

# CPS Registry 01 Initial Registration

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## Patient with Cancer Predisposition Syndrome (CPS)

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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 |\_\_\_\_\_|

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## Diagnosis

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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

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## 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)  
| \_\_\_\_\_ |

Chemotherapy  Yes  No  
name of treatment protocol | \_\_\_\_\_ |

Radiation  Yes  No

Surgery  Yes  No

Comment: | \_\_\_\_\_ |

Was 2<sup>nd</sup> 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)  
| \_\_\_\_\_ |

Chemotherapy  Yes  No  
name of treatment protocol | \_\_\_\_\_ |

Radiation  Yes  No

Surgery  Yes  No

Comment: | \_\_\_\_\_ |

Was 3<sup>rd</sup> 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)  
| \_\_\_\_\_ |

Chemotherapy  Yes  No  
name of treatment protocol | \_\_\_\_\_ |

Radiation  Yes  No

Surgery  Yes  No

Comment: | \_\_\_\_\_ |

**Family history:** Please submit pedigree and clinic notes.  
**Physical exam:** Please submit clinic notes / electronic photographs, if available.

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## Surveillance

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- 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.**

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## Accompanying Projects

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### Liquid Biopsy

Informed Consent     Yes     No    Date: |\_|\_|||\_|\_|||\_|\_|

Referring physician name and institution | \_\_\_\_\_ |  
Address | \_\_\_\_\_ |  
Telephone and fax | \_\_\_\_\_ |  
email | \_\_\_\_\_ |

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