MOTHER

Surname: _____ ,

First name: _____

Date of birth: ___ . ____ . _____

CHILD

Name: _____ ,

First name: _____

Date of birth: ____ . ____ . _____

(if child already born when consent is given)

FORM FOR GRANTING OF CONSENT TO NEONATAL SCREENING

I have been informed about **neonatal screening for congenital hormonal, metabolic and hearing defects**. I have read the information sheet for parents and been given a copy. I have been told about what the screening can reveal and been informed of its limitations. I understand that any conspicuous findings arising from the neonatal screening do not amount to a diagnosis but that further tests will be required before the results can be confirmed. The laboratory may contact me directly if the results of the screening are conspicuous.
I was given the opportunity to ask questions about all screenings described and recommended there and all methods employed and **to make use of the telephone advice service.** I was given ample time to ask questions and consider my response. I am aware that the information collected from me and my child (see reverse for details) will be stored electronically by the screening centre to enable swift processing of any conspicuous findings.

I hereby declare before (tick one box only)

☐ _____

☐ the Neonatal Screening Laboratory (head: Dr. med. Oliver Blankenstein)

as competent medical officer that I consent to the recommended early-diagnosis examinations being performed on my child.

I do not consent to my child undergoing

☐ the extended neonatal screening for congenital hormonal and metabolic defects

☐ the neonatal screening for hearing defects

I have been informed about the possible negative consequences for my child's health if I withhold my consent to any recommended screening.

Storage of unused blood samples:
I consent to the storage of surplus test material for the purpose of future verification of results. After 12 months have elapsed the data will be separated from the unused blood sample and stored in encrypted form (under pseudonym). Only with the consent of a parent or guardian may data and blood sample be re-associated via the code (pseudonym). In Berlin the unused blood sample is destroyed after 18 years. To enable future verification that screenings were performed correctly we recommend that you consent to this extended storage of samples.

☐ I do not consent to the extended storage of unused blood samples.

I consent to the utilisation of pseudonymised blood samples for scientific purposes (e.g. for the improvement of screening methods, quality assurance measures, etc).

☐ I do not consent to the utilisation of anonymous unused blood samples for scientific purposes.

Date

_____	_____
Surname, first name Signature	Surname, first name Signature
Doctor	Parent / guardian

Delegating the taking of blood samples / Copy of screening results:

☐ After I have given my consent the responsibility for taking the blood sample will be delegated to:

MEDICAL OFFICER

☐ A copy of the findings is to be sent to the above-named person

Dear parents,

Below you will see a representation of the data section of the screening card. This shows you which medical and personal data are collected during, and temporarily stored after, the neonatal screening.
The screening ID and barcode allow the medical information to be stored separately from the personal data. A labelled sheet bearing your child's screening ID is stuck into the yellow examination folder that every child receives and establishes the link between your child and the screening ID. After the pseudonymisation of data has taken place information can only be made available to people in possession of the screening ID.
All data are stored securely. They remain on a secure computer for the designated period. Only screening laboratory staff can access the data.

If you have any questions relating to individual parts of the card below, please contact your paediatrician or obstetrician.