

CPS-Registry: Annual Follow Up

Patient with Cancer Predisposition Syndrome (CPS)

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

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

Sex male female

Survival status:

Alive Date of last examination |__|__||__|__||__|__| Karnofsky/Lansky score |__|__| %

Dead Date of death |__|__||__|__||__|__| Autopsy no yes

Main cause of death: Please specify |_____|

Malignancy

Diagnosis of malignancy since last follow-up:

No

Yes specify (histology/site) |_____|

Date of malignancy diagnosis |__|__||__|__||__|__|

Chemotherapy Yes No

Radiation Yes No

Surgery Yes No

Comment: |_____|

Yes specify (histology/site) |_____|

Date of malignancy diagnosis |__|__||__|__||__|__|

Chemotherapy Yes No

Radiation Yes No

Surgery Yes No

Comment: |_____|

Please submit copies of

- Clinic notes summarizing the diagnosis of malignancy

- Pathology reports

- (cyto)genetic characterization

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Surveillance

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

Accompanying Projects

Liquid Biopsy

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

Referring physician name and institution |_____|

Address |_____|

Telephone and fax |_____|

email |_____|

Date |_|_|_|_|_|_|_|_|_|_|_|_|

Signature _____