

Hilda Biobank Freiburg

Information für Kinder von 7-11 Jahren – Englisch

Information for children aged 7-11 years

on the donation, storage, and use of biomaterials as well as the collection, processing and use of data for scientific purposes

Dear Patient,

we would like all patients to receive the best possible examination and treatment. We can achieve this only by learning more about diseases and performing research in the laboratory. A biobank is needed for this.



You are probably wondering what exactly a biobank is?

On the following pages, we will explain everything to you which you should know about the Hilda Biobank. Then, together with your parents, you can think about and freely decide whether you want to participate in our project.

1. What exactly is a biobank?

In a biobank, we collect all materials which are taken during a physical examination. What is collected always depends on what is being investigated because of your disease. This can be, for example, blood or also tissue



which was removed during surgery. The examination material is known as **specimens**. The specimens collected are generally materials which are left over after diagnostic tests and are no longer needed. Instead of throwing away the remaining material, it can be stored in the biobank and used for research. This means that, to participate in the biobank, you do not need any additional examinations.

To be able to conduct research successfully, we need information about you and your disease, in addition to the specimens. This information is known as **data**. Data which we collect are, for example, age, sex, nature of the disease and examination results.

With the Hilda Biobank, we hope to better understand the development of diseases in children and adolescents in the future and thus improve the detection and treatment of diseases. We want to help develop better test methods to be able to detect diseases and find new drugs.

2. How will my specimens and data be used?

Your collected specimens and data will be stored for an indefinite period in the biobank and used only for important questions in medical research. To do this, tests will be conducted on the specimens and evaluated with the data. Since we cannot yet say exactly which projects are useful in the future, the specimens may also be used for investigations which will only be developed in the future.



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To answer important questions in research, we work together with other doctors and researchers in Germany and abroad. This means that your specimens and data may also be forwarded to other researchers.



The specimens and data may only be forwarded if the research projects have been reviewed beforehand by experts. The specimens and data can be forwarded to researching doctors, scientists and bioinformaticians only if the planned investigations are considered to be useful.

The results regarding the research questions can then be read about later in various specialist journals.

3. Will it help me if I participate in the biobank?

When you donate your specimens and data to the biobank, this will not have any direct influence on your health. In general, the investigations do not involve individual specimens but rather a number of different specimens from different patients. The analyses are then intended only for the research and we will not inform you of the results.

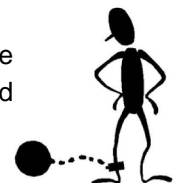


However, with your participation, you may also help other patients who benefit from the development of new test methods and therapies.

In individual cases, it is possible that a researcher will by chance obtain a result which is of great importance for you and your health. This may be, for example, knowledge about other diseases or a predisposition to another disease. In this case, we will contact your treating doctor.

4. Do I have to participate in the biobank and can I change my mind?

You can **voluntarily** decide whether or not you wish to participate in the biobank. Ideally you make a decision together with your parents. You can also change your mind later at any time and withdraw your participation in the biobank. This will not result in any disadvantages for you.



5. What does data protection mean?

Nobody wants personal information, such as name, address, age or also health information to be able to be read by everyone. The doctors and all other employees in the hospital therefore are obligated to maintain confi-



dentiality and may not forward any information about their patients to outsiders. To protect your specimens and data in our biobank, they will be given a letter and number code. This means that, when we use your specimens and data, we do not use your name or other personal information, instead only this code. Therefore, researchers who use your donated specimens for their investigations do not know that these are your specimens. Only a few

employees of the biobank who are obligated to maintain particular confidentiality know the decoding for your specimens. This is important, for example, if you withdraw your consent and we have to once again allocate your specimens to you.

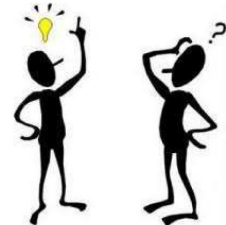


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6. Whom can you ask if you have questions?

If something is not clear to you, you can get in touch with your treating doctors at any time or also the Hilda Biobank Freiburg:

Biobank Coordination
Kinder- und Jugendklinik
Universitätsklinikum Freiburg
Breisacher Straße 62
79106 Freiburg
zkj.hilda-biobank@uniklinik-freiburg.de



7. Would you like to participate?

If you wish to participate in the biobank, please sign this page or simply tell your treating doctor that you wish to participate. You are thus telling us that you wish to donate your specimens and data for research and that you know that this is voluntary. You may say at any time that you no longer wish to participate. You will not have any disadvantages as a result. Your data will then be deleted and the remaining specimens will be destroyed.

I would like to participate in the biobank **Yes** **No**

Date

Name of child (please print)

X

Signature of child

I have conducted the informational discussion and obtained consent.

Date

Physician's stamp

Signature of physician

