

## Parental declaration of consent for participation in the NEOCYST registry

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## Parental declaration of consent for participation in the NEOCYST registry

I, \_\_\_\_\_, give my consent for my child \_\_\_\_\_, date of birth \_\_\_\_\_, to participate in the NEOCYST study, as long as my child is agreeing to do so. I am aware that the participation is voluntary. I am aware that I am free to withdraw my data privacy laws consent at any point in time, without cause and without any consequences for my child's treatment by contacting the person in charge listed on the parent information. I have been made aware, and I agree that data and samples are being collected, saved and stored anonymized. My child's name will not be registered in the study or mentioned in any publications. I received a copy of the parent information and the parental declaration of consent. I had a conversation with my child about the participation in the study. We had adequate time to think the participation in the study over. We were able to ask further questions and discuss concerns with the attending doctor. All questions have been answered in a detailed and understandable way.

Consent for data privacy protection:

1. I agree that the following information about my child is being recorded for study purposes: health conditions, history of disease, gender, age, weight, height, ethnic background.  
The data will be anonymized and forwarded to the following authorities:
  - a) The study initiator (for scientific analyses)
  - b) The surveillance authority (to survey correct study execution).
2. I agree that the study initiators or the surveillance authority appoint a representative to access my child's personal data for surveillance purposes. The authorized representative is obliged to confidentiality.

I agree that anonymized data regarding my child, collected within the context of the NEOCYST registry will be recorded, saved, analyzed and published.

☐ Yes ☐ No

I agree that my child provides the following biological samples for study purposes within the context of the NEOCYST registry.

☐ Urine ☐ Blood ☐ Nasal swabs

I agree that my child's anonymized biological samples are being stored in the Biobank. I agree that my child's anonymized biological samples are being used for future cystic kidney disease research.

☐ Yes ☐ No

I restrict the use of my child's biological samples in the following way:

I agree that my child's anonymized samples are being used to examine genetic changes relevant to cystic kidney diseases.

☐ Yes ☐ No

I agree that retrieved samples from my child's kidney or any other biopsy are being sent to and stored at the biobank in Hannover. Any samples will strictly be retrieved if a biopsy or operation is being ordered for medical purposes. No interventions are being ordered for research purposes only:

☐ Yes ☐ No

I agree that the attending doctor will be informed by the study coordinator in case any relevant medical findings will arise from analyzing my child's data and samples:

☐ Yes ☐ No

In case of participation in any other child nephrological study (please specify here :\_\_\_\_\_): I agree that already reported data from this study are being transferred to the NEOCYST study anonymized:

☐ Yes ☐ No ☐ Not applicable

\_\_\_\_\_  
*Patient: Last name, first name (to be filled in by the patient / legal representative)*

\_\_\_\_\_  
*1. Parent / Legal representative: Last name, first name*

\_\_\_\_\_  
*Place, Date, Signature*

\_\_\_\_\_  
*2. Parent / Legal representative: Last name, first name*

\_\_\_\_\_  
*Place, Date, Signature*

In case of sole custody: I hereby declare that I have sole custody.

\_\_\_\_\_  
*Name Parent / legal representative*

\_\_\_\_\_  
*Place, Date, Signature*

\_\_\_\_\_  
*Attending doctor: Last name, first name*

\_\_\_\_\_  
*Place, Date, Signature and Stamp*