

## **Information about possible future use of patient data and samples for research**

Substantial progress has been achieved over the course of the last decades in the identification and treatment of many diseases. Much of this progress is the result of long-standing medical research, which actively involved many generations of doctors, researchers and patients of all ages. In this sense, the University Children's Hospital in Basel (UKBB) views itself not only as a treatment and service provider, but also as a research institution supporting excellent research for the benefit of children and adolescents.

Information on the illnesses of our patients or unused/left-over samples obtained as part of routine care can be the foundation for medical research. According to Swiss Law (Schweizer Humanforschungsgesetz – HFG) the patients', or in the case of minors the parents'/legal guardians', written informed consent is required to enable future use of such data and samples. We are therefore approaching you as part of your child's registration procedure to provide you with the opportunity to let us know your preference.

**To ensure medical treatment can make further progress, we kindly ask you for your contribution.**

### **What does it mean if I give my consent?**

By consenting to the possible future use of data and samples, you are indicating that you are happy with the following process: Samples (urine, blood, tissue) that are collected as part of patient care at UKBB for diagnostic or treatment purposes usually are discarded immediately after completion of all requested test. If you provide consent, these samples may be kept and made available for future medical research in an encoded (pseudonomised) form. Similarly, encoded (pseudonomised) data from the patient record (e.g. age, test results, family history) may be provided. By consenting you indicate that you are happy with the use of past and future data/samples in encoded (pseudonomised) form for future medical research.

### **How will my child's data and samples be protected?**

The UKBB attaches great importance to adhering to legal requirements and data protection. All information provided by you about your child, family or your child's illness will be treated confidentially. Only certain authorized personnel, such as your treating doctor, have access to your child's complete medical record. Any data that would be used (with parental consent) for future research will be encoded (pseudonomised). This means that all information that enables identification of your child, such as name or date of birth, is replaced by a code. The identifying information linked to the code can only be accessed by a very small group of guardians in charge of the encoding. Researchers will not be able to access this information and therefore would be unable to identify your child from the data they would be working with. This guarantees the protection of your and your child's data at all times.

### **Who is in charge of evaluating whether future research is valuable, scientifically justified and ethical?**

All research with encoded (pseudonomised) data and samples is subject to Swiss legal requirements and has to be approved prior to the start of a project by an independent ethics committee.

**What else is important?**

- The patient and parents/legal guardians have the right to access their/ their child's patient record at any time.
- If you provide your consent, you will not incur any additional costs or charges.
- The hospital must not and will not make any profit from sharing of patient data.
- Your and your child's decision about consenting to possible future use of patient data and samples will not have any influence on your child's medical care.
- Your and your child's decision is entirely voluntary and can be revoked at any time without further explanation.

Should you change your mind in the future and wish to withdraw your consent, please contact:

Universitäts-Kinderspital beider Basel  
Ambulatory Study Center (Ambulantes Studienzentrum)  
Subject: Clinical Research (Klinische Forschung)  
Spitalstrasse 33, 4056 Basel or email [asz@ukbb.ch](mailto:asz@ukbb.ch)

Further information can be found in our brochure "Information zur Verwendung von Patientendaten und –proben", which is available at registration or at [www.ukbb.ch/Forschungskonsent](http://www.ukbb.ch/Forschungskonsent)

**Please indicate your preference on the informed consent form! We thank you for your commitment!**