
Declaration of Consent by Parents
on the scientific study
Identifying the Causes of Rare Diseases
using Genome-Wide Sequencing

We, _____, DOB _____,

and _____, DOB _____,

agree, that

our child _____, DOB _____,

is participating in the scientific study „Identifying the causes of rare diseases using genome-wide sequencing“.

We were informed about the study in a personal conversation by the responsible physician

We declare that we have read the study information for parents and that all our questions about it have been adequately answered.

If applicable: Our child was diagnosed with the following rare disease:

We consent that during the care or the treatment of our child, the team of the above-mentioned scientific study may collect information about our child's state of health or may use the already existing medical data of our child as well as, if applicable, data on the course and treatment of the disease (so-called "patient data" as described in the study information). We also consent that this data is recorded, processed and stored in pseudonymised (i.e. encrypted) form.

We consent to the collection and use of pseudonymised (i.e. encrypted) bio-samples from our child, in particular for genetic analyses, which may include the analysis of the entire genetic material - i.e. the genome - as described in the study information. We also consent to the collection and processing of blood samples from our child up to a maximum total volume of 25 ml per year for further laboratory analyses.

Furthermore, we consent to the scientific use of other biosamples from our child, such as tissue samples and/or bodily fluids, which were taken for diagnostic purposes and/or in context of the treatment of our child and are no longer needed afterwards (so-called residual materials), as part of this study.

Right of withdrawal

Our consent is voluntary!

We can withdraw our consent at any time without giving reasons and without any disadvantages arising for us or our child. The legality of the processing based on our consent until the withdrawal is not affected by this. In the case of a withdrawal, the biosamples provided by our child for research will be destroyed and the patient data of our child stored according to this consent will be deleted. If deletion is not possible or not possible with acceptable technical effort, the patient data of our child will be anonymised by deleting the assigned identification code.

We have been informed about the utilisation of our child's patient data and biosamples as well as the associated risks and give our consent within the abovementioned context. We have had sufficient time to reflect, and all our questions have been answered satisfactorily.

We received a copy of the study information for parents and the signed consent form after the informed consent consultation.

city, date

first name and surname mother
(block letters)

signature mother

city, date

first name and surname father
(block letters)

signature father

I performed the informed consent consultation.

city, date

first name and surname physician
(block letters)

signature physician