



**Krebsprädispositionssyndrom-
Register 01**

Registerleitung:

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Information for adolescents 12-17 years of age

ADDress as a part of

Cancer-Predisposition-Syndrome-Registry-01

- Self-registration -

Dear _____,

Your and /or your parents are interested in your participation in a scientific project (ADDress project). These forms will inform you about the project. You can read them think about it and discuss it with your parents and your physician whether you would like to participate. A physician from the Registry team will also have a telephone or personal conversation with you and your parents to explain everything to you and to answer questions.

You have a very rare kind of disease. It is still very unknown in children and teenagers. That is why a number of physicians have joined forces to research this disease. This is only possible through a very large network of physicians because it is not easy to find out anything about rare diseases.

You already agree to participate in the Cancer-Predisposition-Syndrome-Registry-01.

In a further project we want to investigate, how we can improve the treatment of rare diseases like yours. We want to learn how cancer develops, which will eventually lead to milder and more successful therapies.

In this project we want to take blood, bone marrow, a small piece of skin and a cheek swab from all participating children and adolescents. If a blood or bone marrow sample is taken for your routine medical care, the blood, bone marrow and skin samples required for this project can be taken at the same time, so that

we have to prick you as rarely as possible. The samples taken are either first collected at the Children's Oncology Department and at the Biobank of Hannover Medical School or directly passed on to various researchers and scientists, where the special examinations are carried out.

Your samples and your medical history will be treated confidentially and in accordance with the data protection process. This means that only we can see your name in connection with your medical history and we will not tell your story in connection with your name or address. If we share our experiences in the treatment of your illness with other physicians (e.g. in a publication), your name and address will be deleted, i.e. it is not possible to see that you are meant.

We would be very happy if you would like to help us and other patients with this disease and we could analyse your samples. If you do not want to participate or if you want to withdraw your consent, this is not a problem. Your medical treatment will be continued normally and for your best.

As soon as you are of legal age, we will contact you again to ask if you would like to continue participating in the study.

You can ask your physicians if you do not understand something. They will gladly help you.

Thank you very much.

Your physician's team