

BIOBANK CONSENT AND ACCEPTANCE ON BEHALF OF AN UNDERAGE PATIENT

Using the attached consent and acceptance form, we ask you to give your consent to sample collection from your underage child and to the transfer of samples and associated data to the Finnish Hematology Registry and Clinical Biobank (the FHRB Biobank). We also ask you to consent to being notified of any clinically significant findings. In addition, we ask you to agree to your underage child's health-related data being attached to their sample, and to the disclosure of this data for biobank research. The purpose of research that uses material released from the Biobank is to promote the health of children and adolescents and to improve their care. Samples will primarily be collected as part of your child's treatment, and additional procedures won't be performed. It's important to investigate factors influencing hematological diseases in children and adolescents in both the short and long terms.

The Declaration and the Consent and Acceptance form for FHRB Biobank sample donors have been provided with this Cover Letter. The information will be explained to you by a professional familiar with biobanking. Please read the Declaration, taking as much time as you need, and talk to your child about it to the extent that you think they might be able to understand.

As your child's guardian, you can provide consent and acceptance on their behalf or together with them until they reach adult status. Consent and acceptance must be in the best interests of your child, and we'll also try to establish what they themselves want. Before consent and acceptance can be given, healthcare staff at the healthcare unit your child is visiting will assess your child's level of understanding. Your child will be asked to give their own consent and acceptance along with yours once they are mature enough. If your child has another guardian, it's important that you ask their opinion before signing. Establishing the opinion of the other guardian before consent and acceptance is signed is important.

You can withdraw the consent you have given on behalf of your child before samples and associated data are collected and transferred to the Biobank. You can also object to the use of your child's data at any time, either alone or together with your child. Your underage child can also withdraw their consent and/or object to the use of their data if they are mature enough considering their age and level of development. These situations are always assessed on a case-by-case basis.

We ask that as your child gets older, you tell them about the Biobank and how later on they'll be able to decide whether or not they wish to continue storing their samples and data in the Biobank. After your child turns 18, we'll notify them of the Biobank consent and acceptance, and they'll be able to make their own decision about whether they wish to continue participating in the Biobank or if they wish to object to the use of their samples and data.

Guardians always have the right to ask the Biobank, in writing, whether their child's data and samples are stored in the Biobank. Generally we don't reveal research data obtained from a child's sample unless the data has special significance for the child's current health. Usually we require that both guardians request the data together. If your child is 10 or older, the data should also be requested by them. Such situations are assessed based on the best interests of the child on a case-by-case basis.

Research performed on samples from the Biobank can reveal information that is important for your child's health. On the Consent form, you can choose whether we can, in such cases, contact you and/or your child if they are mature enough to process such information. Please note, however, that the Biobank doesn't actively monitor donors' health.

We also ask you to consent to the Biobank contacting you and/or your child if we have a justified reason for doing so (for example, if we'd like to obtain more information or additional samples from your child).

You can find more information in the *Declaration for Sample Donor - Minors*, which has been provided. You can also contact the Biobank at any time.

Contact details:

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