

IBB-Neurobiobank – Information for Participants

Information regarding the IBB-Neurobiobank and your permission

This note gives a summary of the extensive informed consent form (ICF) and the procedures applicable to the future use of body materials and patient data. The purpose of this note is to clearly inform participants and their families.

1. What is the IBB-Neurobiobank?

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

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.

2. 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 or not to be informed of 'incidental findings' (unexpected results relevant to your health).

3. 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 pseudonymised.
- 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.

4. 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.

5. 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 pseudonymised. Both academic and commercial (for-profit) researchers may apply, always under the same conditions and review procedure.

6. Contact

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

- Your treating physician
- IBB-Neurobiobank (neurobiobank@uantwerpen.be, tel. +32 3 265 26 88)

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More information and the full text of the informed consent can be found at:

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

<https://www.bornbunge.be>