

Li-Fraumeni Syndrome-
Cancer Predisposition Syndrome-
Registry 01

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Informed Consent

Enrollment in Li-Fraumeni-Syndrome-Cancer-Predisposition-Syndrome-Registry-01

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/my child's biospecimen as well as medical information as described in the information sheet, are sent to the LFS-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 LFS-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:

- For the collection of additional medical information/biospecimen yes
- If further consent is necessary for the use of your/your child's medical information yes
- If our research identifies actionable findings that may be relevant to your/your child's health yes

This contact will occur through the institution that collected my/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/my child's health**
- Extracts additional health related data containing identifying information from my/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/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 myself/my child (Art. 15 DS-GVO). If I discover that incorrect personal data of me/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/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/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/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 apply.

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

Patient name (in block capitals)

Place, date

Signature patient or parent/guardian

Place, date

Signature of parent/guardian

CONFIRMATION FROM THE ATTENDING PHYSICIAN

I have discussed the registry LFS-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.

Name of physician (in block capitals)

Place, date

Signature of attending physician