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 primary brain tumors, but some registries supported the CBTRUS mission and included the non-malignant brain tumors in their cancer surveillance practices.
- 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.

Surveillance Associations & Products

Advocacy Relationships

Funding and Support

Acknowledgements: All analyses were conducted under contract to the Central Brain Tumor Registry of the United States whose funding sources in 2011 included the American Brain Tumor Association, the Pediatric Brain Tumor Foundation, the National Brain Tumor Society, and the Dept. of Health and Human Services, National Cancer Institute. MH5626810100057P and the Centers for Disease Control and Prevention #1US57DP003831-01.

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.

Conclusions

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 and CNS tumors and is the second most common histology in adults ages 45-84 years.

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

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