

Person in charge of the database :

Institution :

phone :

Email :

**Consent form for legal representative
of a minor for his participation in the LeukoDB : data and biological samples.**

You are the legal representative of a minor who is invited to participate in a research program on leukodystrophies.

In order to give an enlightened and informed consent, please read the information documents here attached: « Information sheet for the legal representative of a minor patient. Participation to the european database : LeukoDatabase » and « Information sheet for the legal representative of a minor patient. Information update concerning the use of already existing samples in research on leukodystrophies ».

During a consultation between the participant and the physician,
I have received an information sheet and we have discussed:

A. The use of his/her data through the LeukoDB :

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

B. The use of his/her 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.

Minor's rights (exercized by the legal representative) :

- To withdraw from the project at any stage of it, without penalty or loss of benefits to which the minor is entitled, and without affecting his/her medical follow-up.
- To access and to rectify his/her data stored in the LeukoDB.
- To access global results of the research, once scientifically validated
- To access research results, when relevant to his/her health, through the physician in charge of his/her follow-up.

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I thereby give my consent :

A. To the collect, storage and sharing of clinical and biological data of the minor in the LeukoDB :

Data collected is extracted from his/her 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 authorization
- No, I do not give my authorization

B. To the storage and use of the minor’s biological samples :

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

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

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

If your child is alive, he/she can sign here :

Name, Last name :

Date of birth :

The Physiscian:

Name, Last name :

Date of birth :

Date and signature :

The legal representative:

Name, Last name :

Official stamp :

Date and signature :

(This document is delivered in triplicate: one for the patient or his/her legal representative, one for the medical file, one for the database)