CANCER PREDISPOSITION PROGRAM

About 16,000 children under the age of 20 are diagnosed with cancer each year in the United States, and researchers now estimate that at least 10% of childhood cancers have a hereditary basis. To harness the growing understanding of hereditary factors in childhood cancer, Children's Hospital of Philadelphia (CHOP) created the Cancer Predisposition Program in 2005. CHOP's program uses the latest advances in technology to provide genetic testing, genetic counseling and cancer surveillance, and thus improve the outlook for children with a genetic predisposition to develop cancer.

EXCEPTIONAL CARE FOR UNIQUE NEEDS

The Cancer Predisposition team provides coordination of care for children with a genetic predisposition to cancer by providing a multidisciplinary approach to comprehensive care and medical management. Care consists of physicians specialized in hereditary cancers to provide screening assessments and surveillance protocols for those children at risk for developing cancers. The program also has genetic counselors, psychologists and nursing staff.
The program also works closely with other providers to coordinate care from a variety of pediatric specialties, including Oncology, Medical Genetics, the Thyroid Center, Gastroenterology, the Bone Marrow Failure Program, the Neurofibromatosis Program and the Beckwith-Wiedemann Syndrome Clinic. Each member of our staff is dedicated to providing the most skilled and compassionate care available, in an environment that focuses on children and their families.

Also key to the program are community physicians, who are often the most likely to spot signs of predisposition in families, particularly among siblings and other relatives. Some features of cancer predisposition include a family history of the same or related cancers; bilateral or multifocal tumors; more than one cancer under the age of 20; clinical features of a cancer predisposition syndrome; or a cancer occurring at a much younger age than usual.

Children's Hospital of Philadelphia
Cancer Center

KEEPING PATIENTS INFORMED

For patients and families, we:

- Review information about the diagnosis, course and management of specific genetic conditions associated with increased cancer risk
- Explain and coordinate molecular genetic testing to diagnose cancer-predisposition syndromes and to better determine cancer risk
- Review and explain genetic test results
- Assist in ordering appropriate cancer screening tests
- Review family cancer histories to identify other family members potentially at risk
- Offer genetic counseling about the risk of occurrence of a cancer-predisposition condition in future children
- Create and distribute educational materials on genetic testing, cancer-predisposition syndromes and support groups
- Provide access to and enrollment in ongoing research in cancer genetics
- Offer psychosocial support services

For referring physicians, we:

- Provide comprehensive and detailed written reviews of our consultations
- Collaborate in the medical management of patients, coordinate genetic testing, and recommend cancer surveillance testing for early detection of cancers, according to available guidelines

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- Explain and interpret genetic testing and cancer screening results
- Recommend patient referrals to additional specialists, as needed
- Distribute educational materials on genetic testing and cancer predisposition syndrome

WHO CAN BENEFIT?

Referral to the Cancer Predisposition Program is recommended for children suspected of having a cancer-predisposition syndrome. Reasons to refer include:

- Tumor type with strong hereditary component (for example, retinoblastoma, pheochromocytoma/paraganglioma, rhabdoid tumor, adrenocortical carcinoma, pleuropulmonary blastoma, medullary thyroid cancer)
- Multifocal/bilateral cancer, or multiple primary tumors
- Early-onset tumor (adult-type cancer in a child; rhabdomyosarcoma in a child under 3 years old)
- Same or related types of cancer in multiple close relatives
- Patient with cancer and developmental delay/autism, birth defects or dysmorphic features (such as hemihypertrophy, macroglossia, macrocephaly or café-au-lait spots)
- Patient incidentally found to carry a mutation, deletion or duplication involving a cancer predisposition gene (such as on whole exome sequencing or SNP array)
- Patient with a known family history of a cancer-predisposition syndrome
- One or more family members with early onset of bone marrow failure (BMF) syndrome or myelodysplastic syndrome (MDS).

Examples of cancer predisposition syndromes include:

- 11p overgrowth syndromes (Beckwith-Wiedemann syndrome, hemihypertrophy)
- Chromosomal instability syndromes (Fanconi anemia, ataxia-telangiectasia, Bloom syndrome)
- Constitutional mismatch repair deficiency (CMMR-D)
- *DICER1* syndrome
- Familial adenomatous polyposis
- Gorlin syndrome (basal cell carcinomas, medulloblastoma)
- Hereditary neuroblastoma
- Hereditary paraganglioma/pheochromocytoma syndrome
- Hereditary retinoblastoma
- Wilms tumor predisposition syndromes
- Juvenile polyposis syndrome
- Li-Fraumeni syndrome
- Malignant rhabdoid tumors
- Multiple endocrine neoplasias (MEN1, MEN2A, MEN2B)
- Neurofibromatosis 1 and 2
- Peutz-Jeghers syndrome
- PTEN hamartoma tumor syndrome
- Von Hippel Lindau Syndrome

OUR TEAM — HERE FOR YOU

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To refer a patient or request a second opinion:
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LEARN MORE

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