

This guide answers frequently asked questions (FAQ) about donating neuro-related body materials, after death as part of a social commitment by yourself or your loved one, to benefit scientific research into neurodegenerative diseases.

FAQ:

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Why consider donating your body materials?

When you choose to donate body material, you often do so not for yourself, but to help others. It is a special form of solidarity: you contribute to the search for better treatments and solutions for future patients with a similar disease. Your gift can make an important difference for the next generations.

Which body materials are useful?

The value of body materials depends on the disease.

The IBB-Neurobiobank focuses on neurodegenerative diseases such as dementias, movement disorders, neuromuscular conditions, and inflammatory diseases of the nervous system.

- For **all diseases**, preserving the brain and cerebrospinal fluid is essential.
- The **spinal cord** is also very valuable and strongly recommended.
- For **muscle and nerve disorders**, small biopsies of muscle and nerve are useful.
- For **movement disorders**, skin biopsies provide important additional information.
- In the same group of diseases, science is increasingly focusing on the **brain-gut axis**. Therefore, small intestinal samples can also be relevant.

You can view this as a cascade: you decide what you wish to contribute. The order of added value is:

brain and cerebrospinal fluid → spinal cord and/or biopsies (muscle/nerve/skin) → other relevant samples such as intestinal tissue.

What happens with my body materials?

After death, the body materials for which you have given permission are removed at the UZA mortuary by the Neurology & Neurobiobank team of the Institute Born-Bunge, linked to the University of Antwerp.

The materials are then carefully preserved in both fixed and frozen formats. They are studied macroscopically, under the microscope, and with immunohistochemical markers.

These examinations have three goals:

1. **Confirming the diagnosis** with certainty.
2. **Supporting scientific research.**
3. **Providing feedback** to doctors and families.

Each sample receives a unique reference number. This guarantees your anonymity: researchers never know your personal details. The Neurobiobank keeps the secure link so that your treating physician receives a final diagnostic report. Your relatives may choose to receive feedback through your doctor. Please note: this process often takes at least six months or longer.

Why does the neurobiobank also need my medical file?

Your medical file contains valuable information about the course of your illness. Combining this data with the tissue research allows scientists to understand the disease more deeply.

Your medical information, like your samples, is always **coded and pseudonymized**, which ensures your privacy.

Why is the informed consent form so important?

Without your written consent, the Neurobiobank cannot act. The form explains everything clearly and asks for your permission.

<https://www.uantwerpen.be/autopsy>

<https://www.bornbunge.org>

- Pages 1–6 provides information.
- Page 7 describes the procedure.
- Pages 8–9 asks for your signature to confirm consent.

In signing, you also allow your medical file to be linked to the preserved samples. This is preferably done before death, as it can be more complicated legally afterwards.

If I have given consent and I pass away, who does what?

It is important that your GP, caregivers, and funeral director are aware that you have signed the form. Shortly after your death, they contact the IBB-Neurobiobank. If death occurs through euthanasia, your funeral director can contact us in advance. We then arrange transport to the UZA mortuary at an agreed time.

Does my body need to be brought within a certain time?

Yes, ideally within 24 hours, and sometimes sooner. In exceptional cases, up to 60 hours is possible, but this is avoided if possible, to preserve quality.

What if death occurs at night or during the weekend?

The Neurobiobank is always reachable by phone:

1. 03 265 2605
2. 03 265 2688
3. 0472 416179
4. 0486 275552
5. 0477 866677
6. 03 265 2570

However, there is **no need to call between 10:30 p.m. and 8:00 a.m.**, as the autopsy is not urgent and can only take place when the mortuary is open. Mortuary availability is also limited on weekends.

Who arranges the transport and who pays for it?

Usually, your funeral director arranges transport. Sometimes the Neurobiobank arranges a specialized service. This is always done in consultation and after telephone contact. Costs are covered by the Neurobiobank according to standard tariffs, as in forensic medicine.

How much time does this take for my family?

The duration depends on what is examined:

- Brain only: about 45 minutes.
- Brain + spinal cord: about 90 minutes.
- With additional biopsies: about 2 hours total.

This means your body is usually returned within 1.5–2 hours.

Nothing of the procedure is **visible** to those who wish to say goodbye, except in the case of baldness. Funeral or cremation can proceed normally.

Research specific to my disease vs. “donating my body to science”?

Your donation to the Neurobiobank is a direct contribution to research into your disease. This is different from “donating your body to science,” which mainly serves medical education and anatomy training.

It is important to reflect on which purpose you wish to support. The Neurobiobank team will guide you and your family in making this choice.

What is the IBB-Neurobiobank?

The IBB-Neurobiobank is a recognized biobank linked to the Born-Bunge Institute and the University of Antwerp.

www.bornbunge.org

It securely stores biological materials (such as blood, cerebrospinal fluid, muscle or skin tissue) and related clinical data.

These materials and data may later be used for scientific research into neurodegenerative and neuromuscular diseases, such as Alzheimer's, Parkinson's, ALS and others.

Your rights?

Participation is voluntary.

You may withdraw your consent at any time. You can inform your treating physician or the biobank (neurobiobank@uantwerpen.be). You will receive written confirmation.

Your personal data are always pseudonymised and treated confidentially.

You have the right to access and correct your data.

You may choose whether to be informed of 'incidental findings' (unexpected results relevant to your health).

Future and secondary research?

Your biological material and data may also be used in the future for other scientific studies. This always takes place under strict conditions:

- Each request must be approved by a competent Medical Ethics Committee.
- Each request is reviewed by the IBB-Neurobiobank Advisory Board.
- Only the minimum necessary amount of material is used.
- Remaining material always returns to the biobank.
- All data and materials are pseudonymized.
- Researchers may not attempt to re-identify participants.
- Both academic and commercial (for-profit) researchers may apply, always under the same conditions and review procedure.

How applications are reviewed?

The procedure is as follows:

1. The researcher submits a project proposal.
2. The proposal is reviewed by a Medical Ethics Committee.
3. The IBB-Neurobiobank Advisory Board screens the project for scientific relevance and compliance with conditions.
4. If approved, a contract is signed regulating the use and return of material.
5. Only then is access to the material or data granted.

Contact

For questions about your participation, withdrawing participation or more information, you can contact:

- Your treating physician
- IBB-Neurobiobank

<https://www.bornbunge.org>

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Summary of conditions for future use

Future use of my sample or clinical data for research purposes is only possible after approval by a competent Medical Ethics Committee and the IBB-Neurobiobank Advisory Board. The following principles apply: the research must be scientifically relevant, only the minimum necessary material is used, remaining material returns to the biobank, and all use is pseudonymized. Both academic and commercial (for-profit) researchers may apply, always under the same conditions and review procedure.