





Krebsprädispositionssyndrom-Register 01

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Information for children 7-11 years of age

Cancer-Predisposition-Syndrome-Registry 01

Dear				
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You have surely just notice that you and your parents are being asked to participate in a registry. This sheet should explain, what this means. You can read everything on your own, think about it and discuss it with your parents and your treating physicians whether you would like to participate.

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 physicians would give us documents about you and your medical story so that we can examine you 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 your doctors if you don't understand something. They will gladly help you.

Thank you very much. Your physician's team