



This letter is from Statens Serum Institut (SSI), as we are processing your child's heel prick sample (PKU sample) in connection with screening for congenital disorders. In addition to handling and storage of the PKU sample itself, this process involves the handling and storage of personal information for both mother and child.



This letter does **not** contain your child's test results. It explains how SSI processes the PKU sample and personal data in connection with the test.

Storing your child's PKU sample

After testing, the surplus sample material is frozen and stored in secure facilities at Denmark's Neonatal Screenings biobank at SSI.

We store samples for re-analysis and method development

The sample is primarily kept for the benefit of your child e.g., a screening test may need to be repeated or additional tests may be needed that were not available at the time of birth. The sample can also be used to improve future congenital disease screening tests.

We store samples for research

With permission from a scientific ethics committee and approval from the biobank's steering committee, the sample may be used for approved research projects. All projects must also be conducted in accordance with the rules in the data protection regulation and according to the requirements laid down by the Danish Data Protection Authority. If your child is registered in the Tissue Use Register, the sample may not be used for research.

Processing personal data

SSI processes personal data about both mother and child with the aim of screening for congenital diseases. Below is a list of the information we keep:



Child's information

- Date of birth
- Birth weight
- Place of birth
- Sampling time
- Gestational age at delivery
- CPR number
- Screening results
- PKU sample



Mother's information

- Name
- CPR number

Rights

The General Data Protection Regulation (GDPR) gives your child certain rights regarding their personal data.

Here you can find a detailed description of our processing of personal data and the rights of the child (www.ssi.dk/persondataorientering-pku). Your child has the right to know what information we store. As a parent or guardian, you can request this information on their behalf. See contact SSI via Digital Post (www.ssi.dk/sikkerkommunikation).

You can register your child in the Tissue Use Register

If you do not want your child's sample to be used for research, you can register them in the Tissue Use Register. For more information, see the www.sundhedsdatastyrelsen.dk/var.

Possibility of destruction

If you wish to have your child's sample destroyed, contact SSI via Digital Post (www.ssi.dk/sikkerkommunikation). Both parents must consent to the destruction of the sample, and it is important to remember that destroyed samples cannot be recovered.



How to learn more

Here you can find details about congenital disease screening (nyfoedte.ssi.dk), and here is information in other languages available (nyfoedte.ssi.dk/info).

You are also welcome to contact the Center for Neonatal Screening at sikkerpost-ms@ssi.dk or by phone 4171 4792.



Right to complain

You can complain to the Danish Data Protection Authority (www.datatilsynet.dk/english) about how SSI handles your child's information. Here you can find the Data Protection Authority's contact information (www.datatilsynet.dk/english/contact-us).