

LFS-CPS Registry 01 Initial Registration

Patient with Cancer Predisposition Syndrome (CPS)

Patient Initials (first name, last name) |__|__|

Quarter and Year of Birth (q/yyyy) |__|/|__|__|__|__|

Sex male female

Please make sure that the consent form is signed before transmitting these data!

Date signed (dd/mm/yy) |__|__||__|__||__|__|

Referring physician name and institution |_____|

Address |_____|

Telephone and fax |_____|

Email |_____|

Diagnosis

Is a **specific** CPS suspected? No a CPS is suspected, but not a specific one
 yes, specify name of CPS |_____|

Why was CPS considered, specify |_____|

Was the CPS diagnosed unexpectedly on the basis of a genetic analysis that was initiated for another purpose?
 No
 Yes, specify |_____|

Date of CPS diagnosis |__|__||__|__||__|__|

Date of genetic CPS diagnosis (if applicable) |__|__||__|__||__|__| Please submit original report.

Results of genetic testing, specify (provide precise molecular defect, e.g., mutation, nucleotide/ protein change)
Submit copy of report.
|_____|

Classification of pathogenic variant (if known)

pathogenic likely pathogenic uncertain significance likely benign benign

LFS-CPS Registry 01 Initial Registration

Malignancies

Was 1st malignancy diagnosed No
 Yes, specify (histology/site) | _____ |
date of malignancy diagnosis |__|__||__|__||__|__| Please submit reports (pathology to tumor genetics)
Which kind of tumor analysis is available? (e.g. whole genome sequencing)
| _____ |
name of treatment protocol | _____ |

Was 2nd malignancy diagnosed No
 Yes, specify (histology/site) | _____ |
date of malignancy diagnosis |__|__||__|__||__|__| Please submit reports (pathology to tumor genetics)
Which kind of tumor analysis is available? (e.g. whole genome sequencing)
| _____ |
name of treatment protocol | _____ |

Was 3rd malignancy diagnosed No
 Yes, specify (histology/site) | _____ |
date of malignancy diagnosis |__|__||__|__||__|__| Please submit reports (pathology to tumor genetics)
Which kind of tumor analysis is available? (e.g. whole genome sequencing)
| _____ |
name of treatment protocol | _____ |

Further comments: | _____ |

Family history: Please submit pedigree and clinic notes.

Physical exam: Please submit clinic notes / electronic photographs, if available.

LFS-CPS Registry 01 Initial Registration

Surveillance

- No
- Yes, according to the AACR surveillance recommendations for patients with
 - Leukemia-Predisposing Conditions
 - DNA Repair Disorders
 - Inherited Mismatch Repair Deficiency
 - Li-Fraumeni Syndrome
 - Neurofibromatosis 1
 - Neurofibromatosis 2 and Related Disorders
 - Rhabdoid Tumor Predisposition Syndrome
 - Von Hippel-Lindau and Hereditary Pheochromocytoma/Paraganglioma Syndromes
 - PTEN, DICER1, FH Related Tumor Susceptibility Syndromes
 - RASopathies and other Rare Genetic Conditions with Increased Cancer Risk
 - Retinoblastoma and Neuroblastoma Predisposition
 - Inherited Gastrointestinal Cancer Syndromes
 - Overgrowth Syndromes and Predisposition to Wilms Tumors and Hepatoblastoma
 - Multiple Endocrine Neoplasia and Hyperparathyroid-Jaw Tumor Syndromes
 - Other**, specify |_____ |

Please submit copies of

- **Clinic notes summarizing pathologic surveillance results.**
- **CD with radiologic images that demonstrate a (suspected) malignancy.**

Date |_|_|_|_|_|_|_|_|_|_| (dd/mm/yy)

Signature _____