

You would like to include a patient in the "LeukoDataBase":
What documents should you give him/her?

Depending on patient status, various different documents are available:



PROCEDURE A

Underage
patient



PROCEDURE B

Adult patient
under
guardianship



PROCEDURE C

Adult patient
(with or
without
curatorship)

NOTE: GENETIC TESTS

Information document & Consent form specific to your centre

PROCEDURE A: You would like to include an UNDERAGE patient in the LeukoDataBase → *What documents should you give him/her?*

Doc 1

CHILDREN:
Story about
GEORGE and
LeukoDB

"Information for the legal representative of an underage patient: participating in the European LeukoDataBase"

Doc 2



There are already biological samples from the patient stored in a biobank

OR

A sample will be taken and there are no biological samples from the patient in any biobank



Doc 3

"Information for the legal representative of an underage patient: update document on information on the biological samples already kept for research on leucodystrophies"

Information and consent document from your research centre on sampling and storage of biological samples



Doc 4

"Authorization form for the legal representative of an underage patient on participation in the LeukoDB : data & biological samples"

Doc 5

"Information for patients coming of age on participation in the LeukoDB » + give documents for ADULT patients

PROCEDURE B: You would like to include an ADULT PATIENT UNDER GUARDIANSHIP in the LeukoDataBase → *What documents should you give him/her?*

**Doc
6**

"Information for the guardian of a protected adult patient: participating in the European LeukoDataBase"

+

+

There are already biological samples from the patient stored in a biobank

OR

A sample will be taken and there are no biological samples from the patient yet contained in the biobank

**Doc
7**

"Information for the guardian of a protected adult patient: update document on information on the biological samples already kept for research on leucodystrophies"

+

Information and consent document from your research centre on sampling and storage of biological samples

+

**Doc
8**

"Authorization form for the legal guardian of a protected adult patient on participation in the LeukoDB : data & biological samples"

PROCEDURE C: You would like to include an ADULT patient in the LeukoDataBase → *What documents should you give him/her?*

**Doc
9**

"Patient information: participating in the European LeukoDataBase"



There are already biological samples from the patient stored in a biobank

OR



A sample will be taken and there are no biological samples from the patient yet contained in the biobank

**Doc
10**

"Patient information: update document on information on the biological samples already kept for research on leucodystrophies"



Information and consent document from your research centre on sampling and storage of biological samples



**Doc
11**

"Consent form to be signed to participate in the LeukoDB: data & biological samples"

These documents are valid for ADULT patients under curatorship