



European Management  
Platform for Childhood  
Interstitial Lung Diseases

## **chILD-EU Registry and Biobank**

### **Patient Information and Informed Consent Form For children (aged 8 to 17)**



Patient information and Declaration of Consent  
for children from the age of 8 to 17 years  
„European chILD registry and biobank (chILD-EU)“

Dear patient,

You have been diagnosed with a rare lung disease. We would therefore like to ask you to take part in the European chILD registry and biobank of the chILD EU project. To learn more about the registry and its tasks, you should read the following text. In addition, your doctor will talk to you and with your parents about the registry.

Your lung disease is rare. In your country, only a few more children will develop the same lung disease as you within a year. However, in addition to your illness, there are many other rare lung diseases in children. Because those are so rare, not much is known about them yet. The European chILD-EU Register and Biobank of the chILD-EU project should help to better understand the diseases and to improve the therapies.

For this, we will ask you and your parents exactly about your illness and carry out examinations. Your data and samples are collected and stored. Here, we want to explain what this means:

First of all, your doctor will be asking questions to you and your parents concerning your disease. Additionally, you and your parents will fill out questionnaires asking you how you feel about your disease several times a year. Furthermore, we need biomaterial from you (like urine, mucus, blood etc.). In the case of urine and mucus, we would ask you to submit an additional sample. However, the blood sample is only taken as part of a normal blood sample. This means that you will not get extra prick for this blood sample, but that one more tube will be collected, than in case you get a blood sampling for other reasons. The same is true for a sample of your lung tissue and for lung lavage fluid. Using those samples we want to test if there are changes in the genetic construction of your cells.

Your data is not saved under your name, but only under a number, so that it cannot be easily seen that the data comes from you. Due to the rarity of your illness, the data is stored long-term. When you are 18 years old, we will ask you again if you would like to continue participating in the European chILD-EU register and biobank of the chILD-EU project.

Participation in the register has no direct advantage for you. However, experienced doctors in this area support your doctor in diagnosing and treating your illness. We will also contact you and your parents if you could take part in a new study. For this we need, among other things, your address and telephone number. There is no risk for you by participating in the register.

We will take care that your data can not be read by strangers, i.e. any subjects not authorized to. Your data will also not be passed on to others for research, unless you agree to it. If you agree, your data will only be passed on without reference to your person. This means that you cannot see that the data comes from you

**I hereby consent to participate in the European chILD Registry and Biobank and to storage and processing of my biomaterials and clinical data for the purpose of medical research.**

\_\_\_\_\_  
Patient's Name

\_\_\_\_\_  
Place, Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Physician's Name

\_\_\_\_\_  
Place, Date

\_\_\_\_\_  
Signature



## Additional information according to the European General Data Protection Regulation

### You have the following rights with regard to your data

#### **Right to information:**

You have the right to information about your personal data that are collected, processed or, if necessary, transmitted to third parties in the chILD-EU register (handing over a free copy).

#### **Right to rectification:**

You have the right to have incorrect personal data concerning you corrected.

#### **Right to deletion:**

You have the right to have your personal data deleted, e.g. if this data is no longer necessary for the purpose for which it was collected.

#### **Right to restriction of processing**

Under certain conditions, you have the right to request that processing be restricted, i.e. the data may only be saved, not processed. You have to apply for this. Please contact your investigator or the data protection officer of the chILD-EU registry.

#### **Right to data transfer**

You have the right to receive the personal data concerning you, which you have provided to the person responsible for the chILD-EU register. You can use this to request that this data be transmitted either to you or, as far as technically possible, to another body designated by you.

#### **Right to object**

You have the right to object to specific decisions or measures to process your personal data at anytime. Such processing then generally no longer takes place.

#### **Consent to the processing of personal data and right to withdraw this consent**

The processing of your personal data is only lawful with your consent.

You have the right to withdraw your consent to the processing of personal data at any time. However, the data collected up to this point in time may be processed by the bodies mentioned in the patient information and consent declaration of the chILD-EU register.

**If you would like to exercise any of these rights, please contact** your principle investigator or the data protection officer of your chILD-EU registry centre directly. **You also have the right to lodge a complaint with the supervisory authority (s)** if you believe that the processing of your personal data violates the data safety regulations.

**Data protection:** Contact details chILD-EU register centre

**Person (s) responsible for data processing** at the chILD-EU Register Center (see page 1 of patient information and patient consent)

**Data protection: contact details of head of register of the chILDregister**



European Management  
Platform for **Childhood**  
Interstitial Lung Diseases

<b>Data Protection officer</b>		<b>Data protection supervisory authority</b>	
Name:	Herr Gerhard Meyer Official data protection officer Hospital of the University of Munich	Name:	Bayerischer Landesbeauftragter für den Datenschutz (BayLfD) Prof. Dr. Thomas Petri
Address:	Pettenkoferstr. 8 80336 Munich	Address:	Adresse: Post Office 22 12 19, 80502 Munich Hausanschrift: Wagnmüllerstr. 1, 80538 Munich
Telephone:		Telephone:	Tel.: 089 212672-0 Fax: 089 212672-50
E-Mail	<a href="mailto:datenschutz@med.uni-muenchen.de">datenschutz@med.uni-muenchen.de</a>	E-Mail	

The Federal Commissioner for Data Protection and Freedom of Information  
Husarenstr. 30  
53117 Bonn  
Telephone: 0228-997799-0  
Fax: 0228-997799-550  
E-Mail: [poststelle@bfdi.bund.de](mailto:poststelle@bfdi.bund.de)