

NCI-CONNECT

Comprehensive Oncology Network Evaluating Rare CNS Tumors

Providing consultations and treatment options for patients with select rare CNS tumors.

Your participation in **NCI-CONNECT** will help us better understand adult rare brain and spine tumors. Our goal is to improve care for patients with CNS tumors.

cancer.gov/nci-connect

Neuro-Oncology Branch at the NCI/NIH

Referrals

To make an appointment or refer a patient, contact us at nciconnect@mail.nih.gov or call (240) 760-6530. We request that the patient or family member contact us directly to facilitate the consent process for the visit.

Candidates with one of these rare CNS tumors listed should participate if:

- > they are newly diagnosed or have a recurrence and need to make a treatment decision
- > they are interested in a second opinion on follow-up care
- > they are interested in improving their care and the care of future patients

Tumor Types

NCI-CONNECT has a number of studies that are open for patients with these rare CNS tumors:

- > ATRT
- > Choroid Plexus Tumors
- > Diffuse Midline Gliomas
- > Ependymoma
- > Gliomatosis Cerebri
- > Gliosarcoma
- > Medulloblastoma
- > Meningioma (High Grade)
- > Oligodendroglioma
- > Pineal Region Tumors
- > PXA / APXA
- > PNET

Find open studies at: cancer.gov/nci/rare-brain-spine-tumor/refer-participate/clinical-studies

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What are the costs?

- > Consultations are free-of-charge
- > Treatments, tests and other services at the NIH are also free after a patient is accepted on study
- > Please note: NIH does not cover expenses for medical services at other facilities

Questions?

Contact us at
NCICONNECT@mail.nih.gov
or call (240) 760-6530

What items are needed for a consultation?

- > All available MRI and CT scans related to the brain/spine tumor diagnosis and corresponding radiology reports. Most recent MRI should be within 30 days of the appointment.
- > Pathology material from the most recent surgery (including biopsies) sent in advance of the appointment. Receiving this material is critical to schedule the appointment. Appointments can be scheduled as early as two weeks after the pathology material is received.
- > Most recent progress note from the patient's treating physician. Other records, including surgery, radiation, and treatment summaries may be requested to determine trial eligibility.

Our healthcare team provides patients with a comprehensive care plan that, together with their physician at home, will ensure they get the best treatment possible.



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