

**Krebsprädispositionssyndrom-
Register 01**

Registerleitung:

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Information for adolescents 12-17 years of age

Cancer-Predisposition-Syndrome-Registry-01

- Self-registration-

Dear _____,

Your and /or your parents are interested in your participation in a scientific project (Cancer-Predisposition-Syndrome-Registry).

These forms will inform you about the project. You can read them think about it and discuss it with your parents 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.

For this reason, as many and precise medical findings as possible from the individual courses of disease of children and adolescents participating in the project will be documented, stored and evaluated, so that rapid cooperation between the clinics can be ensured. In this way the physicians can benefit from each other's experience. If you want to participate, your parents or, if your parents give the permission, your physicians would send the documents of your medical history (what means: reports about the beginning, the course and the treatment) to us and to centers that help us. These data would be stored and entered into a database there.

Your medical history will be treated confidentially and within the framework of data protection. 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 experience in treating your illness with other physi-

cians (e.g. in a publication), your name and address will be deleted, i.e. it will not be possible to see that you are meant.

In addition, the CPS-Registry-01 team also plans to carry out so-called molecular biological studies. The aim is to clarify questions relating to the development and characteristics of rare diseases in children and young adults so that they can be better recognised and treated. To this end, tissue samples will be collected and stored in order to be able to carry out scientific investigations once we have enough material. With "tissue" we mean small portions of your blood (approx. 5 ml). For this purpose, however, we do not take extra blood, but blood that is collected during routine blood sampling. In case of cancer, we would keep a sample, but only if a sample is taken for medical reasons anyway.

We would be very happy if you would like to help us and other patients with this disease and we could also add your documents to our database.

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