

Person in charge of the database :

Institution :

Phone :

Email :

**« Enlightened consent form » for your participation
to the LeukoDataBase (LeukoDB): data & biological sample**

In order to give an enlightened and informed consent, please read the information documents here attached : « Information sheet - Participation in the european database LeukoDB » and « Information update concerning the using of existing biological samples in research on leukodystrophies ».

During a consultation the physician,
I have received written and oral information about :

A. The **use of my data** through the LeukoDB :

- Yes, I have received this information
- No, I have not received this information

B. The **use of my biological samples** within the LeukoTreat project :

- Yes, I have received this information
- No, I have not received this information

I have understood the interests and conditions of my participation to the LeukoDB and its contribution to solidarity-based research.

N.B : in case of genetic tests, I have received specific information on the this test and I signed a specific consent form.

I am aware I have the following rights :

- To withdraw from the project at any stage of it, without penalty or loss of benefits to which I am entitled, and without affecting my medical follow-up.
- To access and to rectify my data stored in the LeukoDB.
- To access global results of the research, once scientifically validated, available on the LeukoTreat website.
- To access research results, when relevant to my health, through the physician in charge of my follow-up.

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I thereby give my consent :

A. The collect, storage and sharing of my clinical and biological data in the LeukoDB :

Data collected is extracted from your medical record, and from research programs. These are biological, radiological, electrophysiological, genetic and cognitive evaluations data. This data is coded so that only a person with a specially defined responsibility (for example a physician in personal care of an individual patient) will retain the key with which the person can be identified

- Yes, I give my consent
- No, I do not give my consent

B. The storage and use of my biological samples :

This consent concerns the use and storage, for medical research purposes, of my biological samples taken in the frame of my medical follow-up.

- Yes, I give my consent
- No, I do not give my consent

For further interrogations concerning my participation to the LeukoDB, I can contact the resource person, as detailed below, at all times.

The participant :

Name, last name :

Date of birth :

Date and signature :

The physician :

Name, last name :

Official stamp :

Date and signature :

(This document is delivered in triplicate: one for the patient, one for the medical file, one for the database)