

Information Notice Regarding the Processing of Personal Data for Participants in the American VascBrain study

PROJECT TITLE : « Validation of CADASIL disease biomarkers in an independent cohort of American patients »

PERSON IN CHARGE : Anne Joutel, Research Director at Inserm, Head of Team 6
at the Paris Institute of Psychiatry and Neuroscience

- **Identity and Contact Details of the Data Controller**
We inform you that the processing of your data is under the responsibility of the *Institut national de la santé et de la recherche médicale* (Inserm), acting as the data controller of your personal data, located at 101 rue de Tolbiac, 75013 Paris – www.inserm.fr.
- **Contact Details of the Data Protection Officer**
Inserm Data Protection Officer
By email to dpo@inserm.fr or by postal mail at 101 rue de Tolbiac, 75013 Paris.
- **Purposes of the Processing for Which the Personal Data Are Intended**
The project aims, in the long term, to improve the management of CADASIL patients and to enhance understanding of the pathophysiological mechanisms of this disease in order to identify therapeutic strategies.
- **Legal Basis for the Processing and the Use of So-Called Sensitive Data**
The processing of personal data necessary for the implementation of this study is carried out in the performance of a task carried out in the public interest entrusted to Inserm and requires the processing of your health-related personal data for scientific research purposes.

- **Categories of Data Concerned by the Processing**

Your following data will be transmitted to the investigator and/or to the research coordinating team or to persons acting on behalf of Inserm :

- Identification data (age, sex) ;
- Health data (diagnostic status, type of mutation in the Notch3 gene, clinical and MRI parameters related to CADASIL) ;
- Biological data (results of proteomic or biochemical analyses from blood and cerebrospinal fluid samples) ;
- Data associated with the sample (pseudonymized identifier of the sample).

- **Recipients or Categories of Recipients of the Personal Data**

As part of this research, your data will be transferred to the project lead Anne Joutel, Research Director at Inserm. This transfer is necessary to carry out the statistical analyses conducted by the team Team 6 at the Paris Institute of Psychiatry and Neuroscience (U1266).

- **Retention Period of Personal Data (Identifiable/Pseudonymized) in Active Database and in Archives**

Your data will be kept in active databases within the data controller's secure information systems for 5 years (from 2026 to 2031) and archived for 15 years (from 2032 to 2047). Your data will then be deleted.

- **Rights of Data Subjects and How to Exercise Them**

The data necessary for this project are processed in accordance with the General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016) and French Law No. 78-17 of 6 January 1978 as amended, relating to data processing, files, and freedoms. In accordance with Law No. 78-17 relating to data processing, files, and freedoms and the General Data Protection Regulation (Regulation (EU) 2016/679), you have the following rights :

- A right of access to information concerning you, in order to verify its accuracy and, where necessary, to rectify, complete, or update it.
- A right to rectification of data concerning you.
- A right to object: the right to object at any time to the transmission of your data and to obtain that your data are no longer collected in the future.
- A right to restriction of processing: the right to temporarily block the use of your data; no operations may be carried out on them.
- A right to erasure of data concerning you.

If you wish to exercise these rights, you should first contact the principal investigator of your study (anne.joutel@inserm.fr). You may also contact the Inserm Data Protection Officer by email (dpo@inserm.fr) or by post (Inserm Data Protection Officer, 101 rue de Tolbiac, 75013 Paris).

If, after contacting us, you believe that your "Data Protection and Civil Liberties" rights have not been respected, you may lodge a complaint with the CNIL, 3 Place de Fontenoy - TSA 80715, 75334 Paris Cedex 07, or online at <https://www.cnil.fr>.