

**Krebsprädispositionssyndrom-
Register 01**

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Information for children 7-11 years of age

Cancer-Predisposition-Syndrome-Registry 01

- Self-registration -

Dear _____,

You and/or your parents are interested, that you participate in a scientific project (Cancer-Predisposition-Syndrome-Registry).

This sheet should explain, what this means. You can read everything on your own, think about it and discuss it with your parents whether you would like to participate. Additionally, a physician of 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.

Your physicians have discovered that you have a rare disease. There are only a few children who have the same disease. So now, physicians in Germany and all over the world are working together to better understand this disease and to help you and the other children, who have the same illness as you. They want to collect as much and precise information as possible about children with this rare disease to improve how to find it and how to make the children healthy again. The physicians also want to store and examine your blood and other body cells. But you will not be pricked especially for this.

If you want to participate, your parents or, if you agree, your physicians would give us documents about you and your medical story so that we can examine your illness in detail.

We would be happy if you would like to participate and help other children as well. But if you don't want to, that is no problem either. Please ask the physicians of the Registry team if you don't understand something. They will gladly help you.

Thank you very much.

Your physician's team