

CONSENT FOR BIOBANK ON BEHALF OF A PATIENT WHO IS A MINOR

We request for your consent for the purpose of collecting your minor child's samples and related data to the Finnish Hematology Registry and Clinical Biobank, FHRB Biobank, and for using them for biobank research. The purpose of research studies made through the biobank is to promote the health of children and adolescents and to improve their treatment. Samples are primarily collected in connection with other care, and the child is not subjected to any extra procedures. It is important to study factors affecting the hematological diseases in children and adolescents, both in the short and long term.

Please, find attached an information form and consent form to the biobank sample donor. We request that you take your time getting familiar with the contents of the information form and discuss them with your child according to how you estimate your child to understand the matter.

As the child's guardian, you can give consent on your child's behalf or with your child until he or she has reached adulthood. Giving consent must be in the child's best interests, and we also try to establish the child's personal will. Your child will also be requested for his or her own, parallel consent, when he or she is sufficiently mature for that. It is important that you ask the opinion of the other potential guardian on the matter before signing the consent. It is important that the opinion of the other potential guardian has been established before the consent is signed.

You can withdraw the consent you have given on your child's behalf, either on your own or together with your child. The minor may also personally withdraw his or her consent if he or she is sufficiently mature in relation to his or her age and developmental level. These situations are always assessed on a case-by-case basis.

We hope that, as your child grows up you, will tell him or her about the FHRB Biobank and about the fact that he or she can later decide whether he or she wants to continue the storage of his samples and related data in the biobank. When your child turns 18, we will notify him or her about the consent regarding the biobank, and he or she can personally decide whether he or she wants to participate in biobank operations in the future or whether he or she wants to prohibit the use of his or her samples and relevant data.

Guardians always have the right to ask the biobank in writing whether they are storing their child's data and samples. In principle, we do not share the research data determined from the child's sample unless it is of particular relevance for the child's current state of health. We usually require a joint request from both guardians. If the child has reached the age of 10, he or she should also request for this information. These situations will be assessed in accordance with the child's best interests on a case-by-case basis.

Research made using your child's biobank samples may reveal some issues relevant for your child's health. In your consent, you may also take a stand on whether in such a case we can contact you and/or your child if he or she is mature enough to handle such information. Please note, however, that the biobank does not actively monitor the health of the sample donors.

We also ask you for your consent for allowing the biobank to contact you and/or your child later if there is a justified reason for doing so (e.g. we would like to have additional information or samples).

The accompanying document Information Form for Biobank Sample Donors will give you additional information on the matter, and you may also contact the biobank at any time.

Kimmo Porkka
Professor, Chief Physician
HUS Hematology Clinic
kimmo.porkka@hus.fi