

## Child 6-10 years with Interstitial Lung Disease (ChILD)



European Management  
Platform for Childhood  
Interstitial Lung Diseases

### ChILD-EU Database, Biobank and Observational Study.

You are invited to take part in a research project. Hospital Research tries to find answers to questions about why people are unwell. This leaflet explains the research, but if it is not clear or you have questions please talk with your parents or your hospital doctor.

#### **Why are we doing this research?**

Your doctor tells us that you have a problem with your lungs. This isn't a common problem like asthma, but one that doesn't happen in many children. Because it is uncommon we don't know as much about it as we would like. If we knew more then we might be able to give better treatments.

This research is to try and learn more about uncommon lung problems. We are asking children across Europe to help us. If you and your parents agree we are going to collect information from your visits to hospital and store them in a patient database. A patient database collects and stores information from lots of people on a computer. We will also ask to store your x-rays and other tests in one place with those of other children who have lung problems (this is called a biobank).

If we learn more about lung problems such as the one that you have we can help teach other doctors about it so that they may provide better care. We can also help give more information to parents and children.

#### **Do I have to take part?**

No. It is up to you. Talk to your parents about it. If you decide not to take part it won't affect the treatment you will receive in any way.

#### **What will happen if I do take part?**

The doctors you see ask lots of questions and do tests to find out what is wrong. We will put all this information into a patient database (and biobank) on a computer. There are some doctors who know a lot about uncommon lung problems. We will ask them to look at the information on the database and tell us if they have any ideas that might help make things better sooner. They will tell your doctor what they think. When you first find out you have an uncommon lung problem your doctor will see you often. In this next year we will collect information when you see your doctor at the hospital. After that we will update the database once a year with information on how you are doing.

## **Are there any extra tests?**

Who you are comes from your mum and dad. We want to take blood samples from you and your parents to see if there is a reason why you have this uncommon lung problem. If you agree we will try and take this sample when your doctor is already taking blood for another test.

## **Will anyone else know I'm doing this?**

Only your doctors, nurses and the research team will know that you are taking part in this research.

We will be storing information on computers, but your hospital visit information will not have your name stored in the same place. For the study we will use a special number to tell us who you are on the database.

## **Will joining in help me?**

We don't think there will any direct benefits to you from this study but it could help children in the future who have similar lung problems.

## **Can I stop taking part if I don't want to carry on?**

Yes. You are free to stop taking part in the research at any time without giving a reason. Just tell your parents, doctor or nurse. They will not be cross with you and this will not affect the normal treatment you receive.

**Thank you for reading this. If you have any questions, please talk to your parents or the nurses and doctors who you see at hospital.**

## PARTICIPANT ASSENT FORM

Participant's Name	
Study Number	
Title	ChILD-EU database and observational study.
Principal Investigator	

<i>Child (or if unable parent/carer on their behalf) should <b>tick/cross box they agree with</b></i>	YES	NO
Has somebody explained this project to you?		
Do you understand what this project is about?		
Have you asked all the questions you want?		
Have you had your questions answered in a way you understand?		
Do you understand it's OK to stop taking part at any time?		
Are you happy to take part?		

If **any** answers are 'no' or you don't want to take part then don't sign your name!  
 If you **do** want to take part then you can write your name below

Your name .....

Date .....

The doctor who explained this project to you needs to sign too

Print name .....

Signature .....

Date .....

Thank you for your help.

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records