European Management
Platform for Childhood
Interstitial Lung Diseases

3. Patient Information and Declaration of Informed Consent

a. Guardians of children under 18

European Management
Platform for Childhood
Interstitial Lung Diseases

Patient Information and Declaration of Informed Consent for the Research Project "European chILD Register and Biobank" of the European network for rare lung diseases in children (chILD-EU register)

Dear Parents,

Your child was diagnosed with an interstitial lung disease (children´s interstitial lung diseases – chILD) or a disorder masquerading as an interstitial lung disease or a chronic interstitial lung condition of unknown ethology.
We would therefore like to ask you for your child's participation in the European register and biobank of the chILD-EU project. The aim and procedure will be explained in the following. The participation is voluntary. Please contact your child's doctor if you have any questions or want to know more.

...

European chILD Register and Biobank,
Kids Lung Register Foundation (KLR e.V.)

Name/stamp of doctor:

Tel.:

_____

(Patient/LAST NAME, first name)

_____

Date of birth: _____

Summarized explanation of the project:
Interstitial lung diseases in children are very rare and heterogeneous. In order to research the natural course, risk factors, treatments possibilities and to better investigate the reasons for the development of childhood interstitial lung disease **(chILD)** we would like to store and analyse more detailed information about both symptoms, clinical data, quality of life and biological material from your child . The handling of the data and the biological material is specified in the contract .Your child´s data are secured by the mechanisms provided, i.e. the organization of the database and the handling of your child´s biological material make it impossible for unauthorized persons to identify your child. The project was approved by the responsible ethics committee and is described in detail below.

Who conducts the trial?

The **European chILD Register and Biobank (chILD-EU register),** held by the non-profit Kids Lung Register Foundation (KLR e.V.), conducts the clinical trial and consists of several European academic parties. The coordinator of this research association is Prof Matthias Griese, who can be contacted at the following address:

Prof Matthias Griese
Dr. von Hauner Childrens´Hospital
University of Munich
Lindwurmstraße 4
80336 Munich
Germany
Tel ++49 89 4400 5 7871
Fax ++49 89 4400 5 7872
E-mail: matthias.griese@med.uni-muenchen.de

Currently the European chILD-EU Register and Biobank is managed by a number of parties and third-parties, working together in the **chILD-EU** Network. This Network is supported in its work by an Ethics Board and a Data and Safety Monitoring Board. The Boards advise the management committee of the **chILD-EU register** in all aspects of data protection, ethical issues in genetic testing and performing register based clinical trials and all other relevant areas of ethics. Other physicians and scientists may also join the European chILD**-EU** Register and Biobank, if their clinical experience qualifies them sufficiently. In that case, a written agreement between the Kids Lung Register Foundation (KLR e.V.) and the scientist on the spot regulates his/her rights and duties, especially with regard to data protection. Further information, including information specifically for patients, and updated contact details are available on the research network (www.childeu.net).

What this trial is about

The primary aim of the registry is to characterize as comprehensively as possible the natural course and treatment effects of various forms of childhood interstitial lung diseases (children´s interstitial lung disease – chILD)

For the existing European chILD**-EU** Register and Biobank we want to record and carefully characterize a cohort of chILD patients, determine the value of outcomes used for the patients, assess treatment variations used and offer participation in clinical studies with treatments. This should contribute to a better understanding of the disease and to the development of new and effective treatment methods. In order to achieve this goal, patients with rare childhood lung disease or lung disease that can mimic chronic interstitial lung disease or chronic respiratory symptoms of unknown ethology as well as patients with other lung diseases (chronic bronchitis, pulmonary malformations, and pulmonary hypertension) are included in the chILD-EU register. In order to be able to detect underlying genetic changes in the occurrence of frequent familial chILD cases, genetic analyzes of family members of the patients can also be carried out, if this is desired. For this reason, family members can also be included in the chILD-EU register

For patients with childhood interstitial lung disease (chILD) To achieve the goals mentioned above ,detailed information about your child medical history / symptoms and quality of life are not only recorded with the help of questionnaires, but also medical findings from routine examinations are recorded in a structured manner and stored in a database managed by us . The diagnosis of rare lung diseases in childhood is not easy, so we would also like to have the diagnosis made by your child treating doctor confirmed as part of an independent and interdisciplinary assessment process, or, if not yet done, provide advice on finding the diagnosis

Blood, pulmonary lavage fluid, urine, sputum, buccal swabs, and/or tissue samples), that were taken from your child as part of routine measures or specifically for research purposes will be archived in a central biobank in Munich. In conjunction with the stored clinical data, these biological materials can be used to detect new mechanisms for the development of this disease. This is an indispensable part in the development of new therapy options. For future scientific questions, it may be necessary that the biomaterials to be examined are still capable of division. For this reason, we want to enable cellular components of the biomaterials to divide.
On the blood samples we can a. conduct genetic studies and gene expression studies. The aim is to identify factors that enable a reliable diagnostic classification of the disease using a blood test.
In cases of presumably genetically caused cases of rare lung diseases, we want new genome-wide genetic procedures, i.e. Use genetic tests. “Genome-wide genetic procedures” attempt to capture the information of your child's complete genetic makeup as completely as possible (“whole exome sequencing”). For this, sequencing techniques are used that cover parts or all of the genome. This should identify the factors / genes responsible for triggering the disease. There is a potential risk in genome-wide studies that your child can be identified based on the genetic data.
It is quite possible that observations can be made while examining your child biomaterial, which can be of great importance to you and your relatives. For example, your child could be identify with a gene mutation as a disease trigger and it would be entirely possible to investigate this in close family members if your illness occurs frequently in your family. Even if this knowledge does not directly improve your child treatment options, the detection of certain gene mutations can lead to the development of more targeted, i.e. better, forms of treatment that your child could possibly benefit from. One or more factors that allow a reliable prognosis of the further course of your child disease could also be discovered. On the one hand, this precise prediction of your child course of the disease could be quite positive, for example, in the case of a planned lung transplant, but on the other hand it could also be a burden for you and your child if the result is not very positive and treatment options are not yet available.

As there will be a look at the whole genome it is possible to find genes which are likely to cause a different disease that have nothing to do with the reason for which your child was included in the **chILD-EU register**. For example, this may affect the risk of certain tumour diseases or the status of a carrier for an inherited disease. We don´t expect to find those, as we don´t analyse those genes systematically. We do not expect such secondary findings and therefore do not collect them systematically. Such findings can be communicated to you on request, but no guarantee of completeness can be given.

Photographs can be very helpful in confirming a diagnosis. As part of this study, you are being asked to provide consent to the study team to access any medical photographs taken of your child by the treating doctor or the study team and stored with your children´s medical records and upload them in the **chILD-EU register** or transfer them to university and non-commercial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the **chILD-EU register**. These pictures may include unique features which may identify your child. It may also include pictures of your children´s face. This part is voluntary. If you provide consent now, you have the option to withdraw your consent later.

What we are asking you to do

After inclusion of your child in the project, we will ask you to do the following:

- Completing a questionnaire on your child`s medical history and quality of life for the specified time point
- The consent that the treating doctor, who also obtains your consent to carry out this study, fills out a questionnaire with a detailed description of your medical history and forwards it to the children's lung registry e.V. In addition, sufficient pseudonymized doctor's letters and test results can be forwarded to the chILD-EU register. Pseudonymized means that numbers and / or letter codes are used to encrypt the samples. As part of the study, the samples are then processed under this code and not under your name. Subsequent assignment of the data to the person is only possible using a code key, which is stored separately from the data.

- give the treating as well as consenting physician of you permission to pass clinical findings as well as molecular biological analyzes that were made before or during your participation in the registry (results from the physical examination, blood tests, endoscopy of the airways, ultrasound scans, lung function tests, exercise tests, x-rays, and images from high resolution computer tomography (HR-CT) scans, exome analyzes, other sequencing, etc.) to the children's lung registry (KLR) e.V. as the holder of the chILD-EU registry.

- The consent that the attending physician, who also obtains your consent to carry out this study, may forward images of imaging procedures that have been taken in the meantime Transfer ownership to the Kinderlungregister eV of all biological materials which were taken from your child by the treating doctor during routine measures and which are no longer required for your further treatment,. Among the biosamples collected during routine procedures that we would like to store centrally in our biobank are blood, urine, sputum, buccal swabs, the so-called pulmonary lavage fluid and/or tissue samples from lung biopsies, including wax blocks and lung transplants that are no longer needed.
- We would also like to ask you to transfer the ownership rights to samples, which were taken from your child for research purposes by the informing doctor, to the Kinderlungregister e.V. Among the biological materials we are asking your child to donate specifically for this research project only include blood samples (approx. 5 ml for infants and young children, approx. 10 ml for older children and adolescents). The blood samples will be taken at routine blood sample collections, so that an additional puncture of a vein is usually not necessary. These blood draws will be done multiple times throughout the study. Your child´s right to self-determination with regard to information remains unaffected by this transfer of ownership, i.e. if you wish to withdraw your consent for your child participation in the registry all of your child archived biological materials can be completely anonymized or destroyed. Anonymised means that all person-identifying data about you and your samples and the samples determined from them are removed. An assignment to the person is then no longer possible.

Benefits of participating in this trial

You benefit from the help in securing your child diagnosis and, if necessary, therapy by an independent team of experts. In addition you will automatically be informed of the opportunity to take part in clinical trials, if your child meets the entry criteria set for this and if you wish. Finally, you will also benefit from new knowledge about the origin of your child´s disease. If important new findings were obtained during the trial, you would, after consultation of the Ethics Committee, be informed without delay and, in the

case of any doubt, your child will be offered the chance to have these factors investigated in your child´s individual case. This would also apply to the results of genetic tests if you consent to the execution of such tests and would also like to be informed about these results. If relevant results are found in this area, the ethics committee will decide together with the governing body of the European **chILD register** how you will be informed about these results and which accompanying services (e.g. genetic counselling) can be offered.

For patients with other diseases
The relevant clinical data and biomaterials, which were taken either during routine examinations (blood, pulmonary lavage fluid, urine, sputum, buccal swabs and/or tissue samples) or specifically collected for research purposes (blood samples only) are archived centrally in a biobank in Munich
Additional blood samples for research purposes are also taken during routine examinations, so that additional vein piercing is not necessary. During the routine examination, only 10 ml of additional blood is taken (this corresponds to approximately 2/3 tablespoons) We carry out genetic tests and gene expression studies on blood samples with the aim of determining specific factors that allow a safe diagnostic categorization of the various forms of lung diseases in childhood.
Together with the stored clinical information, this will allow a conclusive comparison of data from patients with childhood lung diseases and patients with other diseases, assuming a similar age range and degree of disease.

For family members of patients with rare interstitial lung diseases in childhood, with and without an increased family history of Lung diseases
As it is expected that the some of chILD cases are genetically determined, genetic material from family members will also be required to reliably identify genetic factors that are responsible for the occurrence of the disease in your family. For this we will either need a blood or oral mucosal sample from you. We also ask for the completion of a patient questionnaire, a clinical examination by one of our physicians and a lung function test. Your clinical data and biomaterials regarding data protection will be treated just like the ones from your family members.

For all patients
Your child´s participation in this trial/research project is voluntary. You can stop participation of your child at any time, without giving reasons and without affecting your child medical care or your relationship with your doctor. However, your child can be excluded from the trial if medical or organizationally required. Please notify your treating doctor of withdrawal of your child participation in the register. You can decide whether the re-identifiable data and the biomaterials of your child should be deleted or whether they may be used anonymously for further research projects. As soon as the reference to the biomaterials and the other data to your child have been deleted, destruction is no longer possible. In addition, data from analyses already carried out can no longer be removed.

Risks of participating in this trial
Your child's participation in the European chILD register and biobank, there are no additional costs for you However, we would like to point out that you will not be paid any expenses and that travel expenses cannot be reimbursed. The blood samples are taken as part of routine diagnostics, which means that no additional venipuncture is necessary, so your child should not incur any additional risks. The risks of drawing blood during routine diagnostics include the formation of small bruises at the injection site. In rare cases, permanent nerve damage can occur in the area of the injection site. The amount of blood drawn will not exceed a total of 2/3 of a tablespoon (10 ml).

Your child´s data and samples are secured

The institution responsible for processing your child´s data is the Kids Lung Register Foundation (KLR e.V.). At the moment the coordinator of the European chILD Network is Prof. M. Griese, Ludwig-Maximilian University Munich (for contact details, see above). You can find out who the current data processor is by visiting the consortium's website (www.childeu.net).

For reasons of data protection, your child´s medical data (i.e. your previous history, medical findings, treatment methods, treatment results, quality of life data, prescribed drugs) and identifying data (i.e. the name, address and complete date of birth) will be stored separately at two different sites:

- The above-mentioned and medically relevant data, i.e. history, medical findings, the types of treatment, the prescribed medication and your child sample data are stored in a medical research database in pseudonymised form (for example your child identifying data, in particular name and address, are identified by Number replaced) saved. Identification using the pseudonym alone is not possible. This central treatment database is managed on our behalf in a private high-security data centre that specializes in sensitive data. We ensure that the data centre complies with an appropriate standard of data protection and data security. This pseudonymized medical data can be viewed by other doctors and scientists registered in the register.

- Your child´s identifying data and your child identification number are stored separately from the medical data in the computer centre of the University of Giessen. These personal data (contact details) are treated confidentially. Your contact details are required in order to be able to contact you or your child at a later date and to inform you about relevant results of the assessment by the independent panel of experts or examinations carried out by this research association, as well as possible participation in further clinical studies, if you agree to this.

Only a limited number of people have access to your child's data. These people are bound by a duty of confidentiality. The data are protected against unauthorized access and may only be used for the research project. Only a small, authorized circle of employees has access to the contact data stored in Giessen, and only if this has been decided by mutual consent through a vote by the ethics committee (see above) led by an independent expert and the management committee of the European chILD-EU register and biobank. Your child's contact details will never be passed on to another third party.

For quality assurance, so called monitors can be permitted access to the data for a limited period. Therefore a decision by the management committee of the **chILD-EU register** is necessary. Monitors are bound by a duty of confidentiality.

The blood, pulmonary lavage and tissue samples taken from your child, i.e. the biomaterials, are collected centrally at the University of Munich under the direction of Prof. M. Griese (see above) and used in the scientific investigations planned within this research association. These samples are also pseudonymized, i.e. stored and processed centrally under an identification number. The data relating to these samples are stored in the central treatment database under this identification number

In order to carry out certain scientific questions, it may be necessary to pass on the biomaterials derived from your child - as well as clinical data. In this case too, this will only be done in pseudonymized form. The management committee of the European **chILD registry** and biobank decides on such a transfer of clinical data or biomaterials for scientific purposes after consultation with the ethics committee.

If your child is treated at a center other than Dr. Haunersches Children's Hospital, but they already know your child's identity as part of a co-treatment (e.g. advice on diagnosis or therapy), the treatment team of Dr. Haunersches Children's Hospital may also support data for the **chILD-EU** register, knowing your child name. The treatment team is subject to medical confidentiality towards third parties and receives a copy of the declaration of consent from the **chILD-EU register** and biobank. Of course, the data is only stored in a pseudonymised manner in the register.

The long-term archiving of your child's data and biomaterials in the chILD EU register is guaranteed by the non-profit association Kinderlungregister e.V. You can request information about your child´s stored data at any time. You have the right to have incorrect data corrected. You have also the right to revoke your consent to the processing of your personal data or to have your personal data deleted at any time, unless the provisions of the law conflict with such a request. If you withdraw from the trial, or if the research project is stopped, no further data or biological materials will be collected. All existing data and biomaterials are effectively anonymized by irreversibly deleting the personal data records. This means that this data and biomaterials can no longer be related to you. The study results will be published without personal reference to you.

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 any time. 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 principal 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)

Dataprotection officer		**Dataprotection supervisory authority**	
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
Adresse:	Pettenkoferstraße 8 80336 Munich	Adresse:	Adresse: Post office 22 12 19, 80502 Munich Hausanschrift: Wagmüllerstr. 1, 80538 Munich
Telephone:		Telefon:	Tel.: 089 212672-0 Fax: 089 212672-50
E-Mail	datenschutz@med.uni-muenchen.de	E-Mail	

Data protection: contact details of the federal head of register of data protection

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

Declaration of Informed Consent

Patient (LAST NAME, first name): _____

Date of birth: _____

Place of birth: _____

(The original declaration of informed consent is kept by the Investigator; the parent receives a copy of the declaration of informed consent. The patient information remains with the patient, in the case of a co-treatment agreement, a copy can be handed over to the treatment team of Dr. Haunersches Children's Hospital)

The information sheet we/I received gave us/me an overview about the clinical trial in which our/my child should be included.

On _____ (date) at _____ (time), Dr._____, had a detailed informative discussion with me/us.

Additional information was given regarding following issues

_____

_____

_____

We/I had the opportunity to ask questions. These questions have been answered satisfactorily and in full. We/I have received the written parent information on the above-mentioned trial/research project and have been given a copy of our/my signed “Declaration of Informed Consent”. We/I have read and understood both documents. We/I were/was given sufficient time to think in peace and quiet and decide whether to participate. We/I do not have any further questions at present.

We/I hereby declare that our/my child will take part in the above-mentioned trial/the above-mentioned research project. We/I have been advised that our/my child´s participation in the trial/research project is voluntary, that our/my child does not incur any disadvantages by refusing to participate and that we/I have the right to stop the participation of our/my child at any time, without giving reasons.

We/I agree to the collection, storage, processing and transmission of information on our/my child´s health and biological materials within the context of the trial "European chILD Register and Biobank" described in the Parent Information and were/was informed about our/my rights in handling our/my data

We/I also agree that authorized employees of the domestic and foreign supervisory authorities and of the sponsor may have access to our/my child´s personal data in the course of their duties for monitoring purposes. These persons are bound by a duty of confidentiality. We/I have also been informed of the data protection rights of my/our child. Due to the rarity of our/my child's disease, we/I agree to the non-limited storage time.

_____,_____

<Place> <Date> <1th legal guardian> <LAST NAME, first name> <Signature>

_____,_____

<Place> <Date> <2nd legal guardian> <LAST NAME, first name> <Signature>

(a)We/I hereby expressly declare that we/I transfer all rights of ownership to Kinderlungregister (KLR) eV, which is the holder of the European chILD-EU register and biobank of all biological materials previously collected by the doctors treating our/my child, …….. (names) and, further, all rights of ownership of the biological materials to be collected in the future by the doctor obtaining our/my informed consent for this trial to the European chILD Register and Biobank.
Yes ( ) No ( )

(b) Further we/I agree to the immortalization of cells from the biological materials obtained from our/my child for the investigation of lung diseases.
Yes ( ) No ( )

(c)As far as possible, we/I was informed by my child treating doctor about the purpose, type, scope, meaningfulness and consequences of genetic tests, as well as possible psychological stress caused by the findings. We/I was informed that we/I can withdraw our consent at any time and without giving reasons, as well as the right to not know, even after the findings are available. We/I was informed about the possibility of genetic consultation after the result was available.
Yes ( ) No ( )

(d) Irrespective of my child basic participation in the trial, we/I agree to the performance of genetic tests on the biological materials obtained from our/my child for the investigation of lung diseases.
Yes ( ) No ( )

(e) We/I hereby expressly declare our/my wish to be informed in a suitable way about knowledge obtained from any new and relevant genetic tests of my child´s biological materials.
Yes ( ) No ( )

(f) We/I agree that the results of previous and in the future conducted diagnostic tests including genetic analyses are made available to the register. This also includes the primary data of e.g. Exome analyzes, genome sequencing etc., so that it is avoided to collect these data again
Yes ( ) No ( )

(g) We/I hereby expressly declare our/my wish to be informed about clinical trials investigating the safety and/or efficacy of certain drugs, for which our/my child could, in principle, be considered, on the basis of the status of our/my child´s disease.
Yes ( ) No ( )

(h) We/I also wish to be informed about new knowledge obtained in the context of the research activities of the European chILD-EU Register and Biobank, if these have been obtained from our/my child´s biological materials and permit conclusions about the further course of our/my child´s disease.
Yes ( ) No ( )

(i) For the transmission of information or for the collection of further historical data, I/we agree that the informing doctor / study doctor or appropriately trained study staff will contact me/us directly or via my family doctor / treating doctor by telephone or in writing.
Yes ( ) No ( )

(j) We/I agree that pseudonymized data and biosamples of our/my child are transferred to university and non-commercial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the chILD-EU register.
Yes ( ) No ( )

(k) We/I agree that pseudonymized data and biosamples of our/my child are transferred to industrial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the chILD-EU register.
Yes ( ) No ( )

(l) We/I allow the use and storage of any photos (by uploading them to the chILD-EU register), which are part of my children´s medical file, including any photos of our/my children´s face.
Yes ( ) No ( )

(m) We/I allow the study team to take pictures of our/my child for the patient file and to upload them to the **chILD-EU** register including any photos of my face.
Yes ( ) No ( )

(n) We/I agree that pseudonymized pictures of our/my child are transferred to university and non-commercial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the **chILD-EU** register and biobank for the investigation of lung diseases.
Yes ( ) No ( )

(o) We/I agree that the data and biological materials of our/my child are kept in the register in case of death or after our/my child participation has been withdrawn
Yes ( ) No ( )

In case of allowing further storage of the data and biological materials of my child it is done as currently pseudonymized ( ) or I/we wish that this is done anonymized* ( ) after my child withdrawal

- anonymized means that research results can not be traced back to the patient and therefore possibly important information for other family members can not be communicated.

I alone have the custody of my child ( )

_____,_____

<Place> <Date> <1 legal guardian> <LAST NAME first name> <Signature>

_____,_____

<Place> <Date> <2 legal guardian> <LAST NAME first name> <Signature>

_____,_____

<Place> <Date> <informing physician> <Signature>

If more than two relatives of the patient give their consent, print it out again page 15 and mark it, accordingly and number the relatives!

For relatives:

Relative 1 **Relatives degree:** : _____

I agree that data concerning the medical history and biological materials (blood samples or buccal swab) from our/me is/are collected and stored for research purposes and that genetic tests are performed using theses biological materials (e.g. exome analyzes, genome sequencing etc.).
Yes ( ) No ( )

I would like to be informed about the results of the genetic tests through the informing doctor.
Yes ( ) No ( )

I allow the use of any photos which are part of my medical file, including any photos of my face.
Yes ( ) No ( )

I would like to be informed about the results of the genetic tests through the informing doctor.
Yes ( ) No ( )

I allow the study team to take pictures of our/me for the database, including any photos of my face.
Yes ( ) No ( )

I agree that pseudonymized pictures of our/me are transferred to university and non-commercial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the chILD-EU register.
Yes ( ) No ( )

I have the right to stop our/my participation in the chILD-EU register at any time, without giving reasons. On demand all data and biological samples collected up to then need to anonymized or deleted.

_____,_____ _____ _____ _____

<Place> <Date> <Relative 1> <LAST NAME first name> <Signature>

_____, _____ _____

<Place> <Date> <informing physician> <Signature>

>

.

For relatives:

Relative: **Relatives degree:** _____

I agree that data concerning the medical history and biological materials (blood samples or buccal swab) from me are collected and stored for research purposes and that genetic tests are performed using theses biological materials (e.g. EXOME analyzes, genome sequencing etc.).
Yes ( ) No ( )

I would like to be informed about the results of the genetic tests through the informing doctor.
Yes ( ) No ( )

I allow the use and storage of any photos (by uploading them to the chILD-EU register), which are already part of my medical file, including any photos of my face.
Yes ( ) No ( )

I allow the study team to take pictures of me for the patient file and to upload them to the chILD-EU register including any photos of my face.
Yes ( ) No ( )

I agree that our/my pseudonymized pictures are transferred to university and non-commercial research institutions for research purposes in case of consent of the management committee and the Ethics Board of the chILD-EU register and biobank for the investigation of lung diseases.
Yes ( ) No ( )

I have the right to stop our/my participation in the chILD-EU register at any time, without giving reasons. On demand all data and biological samples collected up to then need to anonymized or deleted.

_____,_____ _____ _____ _____

<Place> <Date> <Relative(s)> <LAST NAME first name> <Signature>

_____, _____ _____

<Place> <Date> <informing physician> <Signature>