

Li-Fraumeni Syndrome- Cancer Predisposition Syndrome Registry 01

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Informed Consent: Enrollment in LFS-CPS R01

Patient (Last, First Name): _____

Date of Birth (dd/mm/yy): _____

I give my informed consent that my / my child's biospecimens 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 biospecimens and medical information will be used are without restriction.

I transfer ownership of the biospecimens to the LFS-CPS R01 of the German Society of Pediatric Oncology and Hematology.

I have read the information sheet and have had the opportunity to ask questions. I know that my participation is voluntary and that I can retract my consent any time without justification and without disadvantages.

I approve that I may be contacted at a later time point for the following reasons (please check the "No" box in case you prefer not to be contacted):

- For the collection of additional medical information / biospecimens ☐ No
- If further consent is necessary for the use of your / your child's medical information ☐ No
- If our research identifies actionable findings that may be relevant to your / your child's health ☐ No

This contact will occur through the institution that collected my / my child's biospecimens 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 biospecimens 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 biospecimens and data may be used for medical research purposes for an unlimited time period.

In a non-identifiable manner, biospecimens 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 biospecimens and data be destroyed, deleted or anonymized. Please note: If an analysis has been completed, the data cannot be removed.

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

Patient Name

City, Date (dd/mm/yy)

Patient and/or Parent (for patients < 18 years of age) Signature

I have conducted the pre-study interview and obtained informed consent of the patient/parent

Physician Name

City, Date (dd/mm/yy)

Physician Signature