



Central Brain Tumor Registry of the United States It Took Many Bridges

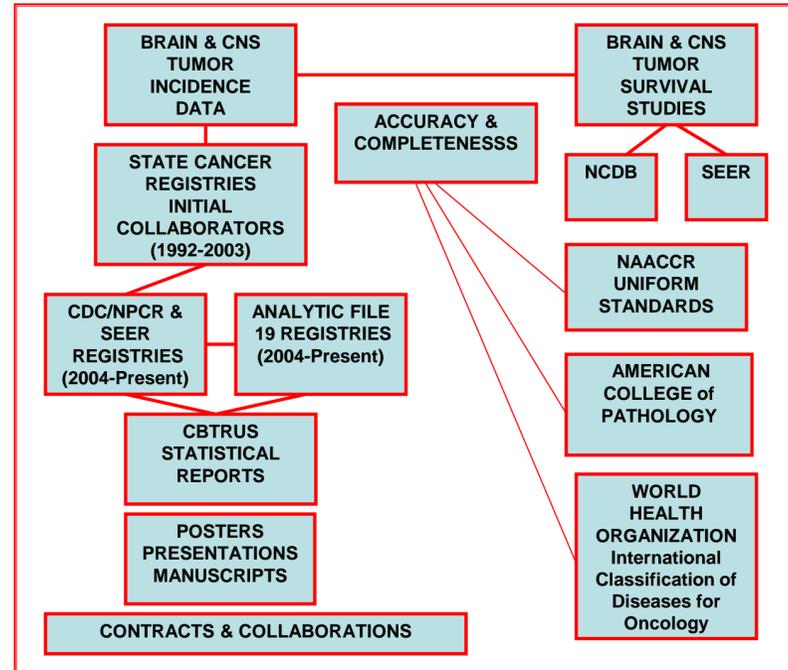


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Background

- The Central Brain Tumor Registry of the United States (CBTRUS) was incorporated as a 501 c (3) with a grant from the Pediatric Brain Tumor Foundation following a 2-year study conducted by the American Brain Tumor Association in 1992.
- Its focus is to provide population-based incidence data on **ALL** primary brain and central nervous system tumors.
- For tumors diagnosed prior to 2004, this entailed agreements with state cancer registries which receive data from tumor registrars located in hospitals within their state.
- The collection of data on primary brain tumors was restricted to malignant brain tumors, but some registries supported the CBTRUS mission and included the non-malignant brain tumors in their cancer surveillance practices.
- CBTRUS was the first organization to ask state cancer registries for data on non-malignant brain tumors. Reports from 1995-2006 were based on data accrued through this mechanism.
- For data from 2004 forward, CBTRUS has been receiving data from the Centers for Disease Control and Prevention through its National Program of Cancer Registries (CDC/NPCR) under a restricted-use agreement for the CBTRUS Statistical Reports, and from the Surveillance, Epidemiology and End Results (SEER) program of the National Cancer Institute.
- Data from the original collaborating state cancer registries are included in the CDC/NPCR or SEER data and are used as the CBTRUS Analytic file.

Surveillance Associations & Products

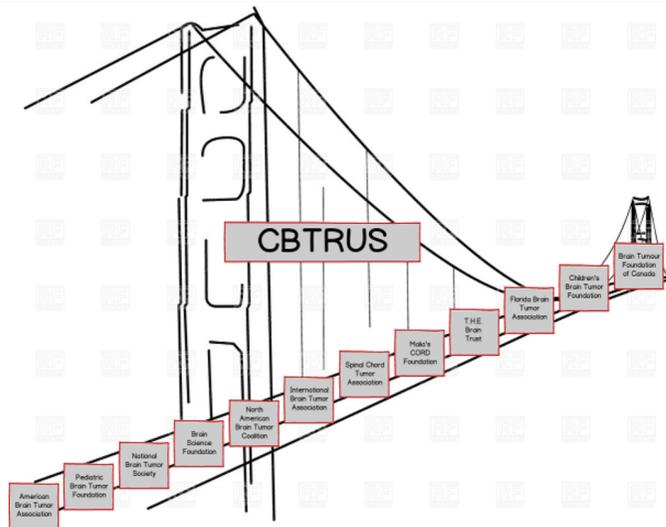


Results

The diagnosis years 2004-2008 CBTRUS data set included **295,986** newly diagnosed brain tumors. Incidence by site, histology, behavior, gender, age group and race were provided in the most recent statistical report. Survival statistics were also provided through analyses of malignant tumors in the SEER research dataset.

- Incidence of all primary brain tumors is **19.9** cases per 100,000 person-years (malignant brain tumors is **7.3** per 100,000 person-years; non-malignant brain tumors is **12.6** per 100,000 person-years).
- 66,290** new cases of all primary brain and CNS tumors are estimated to be diagnosed in 2012 (24,300 malignant; 41,980 non-malignant).
- 4,200** new cases of primary brain and CNS tumors are estimated to be diagnosed in children, **ages 0-19 years**.
- Meningioma** has the **highest incidence by histology of all primary brain and CNS tumors** making it the most common primary brain tumor.
- Glioblastoma** has the **highest incidence by histology of all malignant brain tumors** and is the **second most common histology in adults ages 45-84 years**.

Advocacy Relationships



Funding and Support



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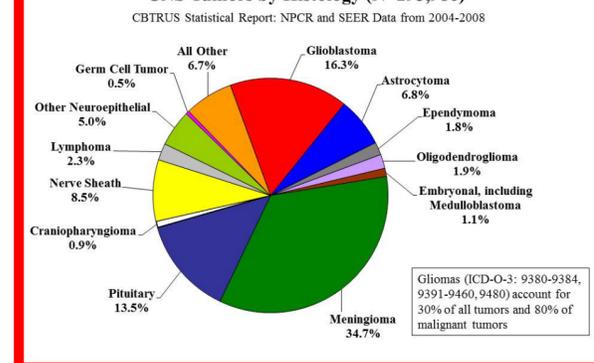
Methods

- Data for newly diagnosed cases of malignant and non-malignant primary brain and central nervous system tumors from CDC/NPCR and NCI SEER population-based cancer registries were received without personal identifiers and analyzed.
- Based on the first CBTRUS Consensus Conference, the International Classification of Diseases for Oncology topography (location) codes for brain (C71.0 –C71.9), meninges (C70.0-C70.9), spinal cord, cranial nerves, and other parts of the CNS (C72.0-C72.9), pituitary and pineal glands (C75.1-C75.3) and olfactory tumors of the nasal cavity (C30.0 [9522-9523]) were included in the analytic data file.
- Incidence counts and rates were calculated using SPSS and SEER*Stat statistical software.
- Statistics were suppressed for cells with counts of less than 16.
- Standardized data elements from all state registries meeting NPCR standards are utilized in CBTRUS analyses.
- The Certified Tumor Registrar (CTR) makes every effort to locate required information as they are responsible for reporting all cancers (non-malignant brain tumors are the exception) at their hospitals.
- One must keep in perspective that the incidence of primary brain tumors is less than 2% of all reportable cancers and involves over 125 different histologies making brain tumor reporting complex.
- Population data for each geographic region were obtained from the SEER program website which receives yearly population estimates from the U.S. Census Bureau for rate calculations.
- Age-adjustment using the direct method was based on five-year age groups and standardized to the Year 2000 U.S. standard population.
- Although pilocytic astrocytoma is listed in the *WHO Classification of Tumors of the Central Nervous System* as uncertain behavior, these tumors are routinely included with malignant brain tumor data.

Most Common Brain and CNS Tumors by Age
CBTRUS Statistical Report: NPCR and SEER Data from 2004-2008

Age (yr)	Most Common Histology	Second Most Common Histology
0-4	Embryonal/medulloblastoma	Pilocytic astrocytoma
5-9	Pilocytic astrocytoma	Malignant glioma, NOS
10-14	Pilocytic astrocytoma	Neuronal/glial
15-19	Pituitary	Pilocytic astrocytoma
20-34	Pituitary	Meningioma
35-44	Meningioma	Pituitary
45-54	Meningioma	Glioblastoma
55-64	Meningioma	Glioblastoma
65-74	Meningioma	Glioblastoma
75-84	Meningioma	Glioblastoma
85+	Meningioma	Neoplasm, unspecified

Distribution of All Primary Brain and CNS Tumors by Histology (N=295,986)
CBTRUS Statistical Report: NPCR and SEER Data from 2004-2008



Conclusion

CBTRUS provides a resource for the neuroscience and public health community including researchers, clinicians, patients and advocacy groups that does not exist elsewhere.