

Person in charge of the database :

Institution :

phone :

Email :

**Authorization form for the legal guardian of a  
protected major for his/her participation in the  
LeukoDB : data and biological samples.**

**You are the legal guardian of a person (« the represented person ») 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 guardian of a protected major. Participation to the LeukoDB » and « information update for the legal guardian of a protected major, on the using of existing biological samples in research on Leukodystrophies ».

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

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
- Non, I have not received this information

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

Represented person's rights (exercized by the legal guardian) :

- 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 represented person 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 represented person’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.

The participant :

Name, Last name :

Date of birth :

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 or his/her legal guardian, one for the medical file, one for the database)*