valuable to the advancement of medical and scientific learning. We ask that you read the enclosed brochure, entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, to learn about the use of tissue—specifically, brain tissue—in research and how the Douglas Hospital Research Centre Brain Bank functions.

### CONSENT

I have read this consent form (as well as the brochure entitled *The Brain Bank: The Hows and Whys of Using Human Tissue for Research*, (hereafter called "the enclosed brochure"). I understand the contents of these documents, I've had the opportunity to ask any questions I may have had about the research, and I am satisfied with the answers provided. I understand that my participation is on a purely voluntary basis, and that I remain free to withdraw at any time without prejudice. Therefore:

I, **THE UNDERSIGNED**, \_\_\_\_\_  
PLEASE PRINT YOUR NAME

**DONOR**                     
  **LEGAL REPRESENTATIVE**                     
  **CLOSEST RELATIVE**  
APPROVED BY A COURT OF LAW  
 (TUTOR/CURATOR/MANDATARY)

In the name of:  
**DONOR NAME** \_\_\_\_\_  
PLEASE PRINT THE DONOR'S NAME

**HEREBY ACCEPT**, (place a check mark and your initials below, where appropriate):

**1** Brain removal and autopsy **2** Access to all of the donor's confidential medical files for diagnosis and research and **3** That the donor's brain be preserved and used for the research purposes described in this consent form (and the enclosed brochure) in order to better understand, prevent, treat and cure neurological and mental illnesses:

**YES**    
INITIALS

#### Research into other diseases

That the donor's brain be preserved and used for research purposes into diseases other than neurological and mental illnesses (i.e. diabetes, cancer, vascular diseases):

**YES**    
INITIALS

**NO**    
INITIALS

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE DONOR OR THE LEGAL REPRESENTATIVE

**ADDRESS** \_\_\_\_\_

**CITY/PROVINCE** \_\_\_\_\_ **POSTAL CODE** \_\_\_\_\_

**TELEPHONE** (        ) \_\_\_\_\_ **E-MAIL** \_\_\_\_\_

**SIGNATURE** \_\_\_\_\_ **DATE** \_\_\_\_\_  
SIGNATURE OF THE WITNESS

*If someone close to you expresses a desire to make an organ donation, tell him or her about the Douglas Hospital Research Centre Brain Bank. We tend to think of organ donation for transplant purposes, but why not also consider a brain donation—a donation of hope!*

*To honor the memory of a loved one and financially support the Brain Bank's activities, you can make a monetary donation. It's a highly effective donation because it helps maintain an organization working in the area of mental health. We issue tax receipts.*

*Cheques may be addressed to:*

*"The Douglas Hospital Foundation / Brain Bank"*

*A brain donation, a precious and ultimate gift that can help advance scientific research — the hope of future generations*



For additional information, please contact:

**The Brain Bank**

Douglas Hospital Research Centre  
6875 LaSalle Blvd.  
Borough of Verdun  
Montreal, Quebec H4H 1R3

Telephone: (514) 761-6131, dial 0, then ask for the "Brain Bank"

Fax: (514) 762-3033

E-mail: [brain.bank@douglas.mcgill.ca](mailto:brain.bank@douglas.mcgill.ca)

[www.douglas.qc.ca](http://www.douglas.qc.ca)