This document is a translation of the Dutch NBB registration form used by donors. This translation is ONLY to inform researchers about the NBB's informed consent and is not to be used for donor registration.

NEDERLANDSE HERSENBANK

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 alway 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.

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Do not complete	version 20240513
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:	Optional (only possible in combination with brain donation):
☐ Brain	☐ Spinal cord
	☐ Eyes
	☐ Cervical lymph nodes

- The Netherlands Brain Bank may share information with my treating physician's office and request my medical (and, if applicaple, psychological) records.
- My medical records may be processed by the employees of the Netherlandse 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.

I give permission for scientific research with my genome. ☐ **Yes** ☐ **No**
Your genome includes your entire DNA. See the information folder, page 4, what research with your genome means.

I give permission to share the neuropathological findings with my next-of-kin ☐ **Yes** ☐ **No**

Donor signature: Signature:

City

Date _____

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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.

☐	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:
☐	Via the patient and/or family association of which I am a member. Name association:
☐	Via a family member or acquaintance
☐	Via one of the NBB's websites
☐	Via the media
☐	Other, please specify:

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

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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		☐ Male ☐ Female
Initials		
Relationship to donor		
Date of birth		
Address		
Postal code, city		
E-mail address		
Phone number		Mobile phone number

I want to be informed about the neuropathological findings concerning the donor and understand that, if applicable, this can include information regarding a genetic disorder. ☐ **Yes** ☐ **No**

City

Date

Signature

_____

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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?	☐ Left handed	☐ Right handed	☐ Both
What is your lenght and weight?	Lenght(in cm):	Weight (in kg):	
Are you part of a multiple birth?	☐ Yes, namely:	☐ No	
What is (or was) your profession?			
What is your highest level of education (completed / not completed)?	☐ Primary education ☐ Secondary education ☐ Post-secondary vocational education (MBO) ☐ University for applied sciences (HBO) ☐ University ☐ Other:		

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		☐ M ☐ F
Name institution (if applicable)		
Address		
Postal code, city		
Telephone number		

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Are you currently being treated or have you been treated by a specialist in relation to a psychiatric and/or neurological disorder?	☐ Yes ☐ No	*If yes, please note the details of the specialist(s) below.*

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.

1. Name specialist		☐ M ☐ F
Specialisation		
Reason for treatment		
Name institution/hospital		
Address specialist/institution/hospital		
Phone number specialist/institution/hospital		
Treatment period (from – to)		
2. Name specialist		☐ M ☐ F
Specialisation		
Reason for treatment		
Name institution/hospital		
Address specialist/institution/hospital		
Phone number specialist/institution/hospital		
Treatment period (from – to)		
3. Name specialist		☐ M ☐ 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?

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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?
Example: Multiple sclerosis	*Yes ● No O*
Multiple sclerosis (MS)	Yes ○ No ○
Dementia, which type: *Age of onset:*	
Parkinson's disease	Yes ○ No ○
Autism spectrum disorder	Yes ○ No ○
ADHD	Yes ○ No ○
Major depressive disorder	Yes ○ No ○
Bipolar disease Type I ○ Type II ○	Yes ○ No ○
Schizophrenia/psychoses	Yes ○ No ○
Obsessive compulsive disorder (OCD)	Yes ○ No ○

Disorder	Have you been diagnosed?
Body dysmorphic disorder	Yes ○ No ○
PTSD	Yes ○ No ○
Addiction, indicate to what	
Anxiety disorder, indicate which	
Personality disroder, indicate which	
Progressieve supra-nuclear palsy [PSP]	Yes ○ No ○
Multi system atrophy [MSA]	Yes ○ No ○
Amyotrofic Lateral Sclerosis [ALS]	Yes ○ No ○
Narcolepsy	Yes ○ No ○
Myalgic encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	Yes ○ No ○

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

Disorder	Have you been diagnosed?
Thyroid disease, indicate which	
Epilepsy	Yes ◯ No ◯
Migraine	Yes ◯ No ◯
Celiac disease	Yes ◯ No ◯
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.*

Do you have a DBS (Deep Brain Stimulator) device? Yes ◯ No ◯

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, continous treatment)
☐ Head injury without loss of consciousness	
☐ Head injury with loss of consciousness	

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Complaint / incident	Further details: year/date, residual effects (example: paralysis, continous treatment)
☐ Meningitis	
☐ TIA	
☐ Stroke	
☐ Cerebral infarction	
☐ Tropical diseases, for example malaria	
☐ Hepatitis B and/or C	

Habits		Further details: when, amount, kind, frequency*
Do you smoke? If no, have you ever smoked?	Yes ◯ No ◯ Yes ◯ No ◯	
Do you drink alcohol? If no, have you ever drunk alcohol?	Yes ◯ No ◯ Yes ◯ No ◯	
Do you use drugs? If no, have you ever used drugs?	Yes ◯ No ◯ Yes ◯ No ◯	

**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!