

Ependymoma Statistical Report

The Collaborative Ependymoma Research Network (CERN), in collaboration with the Central Brain Tumor Registry of the United States (CBTRUS), has prepared this report on the incidence, prevalence, lifetime risk, and survival associated with ependymoma. All data in this report are reproduced from the **CBTRUS Statistical Report on Primary Brain and Central Nervous System Tumors Diagnosed in the United States in 2004-2006**, published in February 2010. [Citation: CBTRUS (2010). 2009-2010 CBTRUS Statistical Report: Primary Brain and Central Nervous System Tumors Diagnosed in the United States in 2004-2006. Source: Central Brain Tumor Registry of the United States, Hinsdale, IL.]

What is CBTRUS?

CBTRUS is a not-for profit research corporation whose mission is to provide a resource for gathering and disseminating current epidemiologic data on all primary brain and central nervous system tumors, malignant and non-malignant, for the purposes of accurately describing their incidence and survival patterns, evaluating diagnosis and treatment, facilitating etiologic studies, establishing awareness of the disease, and ultimately, for the prevention all brain tumors. More information on CBTRUS and additional statistical data are available at www.cbtrus.org.

Statistical Definitions

Incidence: The occurrence of newly diagnosed disease that appears in a particular population during a **specified period of time** (typically yearly). In this report, the crude incidence rates are calculated by counting the number of people with newly diagnosed primary brain and central nervous system(CNS) tumors and dividing by the total population at risk (e.g. the total population in a state or collection of states) and are usually expressed per 100,000 person-years. Incidence rates can also be calculated specifically for those diagnosed with ependymoma.

Age adjustment: Age-adjustment is a procedure designed to minimize the effects of differences in age composition when comparing incidence and mortality rates among different populations. Age-adjustment of rates in this report are calculated by the direct method adjusting to the 2000 U.S. standard million population.

Prevalence: The number or proportion of people with a particular disease or attribute (in this case, both those with a newly diagnosed brain or CNS tumor and those who may have been diagnosed in the past and are living with the disease) in a given population during a **specified period of time**.

5-year survival rate: The probability that a patient will survive for 5 years from the date of diagnosis of a disease (in this case, diagnosis of a brain or CNS tumor).

Incidence of Primary Brain Tumors and Ependymomas

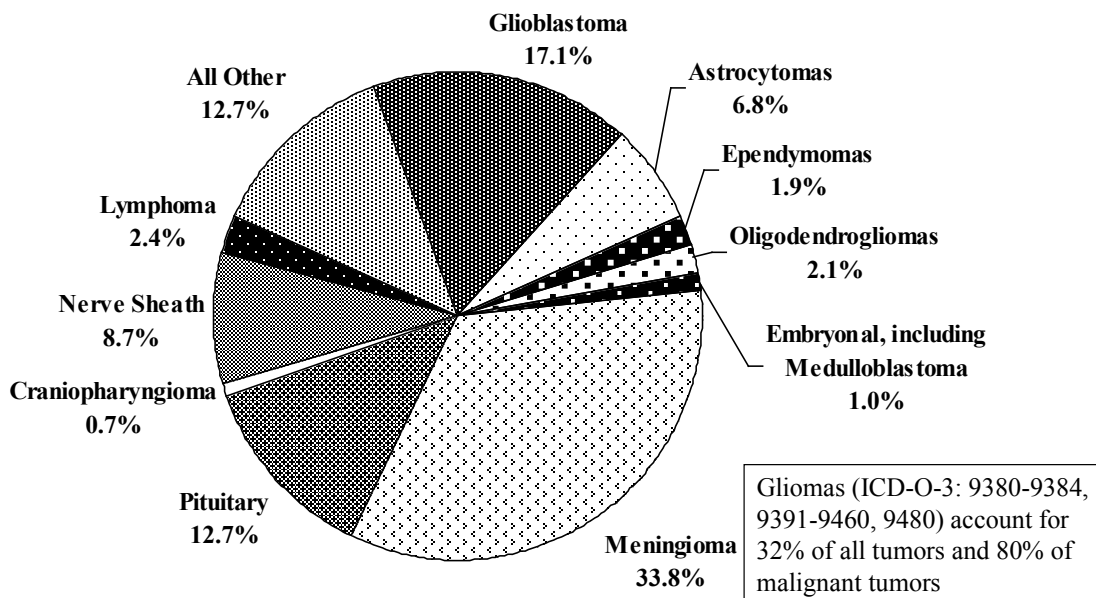
Primary Brain Tumors: For all primary brain and central nervous system tumors, CBTRUS estimates that the average annual age-adjusted incidence rate is 18.71 cases per 100,000 person-years for the years 2004-2006, with an estimated 62,930 new cases of primary brain and other central nervous system tumors expected to be diagnosed in the United States in 2010.

Children (aged 0-19 years): For all primary brain and central nervous system tumors, the incidence rate is 4.71 cases per 100,000 person-years, with an estimated 4,030 new cases expected to be diagnosed in 2010.

Worldwide, data were available to estimate that 189,582 malignant and 186,678 non-malignant newly diagnosed brain and central nervous system tumors were diagnosed in 2002 (McCarthy BJ, Schellinger KA, Propp JM, Kruchko C, Malmer B. A Case for the Worldwide Collection of Primary Benign Brain Tumors. *Neuroepidemiology* 33(3):268-275, 2009).

Figure 5.
Distribution of All Primary Brain and CNS Tumors by Histology
(N=158,088)

CBTRUS Statistical Report: NPCR and SEER Data from 2004-2006



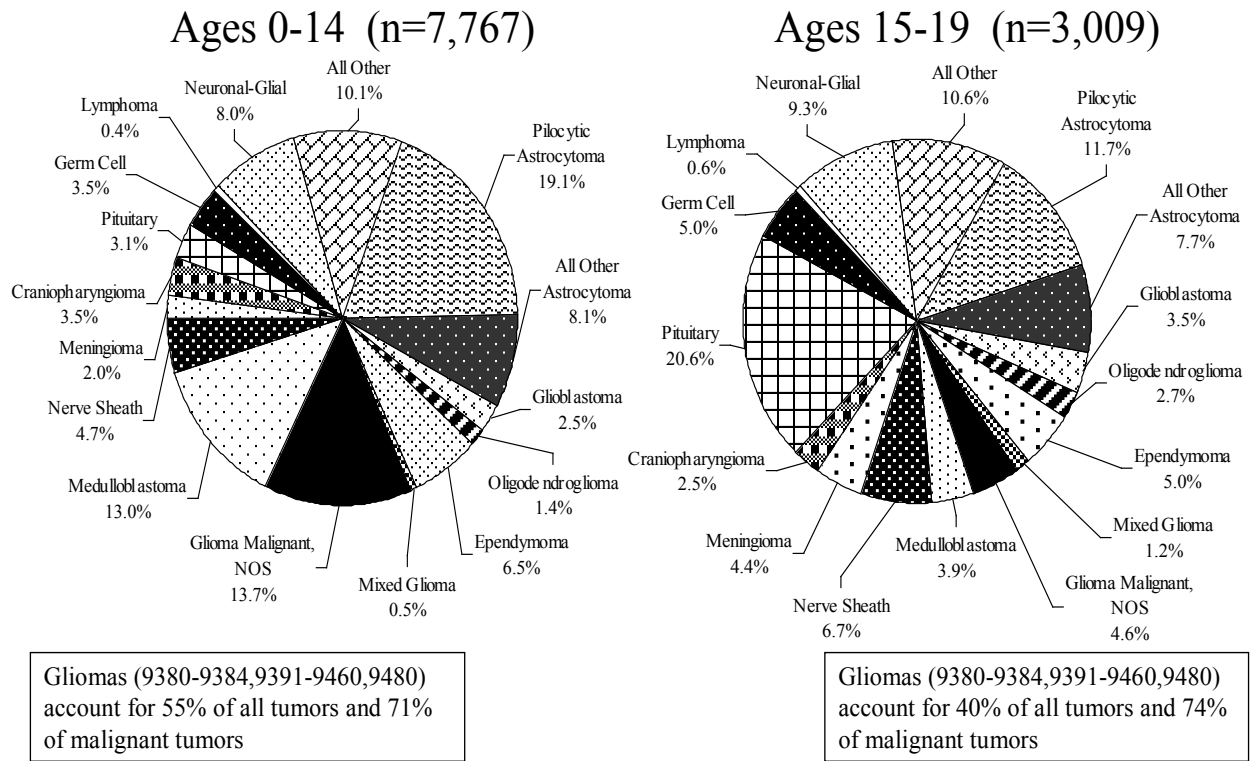
Ependymoma: Ependymomas (ependymoma, NOS (not otherwise specified), epithelial ependymoma, cellular ependymoma, clear cell ependymoma, tanycytic ependymoma, anaplastic ependymoma, ependymoblastoma, capillary ependymoma) and ependymoma variants (myxopapillary ependymoma) are rare, and represent 1.9% of all primary brain and CNS tumors (see Figure 5 from CBTRUS Statistical Report). Approximately 3000 ependymomas and ependymoma variants were diagnosed from 2004-2006. Ependymomas/ anaplastic ependymomas occur with similar incidence in males (0.26 per 100,000 person-years) and females (0.25 per 100,000 person-years). The incidence of ependymoma variants is higher in

males (0.11 per 100,000 person-years) than females (0.08 per 100,000 person-years). The incidence of both ependymomas/anaplastic ependymomas and ependymoma variants was higher in whites (0.27 and 0.11 per 100,000 person-years, respectively) than blacks (0.16 and 0.04 per 100,000 person-years, respectively).

In children aged 0-14 years, ependymomas accounted for 6.5% of all tumors diagnosed, with approximately 500 children diagnosed during the years 2004-2006 (see Figure 15 from CBTRUS Statistical Report). For those children aged 15-19 years, 5% of all primary brain and central nervous system tumors are ependymoma, with approximately 150 teenagers diagnosed during the years 2004-2006. The incidence of ependymomas/anaplastic ependymomas in children (aged 0-19 years) was similar in males and females (0.25 per 100,000 person-years for both). The incidence of ependymoma variants is higher in males (0.05 per 100,000 person-years) than females (0.03 per 100,000 person-years).

Figure 15.
Distribution of Childhood Primary Brain and CNS Tumors by Histology

CBTRUS Statistical Report: NPCR and SEER Data from 2004-2006



For tumors involving the spinal cord and cauda equina, ependymomas accounted for 33.6% of all tumors diagnosed in adults aged 20+ years and 24.1% of all tumors diagnosed in children aged 0-19 years.

Prevalence of Primary Brain Tumors

[Citation: Porter KR, McCarthy BJ, Freels S, Kim Y, Davis FG. Prevalence estimates for primary brain tumors in the US by age, gender, behavior, and histology. Neuro-Oncology Advance Access published online on February 8, 2010; Doi:10.1093/neuonc/nop066]

The prevalence rate of primary brain and central nervous system tumors was estimated to be 209.0 per 100,000 in 2004. This leads to an estimate that more than 612,000 persons in the U. S. were living with a diagnosis of primary brain and central nervous system tumors in 2004.

For children (aged 0-19 years), the prevalence rate for all pediatric primary brain and central nervous system tumors was estimated at 35.4 per 100,000. Therefore, there were more than 28,000 children estimated to be living with one of these diagnoses in the U.S. in 2004.

5-year survival rates for Primary Brain Tumors and Ependymoma

The 5-year relative survival rate for all primary brain and central nervous system tumors is 33.6% for males and 37.0% for females. For children aged 0-19 years, the 5-year relative survival rate is 72.1%.

For those with ependymoma, the overall 5-year relative survival rate is 81.86%. For children aged 0-19 years, the 5-year relative survival rate is 72.1%. Five-year relative survival rates are highest for those aged 20-44 years (90.8%), and decrease with increasing age at diagnosis with a 5-year relative survival rate of 61.9% for those aged 75+ years.

***** Please recognize that these numbers are helpful for general information related to ependymoma, but may not be meaningful for any one individual. Please discuss any questions or concerns that you have about your own diagnosis with your treating physician.***

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Visit www.cern-foundation.org or www.cbtrus.org for more information.