

## PERSONAL DATA PROTECTION POLICY

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*November 2024*

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## 1. PURPOSE AND SCOPE

Paris Brain Institute is a private foundation recognized as being of public utility by decree on 13 September 2006. Its aim is to support and develop research into the brain and spinal cord, and it is located at the Hôpital Pitié-Salpêtrière, 47 boulevard de l'Hôpital, 75013 Paris.

Paris Brain Institute is particularly committed to protecting personal data and privacy of all those whom it interacts via all digital or paper means, including its website.

In accordance with the applicable legal and regulatory provisions, in particular Law no. 78-17 of 6 January 1978 relating to information technology, files and freedoms, known as the 'Information Technology and Freedoms' Law, as amended, and European Regulation no. 2016/679/EU of 27 April 2016 (applicable since 25 May 2018) on personal data protection ('GDPR'), Paris Brain Institute, as data controller, processes and protects personal data it collects.

In addition, Paris Brain Institute has appointed a Data Protection Officer, who is the privileged contact for the French Data Protection Authority (Commission Nationale de l'Informatique et des Libertés – CNIL) and the point of reference within Paris Brain Institute for personal data protection issues.

## 2. AUDIENCES

The audiences concerned by the present Policy are in particular employees and applicants, as well as service providers, foundation's partners, patrons, donors, prospects, testators, visitors of our premises, visitors of our websites, partners, researchers... any person in contact with Paris Brain Institute.

Processing of health data for research purposes in the health field is not covered by this Policy and will give rise to a specific institutional Policy.

## 3. CATEGORIES, RELEVANCE AND PROPORTIONALITY OF DATA COLLECTED

Personal data likely to be collected by Paris Brain Institute is in particular:

- Identification data: surname, first name, title, age/date of birth, photo
- Contact data: postal address, email, telephone number
- Transactional data: bank details, amount and date of donation or invoice
- Connection data: date, time, IP address, cookies
- Life data: interests, personal or professional life, family life,
- Etc.

Only data that is adequate, relevant and limited is processed.

We also take care to ensure that your personal data is accurate by updating it regularly.

Depending on the purpose, this data may be compulsory or optional, as specified when the data is collected.

Your data may be collected directly from you (via the contact form, donation form, response to your job application, etc.) or indirectly (via partners, subcontractors, etc.) in compliance with articles 13 and 14 of the GDPR.

## 4. PURPOSES OF PROCESSING

The mission of Paris Brain Institute is to understand how the healthy brain works and the causes and mechanisms of diseases of the nervous system, with the aim of developing treatments rapidly in order to apply them to patients as quickly as possible.

To fulfil its missions, Paris Brain Institute collects your personal data for the following main purposes:

- To manage the Institute's internal and external communications
- To manage subscriptions: newsletters
- To manage applications (jobs, internships, volunteers)
- To respond to your requests (information, exercise of the rights of the data subjects)
- To give you access to information and services
- To ensure the proper administrative management of donations
- To inform and solicit you for fundraising campaigns
- To manage bequests and other donations
- To meet legal, administrative or contractual obligations
- To manage relations with the Institute's service providers
- To collect data for statistical purposes
- To guarantee the security of information systems and premises

Should we use your personal data for purposes other than those defined, we undertake to keep you informed and give you the opportunity to give your consent, where appropriate.

## 5. LAWFULNESS OF PROCESSING

Depending on the processing carried out on your data, Paris Brain Institute relies mainly on one of the following legal bases:

- Your consent to the processing of your data (e.g. for your subscription to our newsletter)
- The legitimate interest pursued in the context of Paris Brain Institute activities and missions (e.g. to solicit you as part of fundraising campaigns)
- The compliance with a legal obligation to which Paris Brain Institute is subject
- The performance of a contract.

## 6. SECURITY MEASURES TAKEN TO ENSURE THE CONFIDENTIALITY, INTEGRITY AND AVAILABILITY OF DATA

We undertake to process your data securely in order to guarantee its confidentiality, integrity and availability. To this end, we undertake to take physical, technical and organizational measures to guarantee a level of security appropriate to the risks for individuals. Security measures are regularly reviewed and adjusted to take account of changing risks.

We attach great importance to working only with service providers and partners who offer sufficient guarantees to comply with French and European regulations on personal data protection and we ensure that the service is formalized in a contract defining the obligations of the parties in terms of data protection.

## 7. STORAGE LIMITATION

We keep your personal data for a period strictly necessary for the purposes for which it was collected. When the retention periods come to an end, your data is deleted or made anonymous so that it can be used without infringing your rights.

## 8. RECIPIENTS OF YOUR PERSONAL DATA

Paris Brain Institute only communicates the data it collects to its internal departments authorized by virtue of their functions and to its appointed service providers insofar as this is strictly necessary to achieve the purpose(s) of the processing. All persons having access to the data are bound by a written and signed confidentiality obligation.

Paris Brain Institute asks all its service providers who process personal data on its behalf to comply with the regulations in force and to respect their obligations towards audiences and authorities.

→ Specific cases of data exchanged with other associations

In order to limit fundraising management costs, Paris Brain Institute may share your data with external partner organizations. You have the right to object to exchanges with other associations for their own fundraising campaigns by exercising your right to object to the exchange directly with the donor service at the following email : [rgpd@icm-institute.org](mailto:rgpd@icm-institute.org)

## 9. TRANSFER OF PERSONAL DATA OUTSIDE THE EUROPEAN UNION

Paris Brain Institute endeavours, as a matter of principle, not to transfer personal data outside the European Union. Nevertheless, Paris Brain Institute may outsource some of its processing and may therefore transfer data outside the European Union. In the event of such transfers, Paris Brain Institute undertakes to take all contractual, technical and organizational measures to guarantee an adequate level of protection for your personal data and to give you the right to access the documents authorizing this transfer.

## 10. YOUR RIGHTS CONCERNING YOUR PERSONAL DATA

In accordance with the applicable laws and regulations on personal data protection, you have the following rights regarding your data:

- The right to be informed of how your personal data is processed.
- A right of access to your personal data.
- A right of rectification of inaccurate personal data concerning you.
- A right to object, on grounds relating to your particular situation, at any time, to processing of personal data concerning you.
- A right to withdraw your consent where it forms the legal basis for the processing.
- A right to restriction of processing (i.e. the right to temporarily block the use of your data; no operations may be carried out on it).
- A right to erase your personal data.
- A right to data portability (i.e. the right to receive the personal data concerning you, which you provided to Paris Brain Institute, in a structured, commonly used and machine-readable format and have the right to transmit those data to a third party of your choice. This right only applies where the processing of your data is based on your consent or on a contract and where such processing is carried out by automated means).

You also have the right to determine what happens to your personal data after your death.

To exercise your rights or if you have any questions about Paris Brain Institute's personal data protection Policy, you can send a request to the attention of our Data Protection Officer:

- By post: DPO, Institut du Cerveau, Hôpital Pitié-Salpêtrière, 47 bd de l'Hôpital, 75013 Paris
- By email: [dpo@icm-institute.org](mailto:dpo@icm-institute.org)

If, after contacting us, you consider that your rights have not been respected, you may lodge a complaint with the French Personal Data Protection Authority:

- ➔ By post : Commission Nationale de l'Informatique et des Libertés (CNIL) : 3 Place de Fontenoy - TSA 80715, 75334 PARIS CEDEX 07
- ➔ Online : <https://www.cnil.fr/fr/plaintes>

## **11. MODIFICATION OF THE PERSONAL DATA PROTECTION POLICY**

Paris Brain Institute reserves the right to amend the Policy at any time to take account of changes in new regulations and practices.