**Krebsprädispositionssyndrom-Register 01**

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**Informed consent for adult patients**

Liquid Biopsy

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 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 participation and make my own decision.

I give my informed consent that my 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 Liquid Biopsy project.
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 my 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 medical information □ yes □ no
- If our research identifies actionable findings that may be relevant to your health □ yes □ no

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

Physician’s 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 first and last name as well as the quarter and year of birth**

**- Collects and stores identifying materials and information related to my health**

**- 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 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 my participation 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 me (Art. 15 DS-GVO). If I discover that incorrect personal data of me are 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 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 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 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 PATIENT**

_____
Name of patient

_____ _____
Place, date Signature of patient

**CONFIRMATION FROM THE ATTENDING PHYSICIAN**

I have discussed the Liquid biopsy project as a part of 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 patient that participation is voluntary.

_____

Name of physician

_____ _____

Place, date Signature of physician