

The NCER-PD brain donation programme

Registration – User Guide

If you are considering registering as a brain donor, please read the information provided thoroughly, as it is essential to be well informed about the whole process. We also advise you to discuss this decision with your family and your caregivers. They too need to understand the process, since the brain bank will be in touch with them to ensure a smooth donation process. If you have any questions or would like to further discuss about brain donation, feel free to contact us by phone or email, we will gladly assist you at every stage.

Parkinson's Research Clinic

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Please note that registration is currently only open to study participants who reside in Luxembourg.

You wish to register as a brain donor?

Please have a look at the registration process described here below:

1. Our clinical study team will mention brain donation during your annual visit.

This way, you will be able to make an informed decision during or after the visit. You can also spontaneously inform us of your interest in registering as a brain donor via phone or e-mail.

2. We will fix an appointment with you and a relative (or a legal representative) at the clinic.

During this appointment, our team will inform you about the programme and discuss your questions and concerns. We then will sign the informed consent together.

3. You and your relative (or legal representative) complete a consent form.

This form confirms your decision to become a donor and you thereby allow NCER-PD to collect the brain tissue after your death. It also confirms that your relative or legal representative is informed of your decision, supports it and will implement it after your passing.

4. You will receive a donor card as well as an information sheet for your entourage, and you will be added to our donor list.

- *Please, always carry your donor card with you. It is important that in case of emergency, people who assist you (e.g. medical staff, family members) can find this information. We advise you to carry your donor card close to your ID papers (i.e. next to your ID card in your wallet).*

- *The people assisting you can find both our contact information and the contact information of your relative or legal representative on your card.*
- *If your contact details or other information change (e.g. address, relative, general practitioner, diagnosis), we kindly ask you to notify the study team in order to keep this information up to date.*

We would like to recommend that from time to time, you re-inform your closest relative or legal representative about your choice. This will help to ensure a smooth donation, without difficulties for your entourage or delay in events related to your passing.