

**Krebsprädispositionssyndrom-  
Register 01**

Registerleitung:

Prof. Dr. med. Christian Kratz  
Prof. Dr. med. Stefan Pfister

Prof. Dr. med. Christian Kratz  
Klinik für Pädiatrische Hämatologie und  
Onkologie der MHH  
Telefon: 0511 532-6711  
Fax: 0511 532-161026  
E-Mail: [kratz.christian@mh-hannover.de](mailto:kratz.christian@mh-hannover.de)  
Carl-Neuberg-Straße 1, 30625 Hannover

Prof. Dr. med. Stefan Pfister  
Hopp-Kindertumorzentrum Heidelberg  
Pädiatrische Neuroonkologie, DKFZ  
Telefon: 06221 42-4617  
Fax: 06221 42-4639  
E-Mail: [s.pfister@dkfz.de](mailto:s.pfister@dkfz.de)  
Im Neuenheimer Feld 580, 69120 Heidelberg

**Informed consent for parents/guardians**

**Enrollment in Cancer-Predisposition–Syndrome-R01**

\_\_\_\_\_  
Patient (Last Name, First Name)

\_\_\_\_\_  
Date of Birth (dd/mm/yy)

\_\_\_\_\_  
Treating Hospital

I have read the information sheet and have had the opportunity to ask questions. My questions were answered comprehensively and comprehensibly. I know that my participation is voluntary and that I can retract my consent any time without justification and without disadvantages. I had enough time to reconsider my decision to participate and make my own decision.

I give my informed consent that my child's biospecimen as well as medical information as described in the information sheet are sent to the CPS-R01 to be used for medical research purposes.

I also give my consent that the specific scientific project, for which the biospecimen and medical information will be used are without restriction. I transfer ownership of the biospecimen to the CPS-R01 of the German Society of Pediatric Oncology and Hematology.

I approve that I may be contacted at a later time point for the following reasons, please check the boxes with “yes” or “no”:

- For the collection of additional medical information/biospecimen  yes  no
- If further consent is necessary for the use of your child’s medical information  yes  no
- If our research identifies actionable findings that may be relevant to your child’s health  yes  no

This contact will occur through the institution that collected my child’s biospecimen and data **or** by the following physician (please give this information to the physician if the latter is preferred):

Physician name and address: \_\_\_\_\_

### **Data Protection Statement**

**I approve that the registry team conducts the following actions (also described in the information sheet):**

- **Collects and stores identifying materials and information related to my child’s health**
- **Extracts additional health related data containing identifying information from my child’s medical records**
- **After the collection, the biospecimen and data will be coded to de-identify the data to be used for medical research purposes**
- **Coded non-identifying information will be used for scientific publications and online databases**

**My child’s biospecimen and data may be used for medical research purposes for an unlimited time period.**

**In a non-identifiable manner, biospecimen and data may be transferred to universities, research institutes/companies for the purpose of medical research. This may include international research projects.**

**I was informed that I may withdraw my consent to participate in the registry any time without justification. In case of withdrawal, I may request that any remaining biospecimen and data be destroyed, deleted or anonymized.**

**Please note: If an analysis has been completed, the data cannot be removed.**

I have the right to be informed about the stored personal data concerning my child (Art. 15 DS-GVO). If I discover that incorrect personal data of my child is being processed, I can demand correction (Art. 16 DS-GVO).

I have the right to demand the deletion of personal data if certain reasons for deletion exist. This is the case, for example, if the personal data are no longer necessary for the purpose for which they were

originally collected or processed, or if I revoke my consent and there is no other legal basis for the processing (Art. 17 DS-GVO). Furthermore, I have the right to limit the processing of my child's personal data (Art. 18 DS-GVO), to data transferability (Art. 20 DS-GVO) and a general right of objection (Art. 21 DS-GVO).

Data controller: Christian Kratz, MD  
Pediatric Hematology and Oncology, OE 6780  
Carl-Neuberg-Straße 1  
30625 Hannover  
Germany

If I have any questions or if I have the opinion that the processing of my child's personal data is not lawful, I have the option of contacting the MHH data protection officer:

Datenschutzbeauftragte der MHH  
OE 0007  
Carl-Neuberg-Straße 1  
30625 Hannover  
Germany

I have the right to complain at the supervisory authority if I believe that the processing of my child's personal data is not lawful.

The address of the supervisory authority responsible for the MHH is:

Die Landesbeauftragte für den Datenschutz Niedersachsen  
Prinzenstraße 5  
30159 Hannover  
Germany

I am aware that the data protection regulations set out in the information letter also applies.

I have received a copy of the information sheet and the signed informed consent. The original is kept in the patient's medical record.

In addition, I was orally informed about the study.

#### **CONFIRMATION OF THE PARENT/GUARDIAN**

\_\_\_\_\_  
Patient name (in block capitals)

\_\_\_\_\_  
Place, date

\_\_\_\_\_  
Signature parent/guardian

**CONFIRMATION FROM THE ATTENDING PHYSICIAN**

I have discussed the registry CPS-R01 and the accompanying research including the patient information and the declaration of consent with the custodians. All questions were answered comprehensively. I have explained to the guardians that participation is voluntary. I have obtained the consent of the legal guardian.

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Name of physician (in block capitals)

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Place, date

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Signature of attending physician