

**Patient information and Declaration of Consent  
for children from the age of 8 to 17 years**

**Dear patient,**

You have been diagnosed with a rare lung disease. Therefore we would like to ask you to participate in the European Childhood Interstitial Lung Disease Register and Biobank (chILD-EU register). To inform you about the register and its function, you should read the following text. Additionally your doctor will talk to you and your parents about the register.

The disease of your lung is very rare. In your country each year only one or so other child develops the same lung disease as you. However, besides your lung disease there are many more other rare lung diseases in children. Because of the rarity of those diseases we don't know much about them. The chILD-EU register shall help to better understand the diseases and to improve their therapies.

For this, you and your parents will be questioned concerning your disease and we will do some tests. Your data and your samples will be collected and stored. What that means we would like to explain to you:

First of all, your doctor will be asking you and your parents questions about your disease, additionally you and your parents will receive a questionnaire about your sickness once a year. Furthermore, we need material from you, like urine, mucus and blood. The samples will be taken during routine blood drawing or collection of other samples necessary. That means no extra blood taking will be done, but rather an additional tube will be taken. The same applies to samples from your lungs or lung lavage fluid. Using those samples we want to test if there are changes in the genetic blueprint of your cells.

Your data will not be stored under your name, but rather under a code, so that nobody offhand can tell that the data is from you. Due to the rarity of your disease the data will be stored for non-limited time. When you are 18 years old, we will ask you again if you want to continue to participate in the chILD-EU register.

The participation in the register does not have direct benefits for you. However doctors with much experience in the field of your disease will support your doctor in making a diagnosis and treating your disease. Additionally, we will inform you and your parents if you can participate in new clinical studies. Therefore we need your address and phone number. There are no risks concerning your participation 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 transferred to third parties for research, if you do not agree. If you do agree, your data will be transferred without bearing reference to your person. That means no one can see that the data is from you.

Hereby I, \_\_\_\_\_ (First name; last name), born on \_\_\_\_\_ declare, that I want to participate in the European chILD Register and Biobank.

\_\_\_\_\_  
Place, Date, Signature Physician

\_\_\_\_\_  
Place, Date, Signature Patient