



**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: 0155 532-169020

E-Mail: 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

Im Neuenheimer Feld 580, 69120 Heidelberg

Informed consent for parents/guardians

ADDRESS project

As a part of 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 child's 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 my child's participation 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 especially for the ADDRESS project.

I transfer ownership of the biospecimen to Medical School Hannover.

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 the initials of my child's first and last name as well as the quarter and year of birth,**
- **Collects and stores identifying materials and information related to my child's health**
- **After the collection, the biospecimen and data will be coded to pseudonymised to be used for the ADDRESS project**
- **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.

Identifying data can be exchanged with the ADDRESS subprojects, the therapy study of the corresponding cancer and the children's cancer registry.

I was informed that I may withdraw my consent to my child's participation in the registry/ ADDRESS project 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 ADDRESS project.

CONFIRMATION OF PARENTS/GUARDIANS

Patient name (in block capitals)

Place, date

Signature parents/guardians

CONFIRMATION FROM THE ATTENDING PHYSICIAN

I have discussed the ADDress project 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 parents/guardians that participation is voluntary.

Name of physician (in block capitals)

Place, date

Signature of attending physician