

NCI-CONNECT

Comprehensive Oncology Network Evaluating Rare CNS Tumors

Purpose

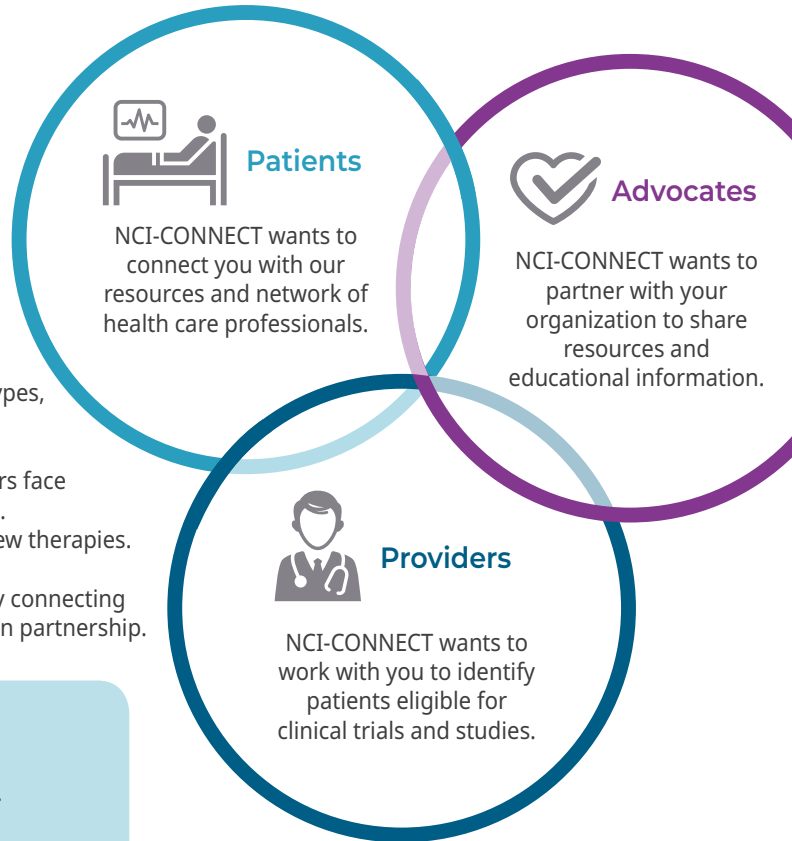
NCI-CONNECT aims to advance the understanding of rare adult central nervous system (CNS) cancers by establishing and fostering patient-advocacy-provider partnerships and networks to improve approaches to care and treatment.

Background

Primary CNS cancers are tumors that start in the brain and spinal cord. They account for less than 2% of all cancers diagnosed a year in the United States, with over 130 different types. Although all primary adult CNS tumors can be considered rare, NCI-CONNECT is starting with 12 types, each with less than 2,000 people diagnosed a year.

The low incident rate of these 12 tumors means patients and researchers face unique challenges. Patients struggle to find expert care and treatments. Researchers have limited resources to study the disease and develop new therapies.

NCI-CONNECT intends to address these challenges and unmet needs by connecting patients, providers, researchers and community organizations to work in partnership.



Goals

NCI-CONNECT is a collaborative, innovative and adaptive program. Its goals are to:

- Develop an infrastructure across a network of national and international sites to study select rare CNS tumors.
- Collect, analyze and share data to promote discovery and improve understanding of select rare CNS tumors.
- Use the network to facilitate the translation of discoveries into new therapies and methods to improve patient outcomes.

NCI-CONNECT selected rare adult CNS tumor types:

- Atypical Teratoid Rhabdoid Tumor (ATRT)
- Brainstem and Midline Gliomas
- Choroid Plexus Tumors
- Ependymoma
- Gliomatosis Cerebri
- Medulloblastoma
- Meningioma (High Grade)
- Oligodendroglioma / Anaplastic Oligodendroglioma
- Pineal Region Tumors
- Pleomorphic Xanthroastrocytoma / Anaplastic Pleomorphic Xanthroastrocytoma
- PNET (Supratentorial Embryonal Tumor)
- Primary CNS Sarcoma / Secondary CNS Sarcoma (Gliosarcoma)

Studies

NCI-CONNECT has a number of studies that are open and available for participation and will be adding more.

Learn more at:
ccr.cancer.gov/Neuro-Oncology-Branch



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NCI-CONNECT is a program within the Rare Tumor Patient Engagement Network (RTPEN), an initiative supported by the National Cancer Moonshot. RTPEN aims to advance research and discover new treatments for rare tumors through a collaborative network of national and international institutions that will provide expertise, personalized health care and education to patients with rare tumors.

NCI-CONNECT as part of RTPEN focuses on rare central nervous system tumors and is managed at the National Institutes of Health, National Cancer Institute Center for Cancer Research Neuro-Oncology Branch.