



Thank you for your interest in the Netherlands Brain Bank (NBB)

If you have received this registration form without the accompanying information folder, we recommend that you read this information carefully via www.hersenbank.nl/hersendonatie, or request the information folder by contacting us.

Before you complete this registration form we would like to point out the following:

The aim of the Netherlands Brain Bank is to disseminate brain tissue to scientific research worldwide. The NBB is forced to limit registrations to those disorders that are being researched via scientific research projects. For some disorders this may not be the case, such as for some combinations of disorders. In those cases we may decide registration at the NBB is not possible. If this is the case we will always inform you in writing.

To be able to properly process registrations, the NBB would like to receive the registration form at least 2 weeks before passing away (also when the registration concerns euthanasia or when a terminal patient is expected to pass away shortly).

Also if the donor is legally incompetent, the NBB would like to receive the Registration Form for Representatives of Legally Incompetent Persons at least 2 weeks before passing away.

We recommend that you make a copy or scan of the completed form for your own records, before returning this form to us.

If you have any questions about the above, you can contact us via info@hersenbank.nl, or by telephone via 020 - 566 5499. On working days we have consultation hours by telephone from 9.30 to 11.30 h. Outside the consultation hours you can leave a voicemail message and we will call you back as soon as possible.







Do not complete version 20210927	
Codicilcode:	Codicilnummer:
Cohort:	

Registration form The Netherlands Brain Bank

Surname Male Female

First name(s)

Date of birth

Address

Postal code, city

Phone number Mobile phone number

E-mail address

I have read and understood the information regarding the procedure of donation of tissue to the Netherlands Brain Bank en give hereby my consent to a post mortem autopsy and the removal of the following bodily material to be stored for an indefinite period of time and to be used for scientific research.

Please check:

Brain

Optional (only possible in combination with brain donation):

Spinal cord

Eyes

Cervical lymph nodes

- My medical (and, if applicable, psychological) records may be requested at my treating physician's office for viewing by the employees of the Netherlands Brain Bank.
- My medical records may be processed by the employees of the Nederlandse Brain Bank and stored for an indefinite period of time for future scientific research.
- The bodily materials and anonymized extraction of the medical records (containing no identifiable data) may be distributed to research projects which have been reviewed by the Netherlands Brain Bank. The research projects are conducted in the field of neurological and psychiatric diseases and normal physiological functioning of the brain. This can also concern genetic research.
- The Netherlands Brain Bank or a research group with an NBB-approved research project may make a MRI-scan of my brain. This happens in case of multiple sclerosis and incidentally in other cases.
- I understand that I can withdraw this consent at any time, without providing a reason.

The neuropathological report may may not be shared with my next of kin.

Donor signature:

Signature:

City

Date

Donating your body to science

It is important for the NBB to know whether a donor also donates their entire body to science, so we can act accordingly after death. Are you registered to donate your entire body to science? If so, also note your body donation registration number and include a copy of your registration:

- No
- Yes, via VUmc Registration number: _____
- Yes, via AMC Registration number: _____

The combination of brain donation and body donation is only possible with body donation to VUmc or AMC. If you are donating your body to another university hospital, we cannot register you as a brain donor.

Research during life

May the Netherlands Brain Bank incidentally inform you about research projects you can participate in during life? The NBB will never pass on your personal information to a third party. In case you wish to participate, we will ask you to contact the researcher in question yourself.

- Yes No

Heart Bank

It is also possible to donate your heart. For this, you need to register separately at the Heart Bank (www.hartenbank.nl). It is possible to be both brain and heart donor. Would you like to receive information about the Heart Bank? Yes* No

**If you choose 'Yes' we will forward your name and address to the Heart Bank, they will send you their information.*

How did you hear about the Netherlands Brain Bank?*

For the Netherlands Brain Bank this information is very valuable. This information will only be used to improve our donor communication.

<input type="checkbox"/>	Via the research project I am participating in (a 'cohort study') I was informed about the possibility to become a brain donor. Name cohort study: <input type="text"/>
<input type="checkbox"/>	Via the patient and/or family association of which I am a member. Name association: <input type="text"/>
<input type="checkbox"/>	Via a family member or acquaintance
<input type="checkbox"/>	Via one of the NBB's websites
<input type="checkbox"/>	Via the media
<input type="checkbox"/>	Other <input type="text"/>

**Check whatever is applicable. More than one answer possible.*



Co-Signing

This part of the form should be filled in by someone near to you, such as your spouse or other life partner. If you do not have a life partner (anymore), a signature by an adult child or other adult family member will suffice. If such a person is not available either, a signature by an adult heir or another chosen confidant(e) will suffice.

I hereby declare to be aware of the donor's decision to register as a brain donor at the Netherlands Brain Bank (NBB). I am aware of the consequences of this registration and of the NBB's procedures. I understand that, unless he or she withdraws the consent, this consent will remain valid regardless of the time passing after its signing.

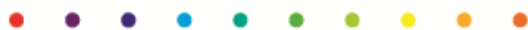
Surname	<input type="text"/>	<input type="checkbox"/> Male <input type="checkbox"/> Female
Initials	<input type="text"/>	
Relationship to donor	<input type="text"/>	
Date of birth	<input type="text"/>	
Address	<input type="text"/>	
Postal code, city	<input type="text"/>	
E-mail address	<input type="text"/>	
Phone number	<input type="text"/>	Mobile phone number <input type="text"/>

City

Date

Signature





Medical questionnaire at registration as brain donor

This questionnaire is to gather information important for your registration. We request that you complete the questionnaire as much as possible and return it to us in the provided envelope. Should you have any questions or have any problems completing the questionnaire, you can contact us by calling 020-5665499.

Thank you in advance for your cooperation!

Please complete in block letters.

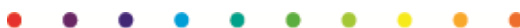
I GENERAL QUESTIONS

Are you left or right handed?	<input type="checkbox"/> Left handed	<input type="checkbox"/> Right handed	<input type="checkbox"/> Both
What is your length and weight?	Length(in cm): <input type="text"/>		Weight (in kg): <input type="text"/>
Are you part of a multiple birth?	<input type="checkbox"/> Yes, namely: <input type="text"/>		<input type="checkbox"/> No
What is (or was) your profession?	<input type="text"/>		
What is your highest level of education (completed / not completed)?	<input type="checkbox"/> Primary education <input type="checkbox"/> Secondary education <input type="checkbox"/> Post-secondary vocational education (MBO) <input type="checkbox"/> University for applied sciences (HBO) <input type="checkbox"/> University <input type="checkbox"/> Other: <input type="text"/>		

II MEDICAL HISTORY

For good and reliable brain research it is necessary that the Netherlands Brain Bank has information about your general medical history, regardless of whether you currently have a disease or not. For this it is necessary that the Netherlands Brain Bank has the name and address of your general physician.

Name general physician	<input type="text"/>	<input type="checkbox"/> M <input type="checkbox"/> F
Name institution (if applicable)	<input type="text"/>	
Address	<input type="text"/>	
Postal code, city	<input type="text"/>	
Telephone number	<input type="text"/>	





NEDERLANDSE HERSENBANK

Are you currently being treated or have you been treated by a specialist in relation to a psychiatric and/or neurological disorder?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If yes, please note the details of the specialist(s) below.</i>
<i>Especially the details of your current specialist(s) are important. In case you still have the details of any previous specialists, please note those too.</i>		
1. Name specialist		<input type="checkbox"/> M <input type="checkbox"/> F
Specialisation		
Reason for treatment		
Name institution/hospital		
Address specialist/institution/hospital		
Phone number specialist/institution/hospital		
Treatment period (from – to)		
2. Name specialist		<input type="checkbox"/> M <input type="checkbox"/> F
Specialisation		
Reason for treatment		
Name institution/hospital		
Address specialist/institution/hospital		
Phone number specialist/institution/hospital		
Treatment period (from – to)		
3. Name specialist		<input type="checkbox"/> M <input type="checkbox"/> F
Specialisation		
Reason for treatment		
Name institution/hospital		
Address specialist/institution/hospital		
Phone number specialist/institution/hospital		
Treatment period (from – to)		

In case this page is not sufficient, would you kindly write the additional details on an extra page?



If you have ever been diagnosed with a psychiatric diagnosis: which diagnosis is/are that, and who determined this diagnosis?

III QUESTIONS ABOUT DIAGNOSES

Could you indicate in the table below with which medical/psychiatric disorder(s) you have been diagnosed?
Because not all disorders may be familiar to you, they are described in the attached list.

Disorder	Have you been diagnosed?
<i>Example:</i> <i>Multiple sclerosis</i>	Yes <input checked="" type="radio"/> No <input type="radio"/>
Multiple sclerosis (MS)	Yes <input type="radio"/> No <input type="radio"/>
Dementia, indicate which type	
Parkinson's disease	Yes <input type="radio"/> No <input type="radio"/>
Autism spectrum disorder	Yes <input type="radio"/> No <input type="radio"/>
ADHD	Yes <input type="radio"/> No <input type="radio"/>
Major depressive disorder	Yes <input type="radio"/> No <input type="radio"/>
Bipolar disease Type I <input type="radio"/> Type II <input type="radio"/>	Yes <input type="radio"/> No <input type="radio"/>
Schizophrenia/psychoses	Yes <input type="radio"/> No <input type="radio"/>
Obsessive compulsive disorder (OCD)	Yes <input type="radio"/> No <input type="radio"/>

Disorder	Have you been diagnosed?
Body dysmorphic disorder	Yes <input type="radio"/> No <input type="radio"/>
PTSD	Yes <input type="radio"/> No <input type="radio"/>
Addiction, indicate to what	
Anxiety disorder, indicate which	
Personality disorder, indicate which	
Progressieve supra-nuclear palsy [PSP]	Yes <input type="radio"/> No <input type="radio"/>
Multi system atrophy [MSA]	Yes <input type="radio"/> No <input type="radio"/>
Amyotrophic Lateral Sclerosis [ALS]	Yes <input type="radio"/> No <input type="radio"/>
Narcolepsy	Yes <input type="radio"/> No <input type="radio"/>

Disorder	Have you been diagnosed?
Maculadegeneration [MD]	Yes <input type="radio"/> No <input type="radio"/>
Retinitis Pigmentosa	Yes <input type="radio"/> No <input type="radio"/>
Rheumatoid Arthritis [RA]	Yes <input type="radio"/> No <input type="radio"/>
Diabetes mellitus Type I <input type="radio"/> Type II <input type="radio"/>	Yes <input type="radio"/> No <input type="radio"/>
Chromosomal aberration: triple X syndrome, Klinefelter syndrome (XXY) or 22Q11-deletion/- duplication syndrome (indicate which)	

Disorder	Have you been diagnosed?
Thyroid disease, indicate which	
Epilepsy	Yes <input type="radio"/> No <input type="radio"/>
Migraine	Yes <input type="radio"/> No <input type="radio"/>
Celiac disease	Yes <input type="radio"/> No <input type="radio"/>
Allergy, indicate which	
Other disorder(s), indicate which	

Do any of these disorders occur in your family? If yes, could you indicate which disorder and which family member?*

Example: 'Parkinson's disease, maternal grandmother'.

* If yes, could you also indicate whether this person is also registered as a brain donor at the Netherlands Brain Bank and indicate their registration number, if known to you.

IV QUESTIONS RELATING TO MEDICAL COMPLAINTS/INCIDENTS

Please check box if applicable and if possible provide further details.

Complaint / incident	Further details: year/date, residual effects (example: paralysis)
<input type="checkbox"/> Head injury without loss of consciousness	
<input type="checkbox"/> Head injury with loss of consciousness	

Complaint / incident	Further details: year/date, residual effects (example: paralysis)
<input type="checkbox"/> Meningitis	
<input type="checkbox"/> TIA	
<input type="checkbox"/> Stroke	
<input type="checkbox"/> Cerebral infarction	
<input type="checkbox"/> Tropical diseases, for example malaria	

Habits		Further details: when, amount, kind, frequency*
Do you smoke? If no, have you ever smoked?	Yes <input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/>	
Do you drink alcohol? If no, have you ever drunk alcohol?	Yes <input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/>	
Do you use drugs? If no, have you ever used drugs?	Yes <input type="radio"/> No <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/>	

*Example: "Since 1978: 10 cigarettes per day", "1990 – 2005: 2 glasses of wine per week".

Medical questionnaire

Do you have a psychiatric diagnosis, or are you a control donor (when you have no psychiatric or neurological diagnosis)? Then we would like to ask if we may contact you once every five years to update your medical information. If you would like to cooperate with this, please indicate here:

I give the NBB permission to contact me once every five years to complete a medical questionnaire.

The NBB may contact me via email regular post

Newsletter

The NBB may inform me about developments once every two years via a newsletter.

If the NBB has your email address we will send the newsletter via email. If not, we will send the newsletter via regular post.

This questionnaire has been completed by:

Name:	Date:
-------	-------

Thank you for your cooperation!

