

Parental Information and Consent Form for Bloods



European Management
Platform for Childhood
Interstitial Lung Diseases

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

Why am I being asked for a blood sample?

To better understand the genetics of ChILD we would like to take a blood sample from all biological parents of participants on the above study. This sample will be stored for future use should a genetic test look promising for ChILD in terms of helping with diagnosis or treatment. The doctors helping us with this study will be informed of any tests that become available and that could be relevant to you and/or your child. The blood samples will be transferred to the biobank in Dr. von Hauner Children's Clinic, Ludwig Maximilians University Munich, Lindwurmstr. 2a, 80337 Munich where they will be analysed and stored.

Do I have to take part?

No. Participation is entirely voluntary and if you do not wish to take part then this will not affect your child's participation on the study or their standard of care.

How much blood would you want to take?

We will take approximately 10 ml of blood which is the equivalent of 2 teaspoons.

Is there any risk to having a blood sample taken?

Standard blood taking procedures will be used and the blood will be taken by a doctor, nurse or phlebotomist qualified to do so. Some people may experience discomfort and mild bruising when having blood taken.

Will my sample have my name on it?

No. A study number will be used to identify your sample not your name. The clinical information for the study and the personal information of those who take part are kept on separate databases. This is called pseudo-anonymisation. The researchers in the biobank will only be able to identify samples by their study number.

Will my blood only be used to study ChILD?

We would like to store your blood for future genetic studies to help assist future medical research. You can choose to opt out of this if you wish in the options below.

<u>Please initial boxes you agree with</u>	
I have read and understood the above information and had the opportunity to ask questions which have been answered to my satisfaction.	— — —
I agree to provide a blood sample for the purposes of genetic analysis to aid with diagnosis.	— — —

<u>Please initial either the “Yes” or “No” box.</u>		
	YES	NO
I consent to my sample being used in future research into chILD. I understand that I can withhold consent to this part of the study and it will not affect my child’s general participation in this study	<input type="checkbox"/>	<input type="checkbox"/>
I consent to my sample being used in future research involving genome wide analysis.	<input type="checkbox"/>	<input type="checkbox"/>

Parent’s Name (Print)

Parent’s Signature

Date

Name of person taking consent (Print)

Person taking consent (signature)

Date

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