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A 3D rendering of numerous question marks in various shades of grey and black, scattered across a dark, reflective surface.

NAACCR

Q&A

Please submit all questions concerning the webinar content through the Q&A panel.

If you have participants watching this webinar at your site, please collect their names and emails.

We will be distributing a Q&A document in about one week. This document will fully answer questions asked during the webinar and will contain any corrections that we may discover after the webinar.

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Fabulous Prizes

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Guest Presenters

- Carol Kruchko, BA
- Jennifer Ruhl, RHIT, CCS, CTR

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Agenda

- The Central Brain Tumor Registry of the United States (CBTRUS)
- Anatomy
- Solid Tumor Rules
- Stage
- SSDI



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The Central Brain Tumor Registry of the United States

A Resource for Population-Based Data on Primary Brain Tumors

Carol Kruchko

NAACCR Webinar
July 31, August 1, 2024


CBTRUS
Hinsdale, IL, USA



www.cbtrus.org


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What is CBTRUS?

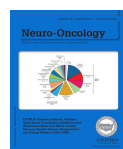


CBTRUS is a unique 501 (c) (3) research organization focused on providing brain and other central nervous system (CNS) tumor statistics.


- Founded in 1992 and has provided 26 reports on primary brain and other CNS tumors and 4 specialized reports
- The largest aggregation of population-based incidence data on primary brain and CNS tumors in the world
- The only organization annually reporting population-based statistical information on brain and other CNS tumors by behavior, histopathology, sex, age, age groups, race and ethnicity, and specific molecular markers for the entire United States
- Recognized globally for reporting brain tumors by clinically relevant histology groupings







Annual report published as supplement in *Neuro-Oncology* since 2011.



Special report focused on children and adolescents (ages 0-19) published in 2022




Special report focused on adolescents and young adults (ages 15-39) published in 2024


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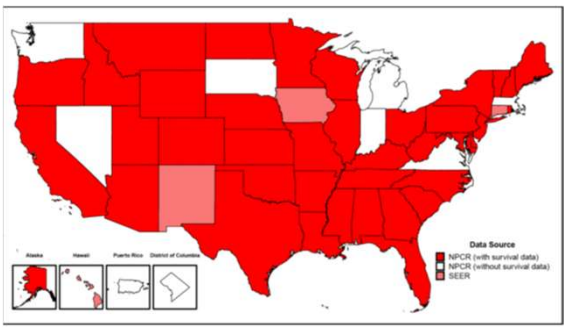
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CBTRUS data sources and processing pipeline



Data collected from CBTRUS, a population-based registry combining data from the CDC's National Program of Cancer Registries and NCI's Surveillance, Epidemiology and End Results Program. Together, the programs cover the entire U.S. population.









NPCR (2016-2020) 452,485 from 48 CCRs	SEER (2016-2020) 13,806 from 4 CCRs
CBTRUS Analytic file (pre-cleaning) 466,291 records from 52 CCRs	
Remove 8 records with ICD-O behavior code of 2*	
Remove 8,758 records with site/histology mismatch	
Remove 1,128 duplicate records	
Remove 720 records by merging paired-site records	
455,677 records remaining after cleaning	
CBTRUS main analytic file (2016-2020) 453,623 records from 51 CCRs*	Records from Puerto Rico (2016-2020) 2,054 records from 1 CCR*

10,614 records removed (2.3%)

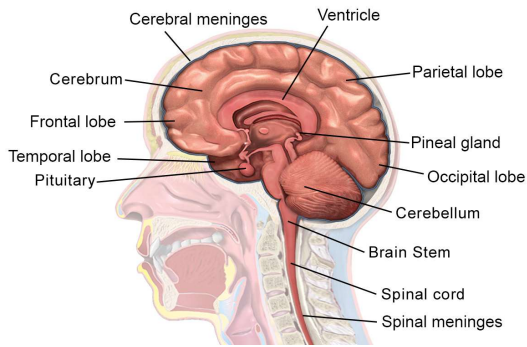
CBTRUS Statistical Report 2023: US Cancer Statistics - NPCR and SEER, 2016-2020

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CBTRUS site definition for brain tumors



Site	ICD-O-3 Site Code
Olfactory tumors of the nasal cavity	C30.0
Meninges (cerebral & spinal)	C70.0-C70.9
Cerebrum	C71.0
Frontal lobe of brain	C71.1
Temporal lobe of brain	C71.2
Parietal lobe of brain	C71.3
Occipital lobe of brain	C71.4
Ventricle	C71.5
Cerebellum	C71.6
Brain stem	C71.7
Other brain (including overlapping lesion of brain and Brain, NOS)	C71.8-C71.9
Spinal cord and cauda equina	C72.0-C72.1
Cranial nerves	C72.2-C72.5
Other nervous system (including Overlapping lesion of brain and CNS, and Nervous system NOS)	C72.8-C72.9
Pituitary and craniopharyngeal duct	C75.1-C75.2
Pineal gland	C75.3

Adapted from https://commons.wikimedia.org/wiki/File:Brain_Anatomy_Striatum.png



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CBTRUS site definition – application in CiNA

NAACCR updates the recode to select cases based on the CBTRUS data definition as of June 2023 release of all CiNA data sets. Available for cancer registries and researchers to calculate on their own data via File*Pro.

Journal of Registry Management 2022 Volume 49 Number 4, The Central Brain Tumor Registry of the United States Histopathological Grouping Scheme Provides Clinically Relevant Brain and Other Central Nervous System Categories for Cancer Registry Data. Ostrom Q, Kruchko C, Neff C, Firth A, Sherman, R

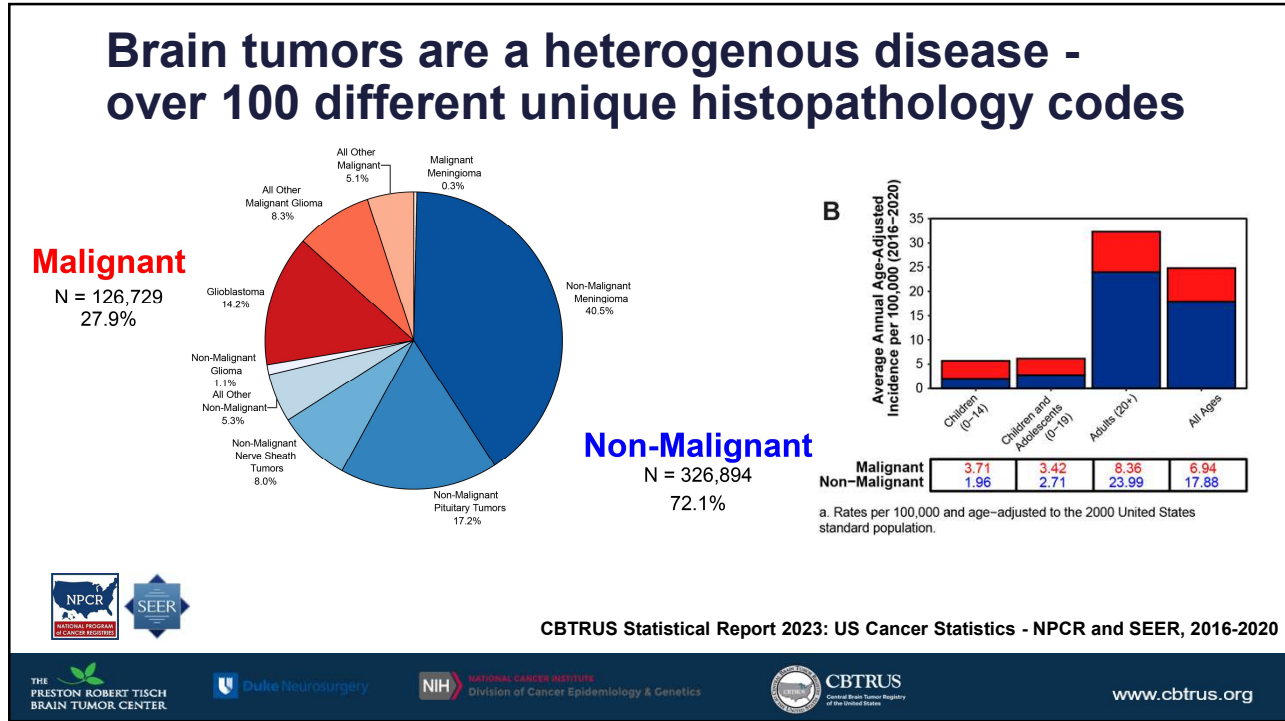
Table 2. Frequency of cases assigned to categories in the CBTRUS and SEER Brain and CNS Histopathologic Recode Schemes, 2015-2019 NAACCR CiNA

	CBTRUS Brain and CNS recode								
	Diffuse astrocytoma	Anaplastic astrocytoma	Glioblastoma	Oligodendroglioma	Anaplastic oligodendroglioma	Oligoastrocytic tumors	Piloicytic astrocytoma	Unique astrocytoma variants	Ependymal tumors
1. Malignant brain/CNS	9,653	7,518	67,795	4,041	2,160	595	5,537	572	4,106
1.1 Glioma	9,653	7,518	67,795	4,041	2,160	595	5,537	572	4,106
1.1.1 Diffuse astrocytoma and anaplastic astrocytoma	8,045	7,518	0	0	0	0	0	0	0
1.1.2 Glioblastoma	1,417	0	67,795	0	0	0	0	0	0
1.1.3 Diffuse midline glioma, H3 K27M-mutant	0	0	0	0	0	0	0	0	0
1.1.4 Oligodendroglioma	0	0	0	4,041	2,143	0	0	0	0
1.1.5 Oligoastrocytoma	0	0	0	0	0	595	0	0	0
1.1.6 Other astrocytic tumors	0	0	0	0	0	0	5,537	559	0
1.1.7 Astroblastoma	0	0	0	0	0	0	0	0	0
1.1.8 Ependymal tumors	0	0	0	0	0	0	0	0	4,067
1.1.9 Glioma, unspecified	0	0	0	0	0	0	0	0	0

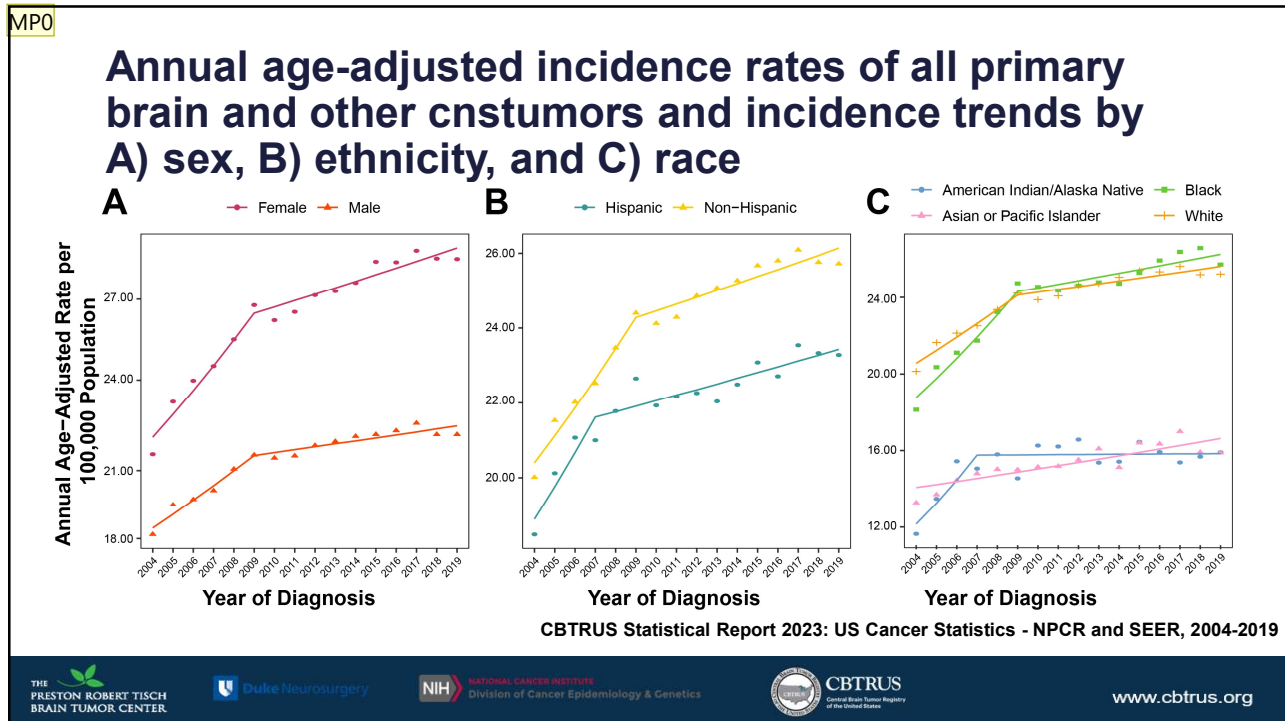


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Slide 12

MPO Suggest this added slide from report

Mackenzie Price, 2024-07-11T12:52:17.514

An estimated 1.3 million people in the US were living with a history of a primary brain tumor diagnosis in 2019, and ~490,000 of these are diagnosed with meningioma

Histopathology	Age group				Total count
	0-14 years	15-39 years	40-64 years	65+ years	
Diffuse and anaplastic astrocytoma	1276	11,179	14,450	3728	30,633
Glioblastoma	241	2723	12,867	8857	24,688
Oligodendroglial tumors	231	6506	14,376	3597	24,710
Pilocytic astrocytoma	6343	18,122	9772	1353	35,590
Unique astrocytoma variants	696	2476	--	--	3986
Ependymal tumors	1793	7060	14,833	9638	33,324
Other gliomas	4005	9543	6137	2154	21,839
Neuronal and mixed neuronal-gliial tumors	2136	10,422	9979	3008	25,545
Choroid plexus tumors	742	1508	802	122	3174
Tumors of the pineal region	121	249	--	--	777
Embryonal tumors	3656	7755	2979	131	14,521
Tumors of the cranial and spinal nerves	1557	14,136	67,801	96,770	180,264
Meningioma	141	17,632	175,605	298,131	491,509
Other tumors of the meninges	528	4688	12,155	7683	25,054
Lymphoma and other hematopoietic neoplasm	67	689	3979	4400	9135
Germ cell tumors	519	3281	1432	26	5258
Tumors of the sellar region	2642	61,617	161,174	121,294	346,727
Unclassified tumors	1525	9801	20,276	14,785	46,387
Total	28,219	189,387	529,670	575,845	1,323,121
Total malignant	18,467	66,341	78,121	32,119	195,048
Total non-malignant	9752	123,046	451,549	543,726	1,128,073

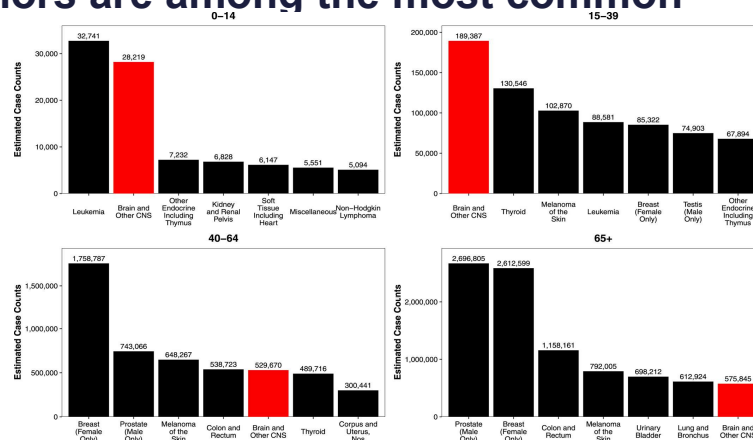
Neff, Price, et al 2023 (PMID: 37199898)



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Among children and adolescents/young adults living with a history of cancer diagnosis, brain and other CNS tumors are among the most common



Neff, Price, et al 2023 (PMID: 37199898)



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Distribution of selected histopathologically-confirmed brain and other CNS tumors by WHO grade completeness

Histopathology	Number of Newly Diagnosed Tumors	Histopathologically-Confirmed (%)	WHO Grade Completeness (%)			Assigned WHO Grade			
			Complete	Incomplete	Not Applicable	WHO Grade 1/I	WHO Grade 2/II	WHO Grade 3/III	WHO Grade 4/IV
Diffuse Astrocytic and Oligodendroglial Tumors	84,389	94.4%	91.5%	8.5%	0.1%	0.5%	10.4%	12.0%	77.1%
Glioblastoma	64,548	93.8%	91.9%	8.0%	0.1%	0.3%	0.2%	0.7%	98.7%
Pilocytic astrocytoma	5,417	87.0%	86.8%	12.9%	0.4%	95.9%	3.0%	0.5%	0.5%
Ependymal Tumors	6,858	84.4%	88.3%	11.5%	0.2%	37.0%	47.8%	14.4%	0.8%
Malignant	3,813	92.8%	89.5%	10.2%	0.3%	3.0%	72.8%	23.0%	1.2%
Non-Malignant	3,045	73.9%	86.4%	13.5%	0.0%	92.8%	6.8%	0.2%	0.2%
Other Gliomas	8,977	44.8%	52.3%	46.9%	0.8%	8.3%	20.5%	16.4%	54.8%
Glioma malignant, NOS	8,877	44.3%	52.2%	47.0%	0.8%	8.3%	19.3%	16.4%	56.1%
Neuronal and Mixed Neuronal-Glial Tumors	5,304	91.2%	60.3%	26.8%	12.9%	83.4%	13.0%	2.7%	0.9%
Choroid Plexus Tumors	808	87.1%	78.4%	21.4%	0.1%	62.6%	23.7%	13.0%	0.7%
Malignant	723	96.7%	74.8%	24.4%	0.8%	10.0%	4.4%	81.1%	4.4%
Non-Malignant	685	85.4%	79.1%	20.9%	0.0%	72.7%	27.3%	0.0%	0.0%
Tumors of Meninges	191,055	36.2%	82.1%	17.9%	0.1%	80.0%	17.9%	2.0%	0.1%
Meningiomas	185,195	34.9%	83.6%	16.4%	0.0%	80.1%	18.3%	1.5%	0.1%
Malignant	1,571	79.0%	87.8%	12.2%	0.0%	21.0%	13.8%	64.1%	1.1%
Non-Malignant	183,624	34.5%	83.6%	16.4%	0.0%	81.4%	18.4%	0.2%	0.1%
Lymphomas and Hematopoietic Neoplasms	8,628	95.2%	1.3%	97.9%	0.7%	60.6%	2.8%	15.6%	21.1%
Lymphoma	8,583	95.1%	1.3%	98.1%	0.6%	60.2%	2.8%	15.7%	21.3%
Other hematopoietic neoplasms	45	97.8%	2.3%	65.9%	31.8%	100.0%	0.0%	0.0%	0.0%
Germ Cell Tumors	1,255	87.3%	9.5%	43.5%	47.0%	23.5%	8.8%	8.8%	58.8%
Malignant	1,092	89.3%	6.2%	31.6%	34.2%	3.7%	11.1%	11.1%	74.1%
Non-Malignant	163	73.6%	10.9%	17.0%	18.4%	100.0%	0.0%	0.0%	0.0%
Tumors of Sellar Region	81,166	42.5%	18.9%	0.3%	80.8%	100.0%	0.0%	0.0%	0.0%
Tumors of the pituitary	78,082	40.9%	16.8%	0.0%	83.2%	100.0%	0.0%	0.0%	0.0%
TOTAL	453,623	52.4%	67.2%	18.0%	14.8%	40.9%	13.8%	7.2%	38.1%
Malignant	126,729	86.1%	79.6%	18.6%	1.8%	5.7%	12.6%	12.8%	68.9%
Non-Malignant	326,894	39.3%	57.1%	17.6%	25.3%	84.4%	15.3%	0.2%	0.1%

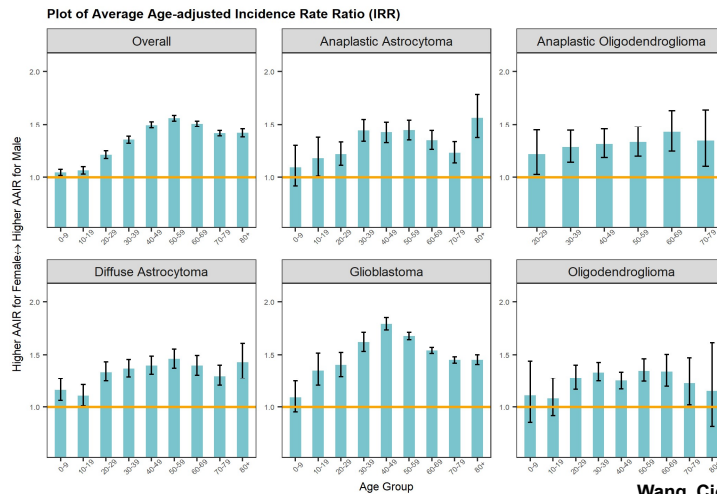
CBTRUS Statistical Report: US Cancer Statistics – NPCR and SEER, 2016-2020



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Male-to-female incidence ratio in malignant glioma is lowest in childhood and increases in adulthood

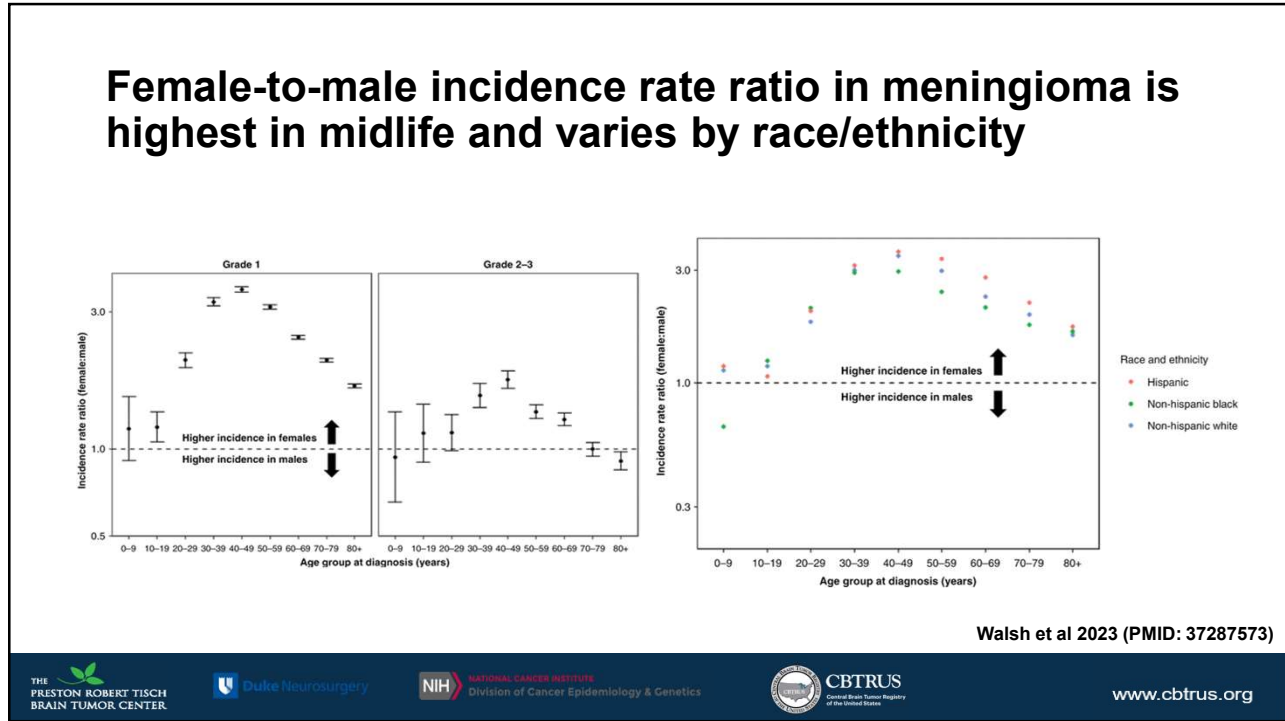


Wang, Cioffi, et al 2021 (PMID: 34387331)

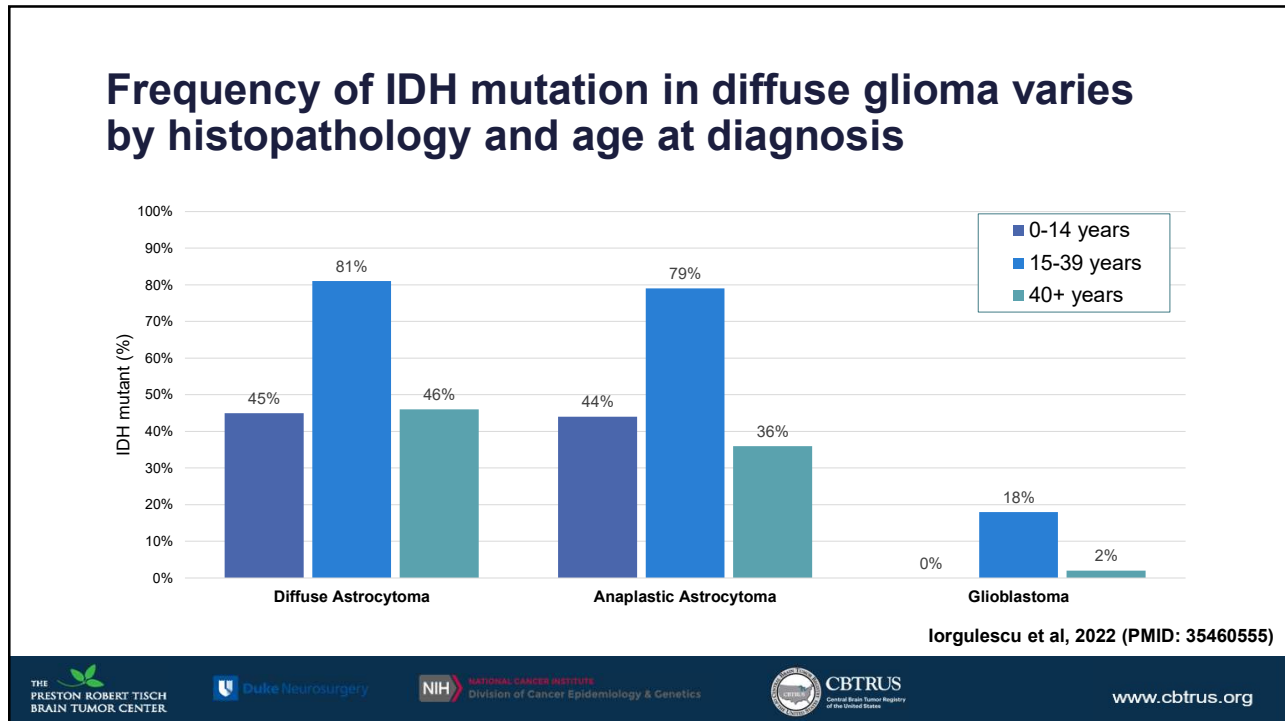


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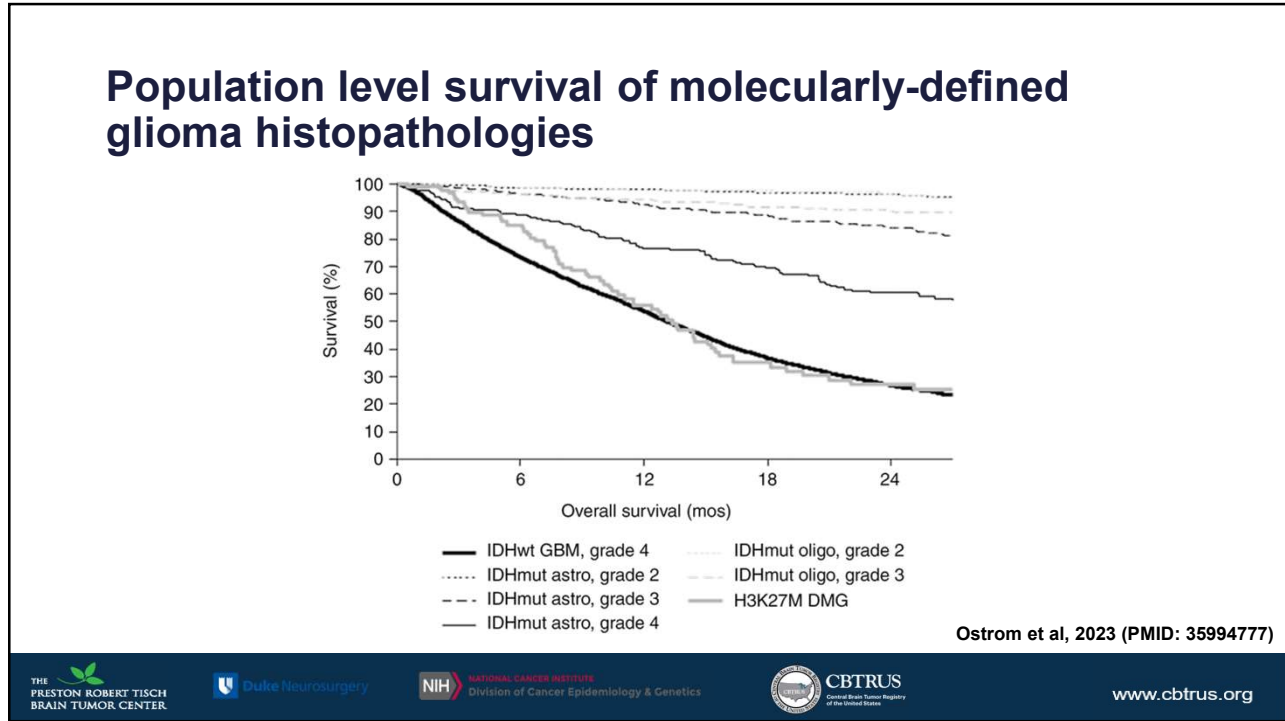
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CBTRUS partnership with NCI Neuro-Oncology Branch-NCI CONNECT

- **Manuscript on 12 especially rare CNS tumor types- Capturing evolving definitions of 12 select rare CNS tumors: a timely report from CBTRUS and NCI-CONNECT.** Price M, Neff C, Kruchko C, Barnholtz-Sloan JS, Cordeiro BB, Penas-Prado M, Ozer BH, Cimino PJ, Gilbert MR, Armstrong TS, Ostrom QT. J Neurooncol. 2023 Nov;165(2):279-290. doi: 10.1007/s11060-023-04480-7. Epub 2023 Nov 19. PMID: 37980692
- **AYA Report - CBTRUS Statistical Report: American Brain Tumor Association & NCI Neuro-Oncology Branch Adolescent and Young Adult Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2016-2020.** Price M, Neff C, Nagarajan N, Kruchko C, Waite KA, Cioffi G, Cordeiro BB, Willmarth N, Penas-Prado M, Gilbert MR, Armstrong TS, Barnholtz-Sloan JS, Ostrom QT. Neuro Oncol. 2024 May 6;26(Supplement_3):iii1-iii53. doi: 10.1093/neuonc/noae047. PMID: 38709657
- **Statistical Information for Website - <https://www.cancer.gov/rare-brain-spine-tumor/tumors>**

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Capturing evolving definitions of 12 select rare CNS tumors for NCI Neuro-Oncology Branch NCI-CONNECT collaboration

Tumor Type	1 yr	5 yr	10 yr
Primary/Secondary CNS Sarcomas	~48	~10	~5
Glommatosis Cerebri	~50	~15	~10
PNET	~68	~35	~30
ATRT	~58	~40	~35
Brainstem and Midline Gliomas	~75	~55	~50
High Grade Meningiomas	~82	~60	~55
eddyloblastoma	~90	~75	~65
Piloepithelial Xanthoastrocytomas	~92	~78	~68
Oligodendrogliomas	~93	~80	~70
Pineal Region Tumors	~94	~82	~72
Ependymomas	~95	~85	~75
Choroid Plexus Tumors	~96	~88	~80

Price, M. et al, 2023. (PMID: 37980692)

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CBTRUS, NCI Neuro-Oncology Branch, & ABTA AYA report

- Primary brain tumors in AYA overall are the second most significant contributor to cancer death
- Primary brain tumors are the leading contributor in those who die at 15-24 years of age

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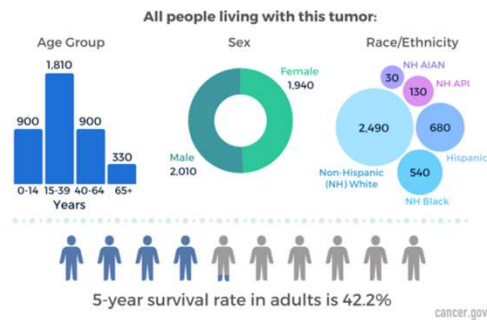
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NCI-CONNECT website

Brainstem and Midline Gliomas

an estimated
3,940 people living with this tumor
2,560 are adults (age 20+)

an estimated
577 people diagnosed per year
279 are adults



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Other recent or ongoing research projects

County urbanicity and outcomes in spinal astrocytoma and ependymoma (PMID: 37478632 and 37619838)

County socioeconomic status and risk of meningioma (PMID: 38087980)

Survival trends for glioblastoma in the post-Stupp era (DOI:10.1093/neuonc/noac209.416)

The impact of COVID-19 on 2020 monthly incidence trends of primary brain and other CNS tumors (PMID: 38167948)

Comparison of brain tumor diagnoses in United States military veterans as compared to the general population (PMID: 37738677)

County-level air quality index and brain tumor incidence in the United States (ongoing analysis)

County-level meningioma incidence and geospatial analysis (ongoing analysis)



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CKO

Acknowledgments and funding

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Thank you to the tumor registrars at hospitals and treatment centers, the central cancer registries, the staff at national and international organizations responsible for setting the standards that guide collection practices of cancer data, and to the clinicians who provide the information necessary to report brain tumors.

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Contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC nor of the NCI.



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Anatomy



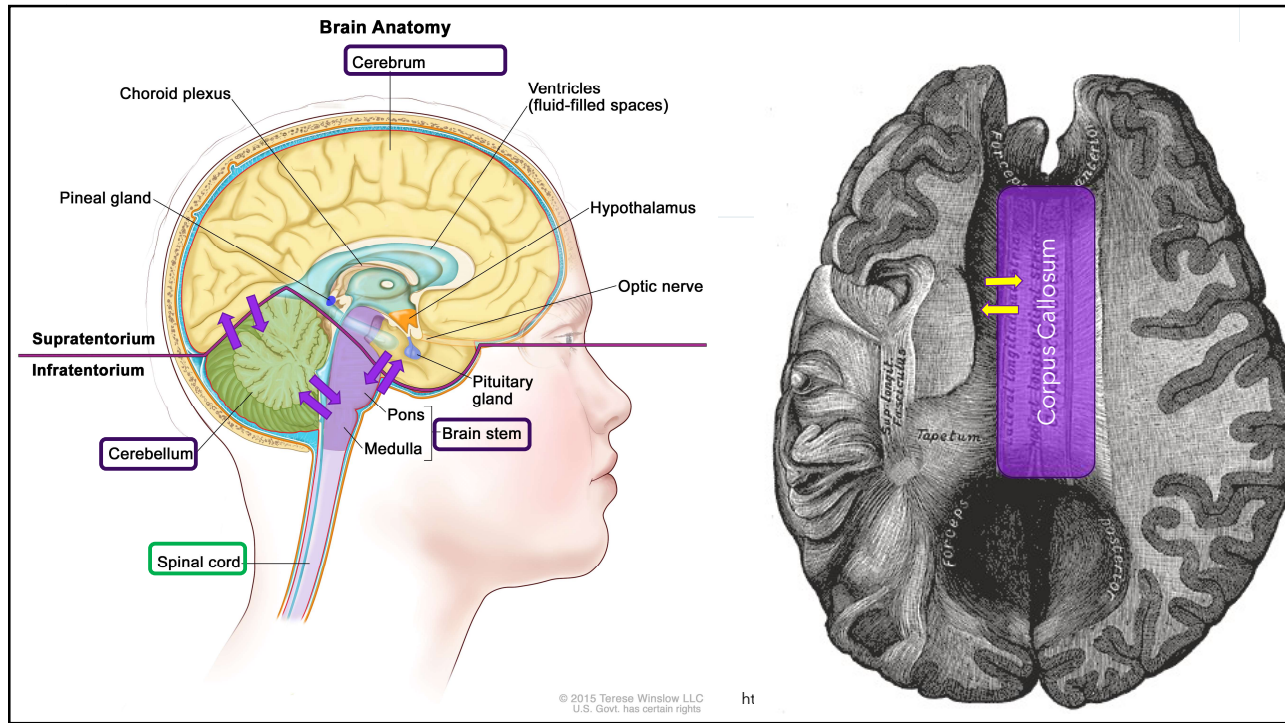
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Slide 25

CKO The slide in the copy you sent me did not include the NCI-Neuro-Oncology Branch so this is a new slide. Please check the placement of the logos.

Carol Kruchko, 2024-07-10T18:07:09.067



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Anatomy

- Frontal lobe (C71.1)
- Temporal lobe (C71.2)
- Parietal lobe (C71.3)
- Occipital lobe C71.4)

Frontal cortex
Prefrontal cortex
Basal ganglia
OFC

Frontal Lobe
Behavior
Decision Making
Inhibition
Initiative
Judgment
Memory
Mood
Movement
Personality
Planning
Reasoning

Parietal Lobe
Calculation
Left-right determination
Reading
Sensation
Writing

Occipital Lobe
Vision

Pituitary Gland
Fertility
Growth
Hormones

Temporal Lobe
Language comprehension
Behavior
Memory
Hearing
Emotions

Brain Stem
Blood pressure
Breathing
Heart beat
Swallowing

Cerebellum
Balance
Coordination
Fine motor control

Right and left laterality

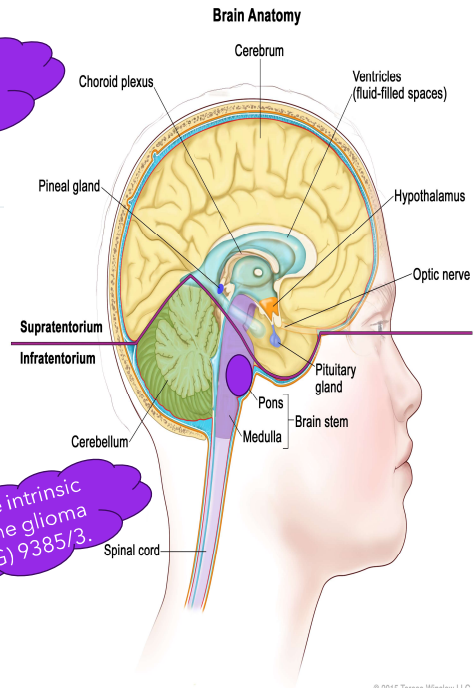
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Brain Stem C71.7

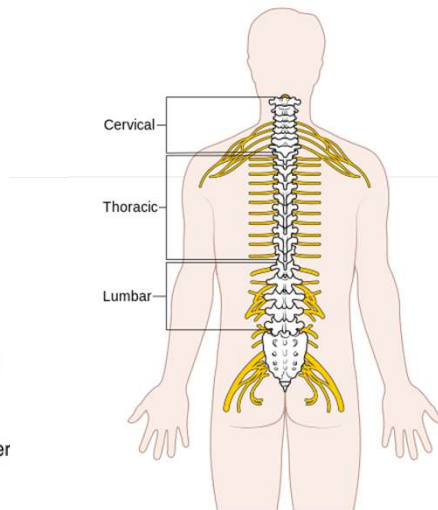
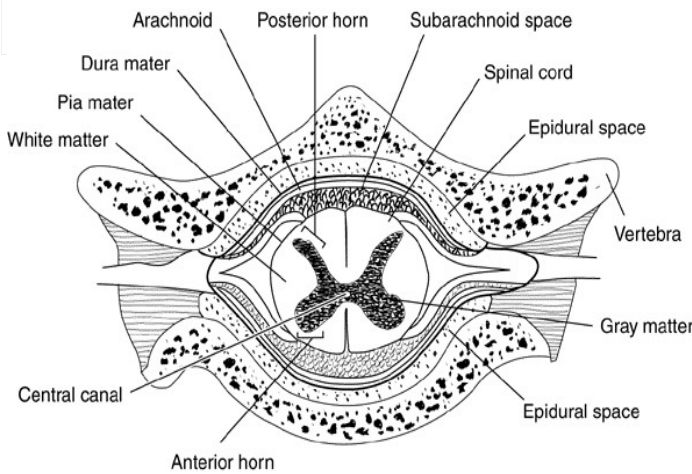
Single code for all subsites!

- Midbrain: mesencephalon; front of brain stem
 - Cerebral peduncle: ventral portion of midbrain
- Pons: portion of brain stem superior to medulla oblongata
- Medulla oblongata: lower portion of brain stem
 - Olive: pair of oval structures in medulla oblongata
 - Pyramid: anterior or ventral portion of medulla oblongata
 - Spinal cord starts at the medulla oblongata



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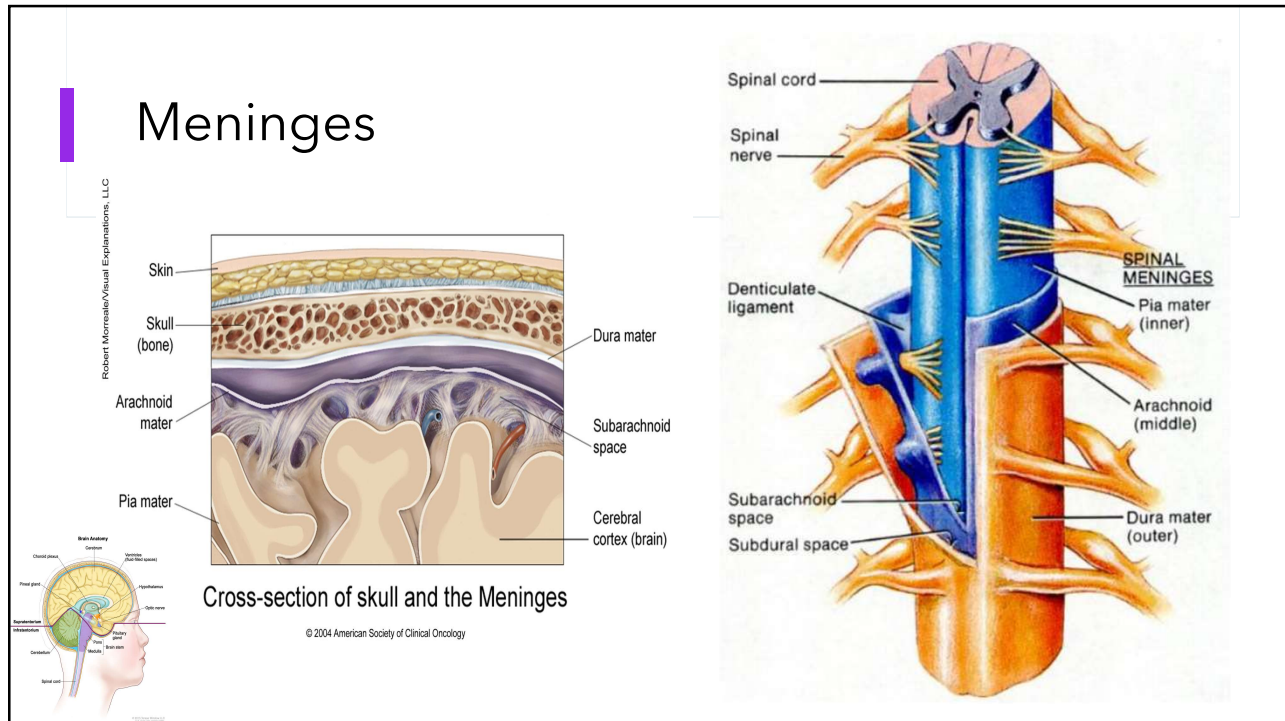
Spinal Cord



https://en.wikipedia.org/wiki/Spinal_cord#/media/File:Diagram_of_the_spinal_cord_CRUK_046.svg



Image source: CDC-NPCR's Data Collection of Primary Central Nervous System Tumors, 2004.



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The Ventricular System

Choroid plexus is a complex network of capillaries lined by specialized cells

- **Ventricle, NOS (C71.5)**
 - Lateral ventricle (right and left)
 - Third ventricle
 - Choroid plexus (lateral and third)
 - Produces cerebral spinal fluid
 - Blood/CSF barrier
 - Secretes various growth factors that maintain the stem cell pool in the subventricular zone.
- **Brain Stem (C71.7)**
 - Fourth ventricle
 - Choroid plexus of fourth ventricle

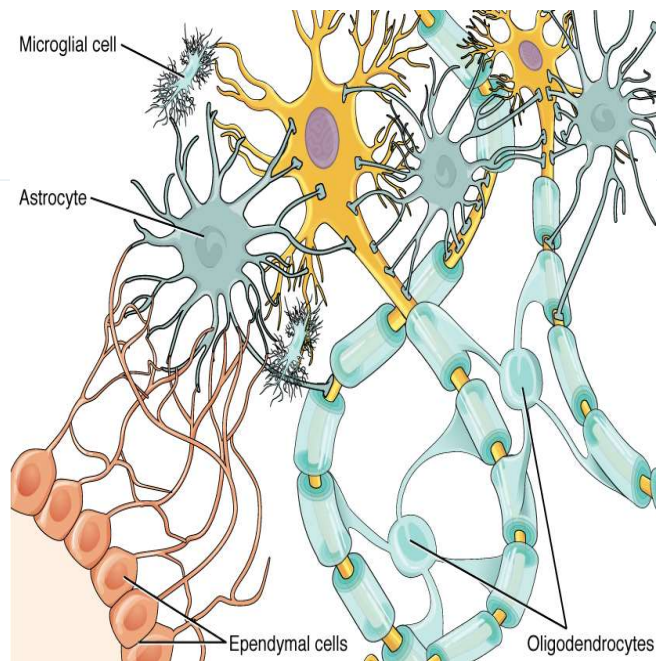
The Ventricles

Image source: CDC-NPCR's Data Collection of Primary Central Nervous System Tumors, 2004.

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Brain Cells

- Neurons
- Glial Cells
 - Astrocytes
 - Oligodendrocytes
 - Ependymal Cells
 - Microglia

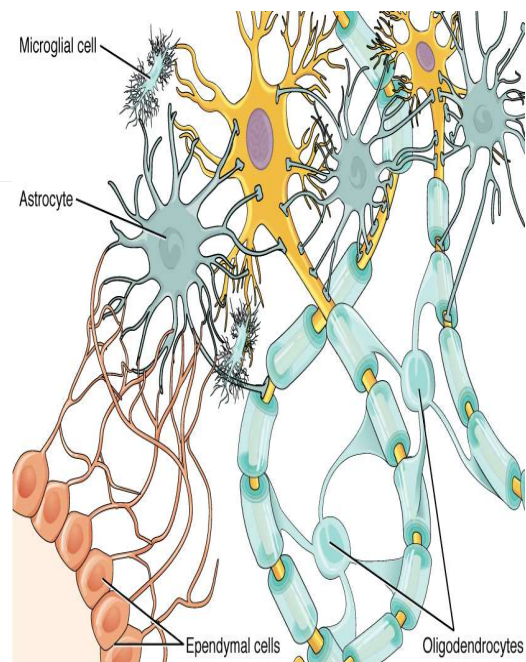


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Glioma

- Gliomas arise from glial cells
 - Astrocytomas (most common)
 - Oligodendrogliomas (develop in the myelin)
 - Ependymomas (develop in the lining of the ventricles)
 - Glioblastoma
 - May be a combination of glial cells (astrocytes or oligocytes)



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Isocitrate dehydrogenase (IDH) mutant

- The **median overall survival** for patients with IDH mutant astrocytoma, CNS WHO grade 3 (previously known as anaplastic astrocytoma), is **65 months** versus **20 months** for IDH wild type

Brain Molecular Markers

Code	ICD-O-3 Code	ICD-O-Description
03	9401/3	Astrocytoma, IDH-mutant, grade 3
04	9401/3	Anaplastic astrocytoma, IDH-wildtype

Same histology code.
Same grade

Median Overall Survival
 • IDH mutant-65 months
 • IDH-wildtype-20 months

Alshiekh Nasany R, de la Fuente MI. Therapies for IDH-Mutant Gliomas. *Curr Neurol Neurosci Rep.* 2023 May;23(5):225-233. doi: 10.1007/s11910-023-01265-3. Epub 2023 Apr 15. PMID: 37060388; PMCID: PMC10182950.



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Pop Quiz 1

- Which of the following is an infratentorial CNS site?
 - Frontal lobe
 - Corpus callosum
 - Left ventricle
 - Medulla oblongata
- Which of the following is not a glial cell?
 - Neuron
 - Astrocyte
 - Oligodendrocyte
 - Ependymal cells



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Solid Tumor Rules

- Non-Malignant
- Malignant

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Malignant

- Review of Manual

Malignant CNS and Peripheral Nerves Equivalent Terms and Definitions
 C470-C479, C700, C701, C709, C710-C719, C720-C725, C728, C729, C751-C753
 (Excludes lymphoma and leukemia M9590 – M9993 and Kaposi sarcoma M9140)

Introduction

- Note 1:** This section includes the following **primary sites**: Peripheral nerves C470-C479; cerebral meninges C700; spinal meninges C701; meninges NOS C709; brain C710-C719; spinal cord C720; cauda equina C721; olfactory nerve C722; optic nerve C723; acoustic nerve C724; cranial nerve NOS C725; overlapping lesion of brain and central nervous system C728; nervous system NOS C729; pituitary gland C751; craniopharyngeal duct C752; pineal gland C753.
- Note 2:** Non-malignant intracranial and CNS tumors have a separate set of rules.
- Note 3:** 2007 MPH Rules and 2018 Solid Tumor Rules are used based on **date of diagnosis**.
- Tumors diagnosed 01/01/2007 through 12/31/2017: Use 2007 MPH Rules
 - Tumors diagnosed 01/01/2018 and later: Use 2018 Solid Tumor Rules
 - The original tumor diagnosed before 1/1/2018 and a subsequent tumor diagnosed 1/1/2018 or later in the **same primary site**: Use the 2018 Solid Tumor Rules.
- Note 4:** There **must be** a histologic, cytologic, radiographic, or clinical **diagnosis** of a **malignant** neoplasm /3.
- Note 5:** Tumors from a number of primary sites metastasize to the brain. Do not use these rules for tumors described as metastases: report metastatic tumors using the rules for that primary site.
- Note 6:** **Pilocytic astrocytoma/ juvenile pilocytic astrocytoma** is reportable in North America as a **malignant** neoplasm 9421/3.
- See the Non-malignant CNS Rules when the primary site is optic nerve and the diagnosis is either optic glioma or pilocytic astrocytoma. The behavior for these tumors is non-malignant and coded 9421/1.
 - **IMPORTANT FOR 2023 FORWARD: Beginning 1/1/2023, all cases diagnosed with pilocytic astrocytoma/ juvenile pilocytic astrocytoma and new related terminology are to be reported with behavior /1. They will no longer be collected with malignant behavior (/3). See the Non-malignant CNS Rules.**
- Note 7:** Tables and rules refer to ICD-O rather than ICD-O-3. The specific version is not specified to allow for updates. Use the currently approved version of ICD-O and all updates.
- Note 8:** For those sites/histologies which have recognized **biomarkers**, the biomarkers may aid in the identification of histologic type. Currently, there are clinical trials being conducted to determine whether these biomarkers can be used to identify multiple primaries. Follow the Multiple Primary Rules; do not code multiple primaries based on biomarkers.
- Note 9:** See the Head and Neck Rules for coding paragangliomas.
- Note 10:** Use Malignant CNS Rules for histologies other than paraganglioma arising in C47_.

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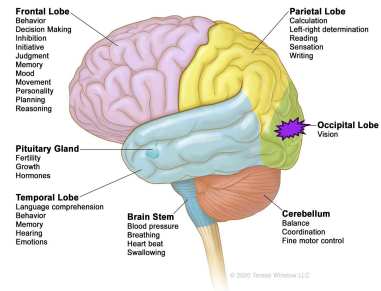
Pop Quiz 2

Case has been abstracted.
C71.3
9450/3

- A patient had a resection of an oligodendroglioma *IDH-mutant and 1p/19q-codeleted, grade 2* in the **right** parietal lobe.
- Nine months later the patient is found to have a new tumor in the **left** occipital lobe. A stereotactic biopsy showed *oligodendroglioma*.
- Is the tumor in the left occipital lobe a new primary?

Same primary per rule M8

Occipital lobe
C71.4
Oligodendroglioma,
nos
9450/3
Multiple tumors...start
with rule M6



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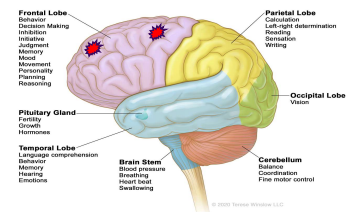
Pop Quiz 3

Both tumors
Frontal lobe
C71.1
Tumor 1
Low-grade glioma
(9380/1)
<https://seer.cancer.gov/seer-inquiry/inquiry-detail/20230080/>
Tumor 2
Astrocytoma, IDH
mutant, grade 3
9401/3

- A patient presents with a history of *low-grade glioma* in the left frontal lobe diagnosed via CT during an ER visit at a different facility on 2/12/2021.
 - No further follow-up
 - No prior history of malignancy
- The patient presents to your facility on 5/23/24 with recurring headache. A CT is done that shows a new tumor occurring in the left frontal lobe.
 - A biopsy of the tumor showed an *astrocytoma, IDH mutant, grade 3*.
- How many primaries are present and what histology and site codes would be assigned to each primary?

Multiple tumors...start
with rule M6

2 primaries per rule M6
1. C71.1 9380/1 Seq 60
2. C71.1 9401/3 Seq 00



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Pop Quiz 4

Frontal lobe
C71.1

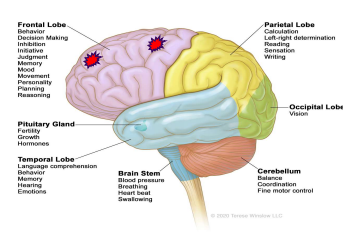
Glioma
(9380/3)

Astrocytoma, IDH
mutant, grade 3
9401/3

- A patient presents with a history of a glioma in the left frontal lobe diagnosed via CT during an ER visit at a different facility on 2/12/2021.
 - No further follow-up
 - No prior history of malignancy
- The patient presents on 5/23/24 with recurring headache. A CT is done that shows a new tumor occurring in the left frontal lobe.
 - A biopsy of the tumor showed an astrocytoma, IDH mutant, grade 3.
- How many primaries are present and what histology and site codes would be assigned to each primary?

Multiple tumors...start with rule M6

Single primary per rule M11
 • C71.1 9380/3 Seq 00



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Non-Malignant

Non-Malignant CNS Equivalent Terms and Definitions
 C700, C701, C709, C710-C719, C720-C725, C728, C729, C751-C753
 (Excludes lymphoma and leukemia M9590 – M9993 and Kaposi sarcoma M9140)

Introduction

- Review of Manual

Note 1: Central nervous system (CNS) includes the following primary sites: Cerebral meninges C700; spinal meninges C701; meninges NOS C709; brain C710-C719; spinal cord C720; cauda equina C721; olfactory nerve C722; optic nerve C723; acoustic nerve C724; cranial nerve NOS C725; overlapping lesion of brain and central nervous system C728; nervous system NOS C729; pituitary gland C751; craniopharyngeal duct C752; pineal gland C753.

Note 2: Malignant CNS neoplasms have a separate set of rules.

Note 3: 2007 MPH Rules and 2018 Solid Tumor Rules are used based on date of diagnosis.

- Tumors diagnosed 01/01/2007 through 12/31/2017: Use 2007 MPH Rules
- Tumors diagnosed 01/01/2018 and later: Use 2018 Solid Tumor Rules
- The original tumor diagnosed before 1/1/2018 and a subsequent tumor diagnosed 1/1/2018 or later in the same primary site: Use the 2018 Solid Tumor Rules.

Note 4: Non-malignant central nervous system (CNS) neoplasms (previously called benign and borderline) are reportable for cases diagnosed 1/1/2004 and later.

Note 5: Pilocytic astrocytoma/juvenile pilocytic astrocytoma:

- For cases diagnosed prior to 1/1/2023, these neoplasms are reportable in North America as malignant 9421/3 for all CNS sites with the exception of the optic nerve:
 - WHO Classification Tumors of the Central Nervous System and IARC designate pilocytic astrocytoma as a synonym for optic glioma
 - When the primary site is optic nerve and the diagnosis is either optic glioma or pilocytic astrocytoma, the behavior is non-malignant and coded 9421/1
 - Beginning with cases diagnosed 1/1/2023 forward, pilocytic astrocytoma/juvenile pilocytic astrocytoma are to be reported as 9421/1 for all CNS sites.

Note 6: Tables and rules refer to ICD-O rather than ICD-O-3. The version is not specified to allow for updates. Use the currently approved version of ICD-O.

Note 7: For those sites/histologies which have recognized biomarkers, the biomarkers may aid in the identification of histologic type. Currently, there are clinical trials being conducted to determine whether these biomarkers can be used to identify multiple primaries. Follow the Multiple Primary Rules; do not code multiple primaries based on biomarkers.

Note 8: See the Head and Neck Rules for coding paragangliomas.

Jump to [Multiple Primary Rules](#)

Jump to [Histology Coding Rules](#)

Non-Malignant CNS Solid Tumor Rules
2024 Update

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Pop Quiz 5

*2 Acoustic Neuromas (9560/0)

*Acoustic Nerve C72.4

Multiple Non-malignant tumors...start with rule M5

*6 Meningiomas (9530/0)

Cranial Meninges (C70.0)

Bilateral acoustic neuromas are a single primary per rule M6

A primary of the cerebral meninges and a cranial nerve are multiple primaries per rule M7

Multiple meningioma arising in the cranial meninges are a single primary per rule M9

- **A patient had an MRI of the brain and spinal cord and was found to have the following:**
 1. Bilateral acoustic neuromas**
 2. Posterior parasagittal meningioma*
 3. Left frontal convexity meningioma*
 4. Posterior falx meningioma*
 5. Olfactory meningioma*
 6. Right sphenoid wing meningioma*
 7. Right frontal parasagittal meningioma*
- **Genetic testing indicates the patient has Neurofibromatosis type 2 (NF2)**

NF2 is not reportable H1 Note 1
- **How many primaries are present and what histology and site codes would be assigned to each primary?**

The patient has 2 primaries

- Acoustic Neuroma C72.4 9650/0 Seq 61
- Meningioma C70.0 9560/0 Seq 62



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Questions?

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EOD, Summary Stage, SSDIs, Grade

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EOD and Summary Stage

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Brain, CNS, Intracranial Gland Schema

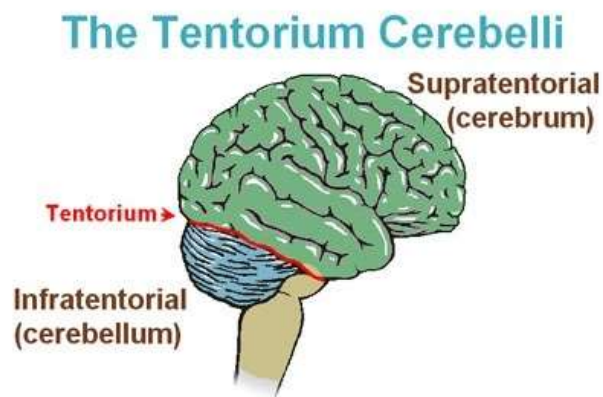
- Reminder that there are two versions of these schemas
- These schemas are based on date of diagnosis
 - 00721 Brain 8th: 2018-2022
 - **09721 Brain V9: 2023+**
 - 00722 CNS Other 8th: 2018-2022
 - **09722 CNS Other V9: 2023+**
 - 00723 Intracranial Gland 8th: 2018-2022
 - **09723 Intracranial Gland V9: 2023+**
- Your software will direct you to the correct schema based on the date of diagnosis



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Brain Schema

- Primary Sites divided into two major groups
 - Infratentorial: These subsites are located below the tentorium cerebelli and contains the cerebellum
 - Supratentorial: Located above the tentorium cerebelli. Contains the cerebrum
- **See Note 1 in EOD PT**
- **See Note 7 in Summary Stage**



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Brain Schema: EOD Primary Tumor/Summary Stage

- Infratentorial Sites
 - All subsites for codes C716-C717
 - Hypothalamus C710
 - Pallium C710
 - Posterior cranial fossa C719
 - Thalamus C710
- Supratentorial Sites
 - All subsites for codes C711-C715
 - Primary site C710 (excl hypothalamus, pallium, thalamus)
 - Anterior cranial fossa C719
 - Corpus callosum C718
 - Middle cranial fossa C719
 - Tapetum C718
 - Suprasellar C719



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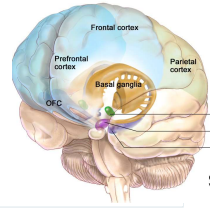
Benign/Borderline Tumors

- Benign/Borderline tumors have a default code
 - EOD Primary Tumor: 050
 - Extension to adjacent structures or midline shift do not factor into Benign/Borderline tumors
 - EOD Mets: 00: Benign/borderline tumors cannot have mets
- Summary Stage: 8 (Benign/borderline)
 - Note that Summary Stage 8 is only applicable for the following schemas: Brain, CNS Other, Intracranial Gland



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Case Scenario 1



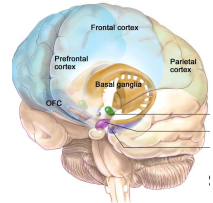
- 1/3 MRI Brain: 65mm dural based extra-axial mass over superior convexity of anterior right frontal lobe with marked mass effect on subjacent right frontal lobe.
 - Most likely meningioma.
- 1/11 MRI Brain 57mm meningioma, extra-axial dural based mass RIGHT frontal region which appears to be causing significant mass effect on the underlying brain parenchyma with approximately 8 mm RIGHT to LEFT midline shift
- 1/12 Right frontal craniotomy for resection of 3.8cm meningioma

Stage Fields	Values
EOD PT	050 (benign/borderline tumor)
EOD Mets	00
Summary Stage	8 Benign Borderline



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Benign Tumors



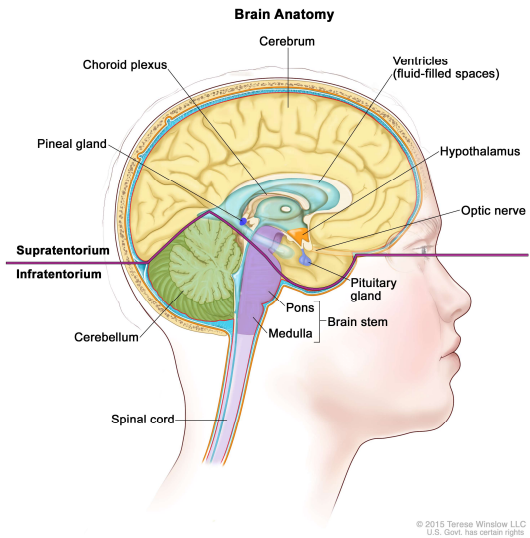
- Related Data items (which have default values for Benign/Borderline tumors)
 - Mets at Dx Bone: 0
 - Mets at Dx Brain: 0
 - Mets at Dx Liver: 0
 - Mets at Dx Lung: 0
 - Mets at Dx Distant Lymph Nodes: 0
 - Mets at Dx Other: 0



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Brain Schema

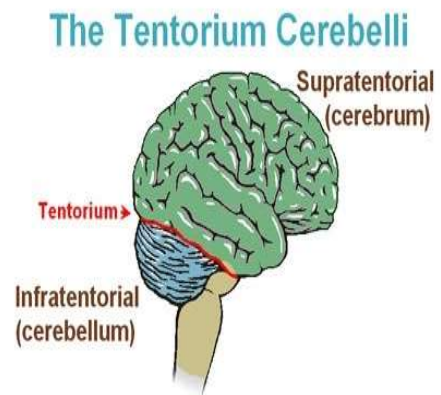
- Knowing if you have an infratentorial site versus a supratentorial site makes a difference when coding EOD PT or Summary Stage
- Both types of tumors can be localized or regional depending on their location and where the tumor has extended to



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Brain Schema: EOD Primary Tumor

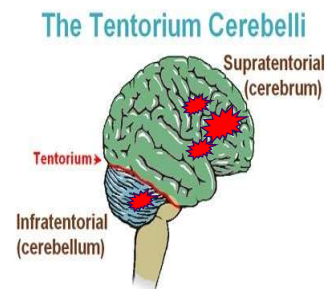
Primary Tumor	Extension to	Single/Multiple	Code
Infratentorial site	Confined to primary site OR Extends to Infratentorial sites only	Single or Multiple	100
Infratentorial site	Supratentorial site	Single or Multiple	500
Supratentorial site	Confined to primary site OR Extends to Supratentorial sites only	Single or Multiple	100
Supratentorial site	Infratentorial site	Single or Multiple	500



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Case Scenario 2

- Imaging: 5/13 CT Head
- Bilat Brain masses Susp for Mets -
 - 2.7 cm in Lt Frontal Lobe & 3 cm in Region of Rt Thalamus w/surrounding vasogenic edema;
- MRI Head -
 - Mult enhancing Supratentorial masses involv Bilat cerebral hemispheres, w/surrounding edema, lgst 4.3 cm in Lt Frontal Lobe; 2 adj masses in Rt Frontal Lobe meas 2.1 & 1.1 cm
- Surgery: 5/16 Subtotal Resection Rt Frontal Tumor (CRMC) - Glioblastoma, IDH Wild Type, WHO grade IV.

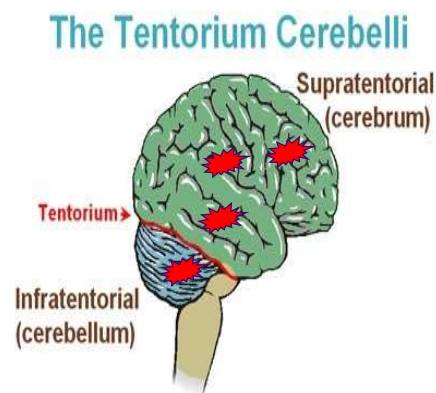


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Case Scenario 2

- Answer:
 - Both Supratentorial and Infratentorial sites are involved: Code 500
 - both hemispheres are involved, which is also code 500
- Multiple tumors are present-but this can still be code 100 or 500
- Need to determine if infratentorial and supratentorial sites are involved
- Sites involved
 - Supratentorial, NOS
 - Frontal Lobe (Supratentorial tumor)
 - Thalamus (Infratentorial tumor)
 - Cerebral Hemispheres (Supratentorial tumor)

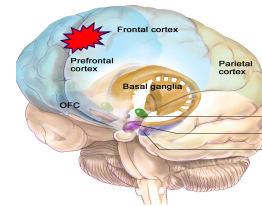


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The "midline"

- Crossing the midline (EOD PT code 500) (SS RE/2)
 - The documentation must state that the tumor has **crossed** the midline
 - A **shift** in the midline, "midline shift" is not the same thing as crossing the midline
 - If a tumor is localized based on location and extent **AND** the documentation mentions a "midline shift," this would still be a localized tumor (code 100)

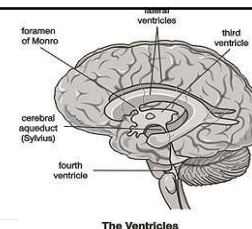


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Case Scenario 3

- CT Head= Mild compression the LEFT lateral ventricle, 4 mm L to R midline shift
- MRI Brain= Mass effect with partial effacement of L ventricle, L to R midline shift
- MRI Brain= Diffuse brain atrophy with microangiopathy disease
- Answer:
 - This case scenario states, "midline shift"
 - The "diffuse brain atrophy" does not factor into staging, or indicate a tumor crossing the midline
 - This would be a localized tumor confined to the ventricles

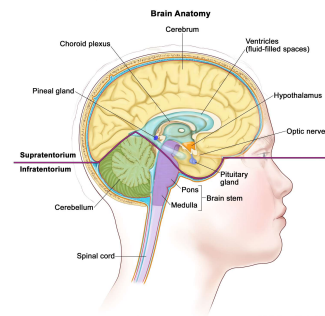


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EOD Primary Tumor: Code 500-cont.

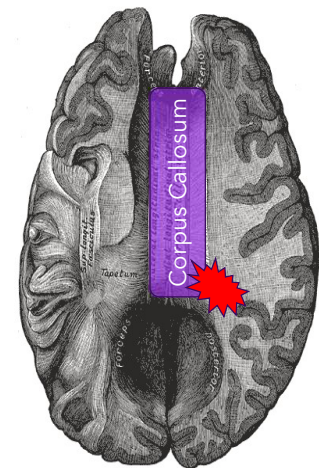
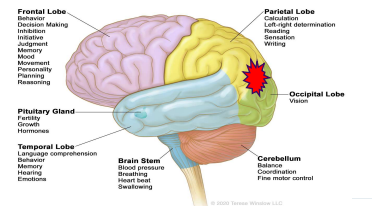
- In addition to code EOD PT 500 (SS RE/2) covering “crossing the midline”, and tumors extending between infratentorial/supratentorial, it also covers
 - Any tumor with extension to (primary site not any of these)
 - Bone (skull) (code 700 would be for other bone involvement)
 - Contralateral cerebral hemisphere
 - Corpus callosum (including splenium)
 - Major blood vessels
 - Meninges (e.g., dura)
 - Nerves (cranial, NOS)
 - Spinal cord/canal



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Case Scenario 4

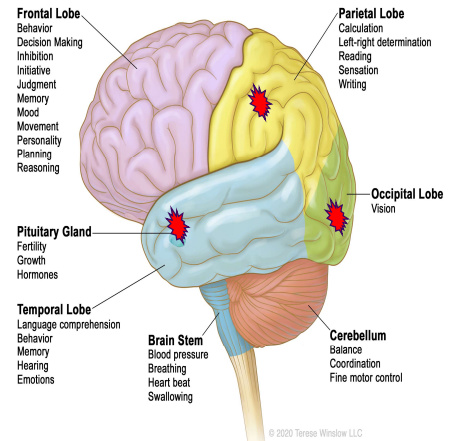
- Parieto-occipital lobe lesion that extends and invades into the corpus callosum
- My doubt comes from p-sites listed as supratentorial and infratentorial on Note 6 on the SS2018 manual, because parietal lobe (C71.3), Occipital lobe (C71.4) and Corpus callosum (C71.8), they all appear listed as supratentorial sites, and then the SS2018 coding options, corpus callosum is also listed as regional.
- Answer:
 - Since the corpus callosum is not the primary site, this would be code 500 since any extension to the corpus callosum is included in Code 500 (Summary Stage 2)
 - Corpus Callum would be included in localized ONLY when it is the primary site



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Case Scenario 5

- What is the appropriate EOD PT Code for a multifocal GBM with satellite nodules present in multiple lobes of the brain (temporal, occipital, parietal), all left brain?
- This wouldn't qualify as drop metastasis...but it's discontinuous rather than spread via direct extension. The tumor in this case does not cross midline or involve infratentorial as well as supratentorial subsites

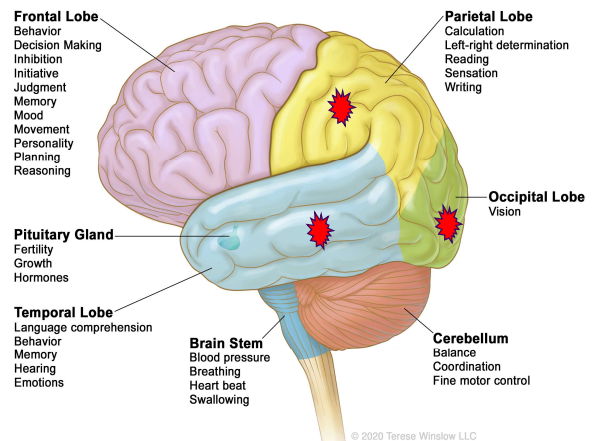


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Case Scenario 5

- Subsites involved
 - Temporal
 - Occipital
 - Parietal
- These are all Supratentorial sites
 - Per table given on previous slide, these are multiple tumors confined to Supratentorial sites

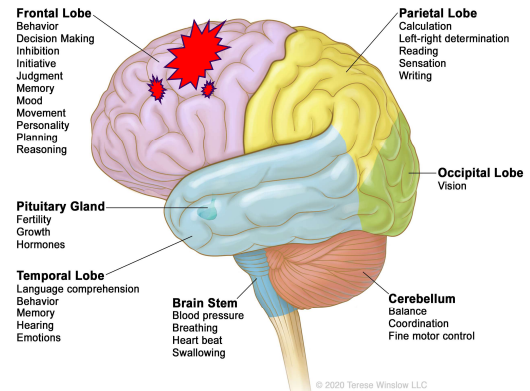
Data Item	Value
EOD Primary Tumor	100
EOD Mets	00
Summary Stage	1 Localized



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Case Scenario 6

- MRI Brain-8.1 cm right frontal lobe mass w/2 satellite lesions in the frontal lobe, favor primary brain likely glioblastoma, substantial midline shift
- What would the Seer Summary Stage be? Do the 2 satellite lesions play into the decision?
- *Note: Registrar did not include information on location of the 2-satellite lesions*
- *If you are sending in questions like this, make sure to include the location of all the tumors*

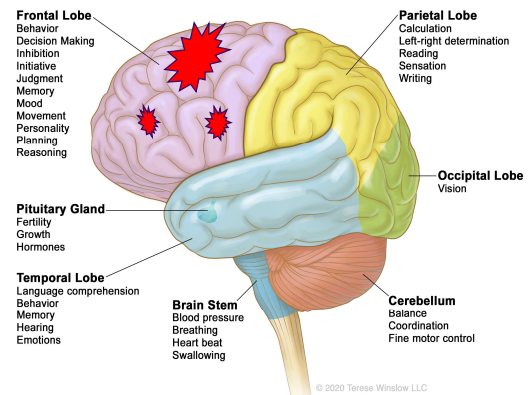


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Case Scenario 6

- Primary tumor and both satellite lesions are in the frontal lobe
- Midline shift is described; however, this is not the same thing as "crossing the midline"

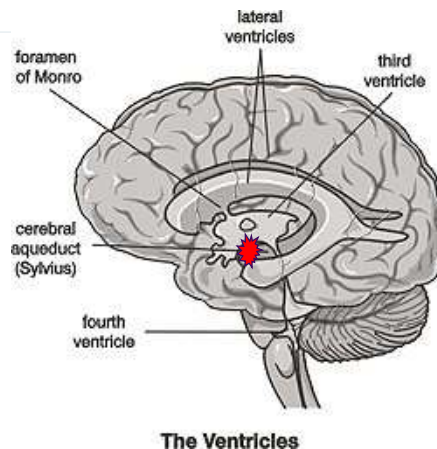
Data Item	Value
EOD Primary Tumor	100
EOD Mets	00
Summary Stage	1 Localized



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Case Scenario 7

- Question:
 - Patient has a hypothalamic/suprasellar pilocytic astrocytoma which extends into the third ventricle
- Discussion:
 - Hypothalamus is an infratentorial tumor
 - Involvement of ventricles would be localized (not indicated as infratentorial or supratentorial)

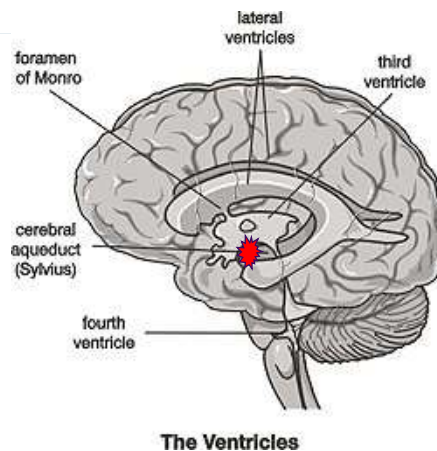


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Case Scenario 7

Data Item	Value
EOD Primary Tumor	500
EOD Mets	00
Summary Stage	2 Regional by direct ext

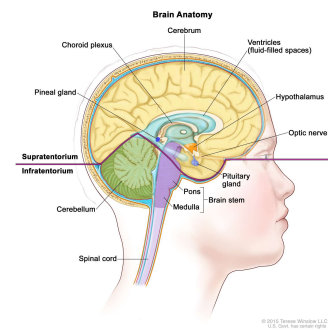
- EOD Primary Tumor:
 - Code 500 or (hypothalamus) extends supratentorially to involve...Suprasellar Brain
 - Note: If the hypothalamic tumor had only invaded the ventricles, this would have been a localized tumor (code 100); however, involvement of the suprasellar makes this a regional tumor (code 500)



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EOD Primary Tumor: 700 (SS D/7)

- Includes the following
 - Bone other than skull (See code 500 for skull) (SS RE/2)
 - Nasal Cavity
 - Nasopharynx
 - Other direct extension outside of CNS
 - Posterior pharynx
 - Further contiguous extension

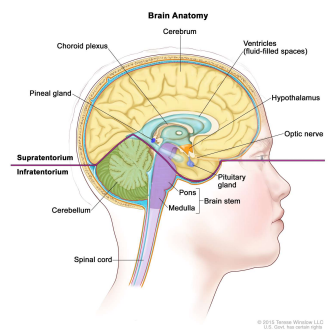


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EOD Mets

- Code 00: No distant metastasis (Summary Stage 1, 2, 8, 9)
- Code 10: Distant lymph nodes (Summary Stage 7)
- Code 70: (Summary Stage 7)
 - Metastasis within CNS and CSF pathways
 - Drop metastasis (documentation must state "drop")
 - Metastasis outside the CNS
 - Extra-neural metastases
 - Carcinomatosis
 - Distant metastasis WITH or WITHOUT distant lymph node(s)
 - Distant metastasis, NOS



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New Schema: Medulloblastoma

Primary Site	Histology	Year of Diagnosis
C700-C729	9362, 9470-9472, 9474-9478, 9501-9504, 9508	2023-9998, 9999
C700-C722, C724-C729	9473	2023-9998, 9999
C753	9362	2023-9998, 9999



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Medulloblastoma

- EOD Primary Tumor/SS
 - Very different from Brain, CNS Other, Intracranial Gland
 - EOD PT and SS L/1 only applicable for a SINGLE tumor with no invasion to adjacent structures (code 150) (SS L/1)
 - Also applicable for a single tumor that crosses the midline but does not invade adjacent structures (code 250) (SS RE/2)
 - If a tumor extends into adjacent structures OR there are multiple tumors, code EOD PT 999
 - This does not mean that Summary Stage is unknown (review code 7)



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Medulloblastoma

- EOD Mets (SS D/7)
 - Code 15: Microscopic confirmation of tumor cells in CSF by cytology
 - Code 25: Any spread beyond a single tumor
 - Includes the presence of multiple tumors
 - Single tumor invading adjacent structures
 - Code 35: "Drop" metastases
 - Code 45: Extra-neural metastases
 - Code 70: Distant metastasis, NOS



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Medulloblastoma

- The code definitions in Medulloblastoma do not apply to the Brain, CNS Other, Intracranial Gland
- The changes for Medulloblastoma are based on the Chang M definition, which is used mostly for Pediatric Brain tumors
 - Majority of Medulloblastomas occur in age ranges 00-19
 - This schema also aligns with Toronto (Pediatric) Staging that will be implemented for 2025+



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Site-Specific Data Items

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Brain Molecular Markers

Same histology, but prognosis is very different!

- Data item captures clinically important brain cancer subtypes identified by molecular markers not distinguishable by ICD-O-3 codes
 - Multiple terms have same iCD-O-3.2 code, even though they may have very different treatments or outcomes
- This Site-Specific Data Item (SSDI) allows surveillance to distinguish these histologies

Code	ICD-O-3 Code	ICD-O-Description
01	9400/3	Astrocytoma, IDH-mutant, grade 2
02	9400/3	Diffuse astrocytoma, IDH-wildtype

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Chromosome 1p, 19q

- Complete deletion of both the short arm of chromosome 1 (1p) and the long arm of chromosome 19 (19q) (1p/19q co-deletion) is the molecular genetic signature of oligodendrogliomas
- Presence of 1p/19q co-deletion is prognostic biomarker associated with improved survival



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MGMT

- MGMT is specifically for high-grade gliomas (glioblastoma, 9440/3)
 - Patients with “methylated” MGMT have better outcomes from the addition of Temodar (Temozolomide) with radiation treatment
 - Code Temodar as chemotherapy
 - Patients with “unmethylated” MGMT
 - Do not have good outcomes with Temodar

Code	Description
0	MGMT methylation absent/not present, unmethylated MGMT
1	MGMT methylation present, low level Hypomethylated Partial methylated
2	MGMT methylation present, high level Hypermethylated
3	MGMT methylation present, level unspecified



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Brain, CNS, Medulloblastoma Schemas: Brain Molecular Markers (Benign/borderline)

Coding Guidelines, Note #3 (Version 3.2)

Code 86 when there is a **benign (/0)** or **borderline (/1)** tumor

- a. This includes microscopically or non-microscopically confirmed cases
- b. *Exception: 9421/1* (see codes 19-20 when microscopically confirmed)
 - i. If codes 19 or 20 don't apply, or not microscopically confirmed, code 99

Note: Exception only applies to cases 2023+



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Benign/Borderline tumors Remaining SSDIs (except Brain Primary Tumor location)

- Chromosome 1p Status (code 6)
- Chromosome 19q Status (code 6)
- MGMT (code 6)
- *Benign/borderline tumors (Behavior /0, /1) **ALWAYS** default to the benign/borderline code REGARDLESS of whether they are histologically confirmed, or how big they are*



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Benign/Borderline tumors ALL SSDIs (except *Brain Primary Tumor Location*)

- This instruction applies to cases diagnosed 2018+.
- For 2025 updates, conversion being done to fix all the benign/borderline tumors
- Edit enforcing this instruction will then start for 2018+
- Will be applied to Brain, CNS, Intracranial Glad (8th edition and Version 9 schemas), Medulloblastoma (2023+)



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Brain, CNS, Medulloblastoma Schemas Brain Molecular Markers

Coding Guidelines, Note #2 (Version 3.2)

Code 85 when histology is NOT 9385/3, 9396/3, 9400/3, 9401/3, 9421/1, 9430/3, 9440/3, 9450/3, 9451/3, 9471/3, 9478/3

- Histologies not listed above **ALWAYS** default to code 85 REGARDLESS of whether they are histologically confirmed or not
- And behavior does make a difference!



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Brain, CNS Schema: Benign/Borderline Brain Molecular Markers

Code 99 is only to be used for the following histologies

- 9385/3, 9396/3, 9400/3, 9401/3, 9421/1, 9430/3, 9440/3, 9450/3, 9451/3, 9471/3, 9478/3
- Code 99 is used when the above histologies are coded **AND**
 - Histology is not confirmed microscopically
 - The specific name from the pathology report is not used (another alternate name for the histology)



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Brain/CNS SSDIs, cont.

- Note contains a listing of the histologies that are applicable to this SSDI
- If the histology is not one of these, likely it wasn't done and can be coded as unknown
 - In other words, don't spend a lot of time looking for the results from these studies, but do spend some time looking for the results for the histologies that are listed
- If histology is not microscopically confirmed, code 9 (these SSDIs require evaluation of tissue)



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Brain Primary Tumor Location

- Clinically important to track these cancers
- Per the Solid Tumor Rules, code
 - 9385: Diffuse intrinsic pontine glioma (DIPG)
 - *Note: ICD-O-3.2 has 9440/3 as the term for DIPG*
 - For brain histologies, ICD-O-3.2 is based on the 4th edition of the WHO Blue Book
 - Current CNS Solid Tumor Rules are based on the 5th edition of the WHO Blue Book



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Brain Primary Tumor Location

- Applies to
 - Benign/borderline/malignant tumors
 - Microscopically and non-microscopically confirmed tumors
 - For example, diffuse intrinsic pontine glioma (DIPG) is rarely biopsied because of its location (too dangerous), so diagnosis will be based off imaging



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The PONS

- Links your brain to the spinal cord
- Common cancer is Diffuse intrinsic pontine glioma (DIPG)
- Rare brain cancer
- Pediatric cancer
- Very aggressive
- Survival less than a year

[Brain Stem Image.source](#)

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Case Scenario 8

- 2023 Diagnosis: high-grade glioma
- Ancillary testing
 - Intact chromosomes 1p and 19q
 - EGFR not amplified
 - No variants of IDH-1 and IDH-2
 - MGMT: hypermethylated

SSDI	Value
Brain Molecular Markers	85 (histology not included in list, assigned 9380/3 for Glioma, NOS)
Chromosome 1p	0 (not identified)
Chromosome 19q	0 (not identified)
MGMT	2 Hypermethylated


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Grade

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Grade and Brain tumors

- Unlike most sites, Brain and CNS have many histologies that have an assigned grade (by WHO), and are always that grade
- Priority
 - Pathology report takes priority for the grade (this applies to all cancers)



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Grade and Brain tumors

- If the grade is not on the pathology report, priority order
 - CAP Protocol/Synoptic report
 - AJCC manual
 - Solid Tumor Rules



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Grade and Brain tumors

- For histologies that have a lot of alternate names, there may be some that don't have an assigned grade
- Don't assume that every histology name assigned to a code has the same grade
- If in doubt of a grade, please review Canswer Forum or post a question



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Treatment

Surgery

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Stereotactic Biopsy of the Brain

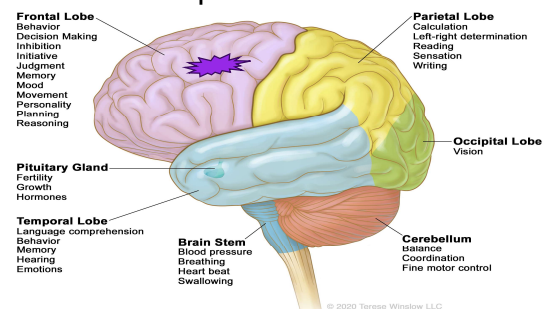
Not a new rule

SEER and CoC have "agreed to disagree"

CoC: Code as Dx Stage Procedure 02

SEER: Assign A200

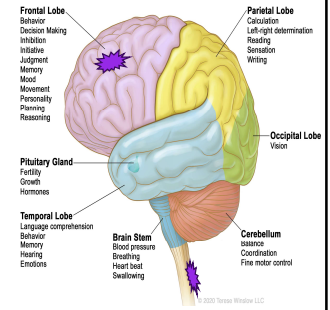
- A stereotactic brain biopsy is a surgical procedure that allows a neurosurgeon to remove a small tissue sample from the brain to diagnose a lesion.
- The procedure is performed in an operating room and uses imaging technology and advanced surgical navigation systems to guide the biopsy needle to the target area.



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Surgery Codes

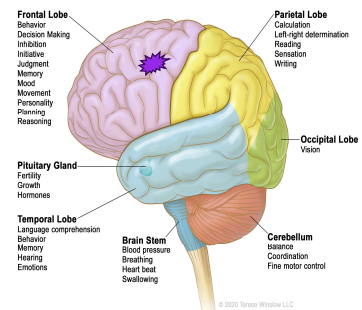
Code	Procedure	Specifics
A200	Local excision of tumor, lesion or mass; excisional biopsy	Used when the surgeon describes the procedure "biopsy," or "excisional biopsy", or when there are no details about the procedure. Unknown whether total or partial tumor resected.
A210	Subtotal resection of tumor, lesion or mass in brain	Near total, partial, subtotal, debulking, open biopsy (if residual tissue).
A220	Resection of tumor of spinal cord nerve	
A300	Radical, total, gross resection of tumor, lesion or mass in brain	The resection of the brain tissue surrounding the tumor is limited to ensure clean margins.



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Surgery Codes

Code	Procedure	Specifics
A400	Partial resection of lobe of brain, when the surgery cannot be coded as A200-A300.	Less than lobectomy, but more than would be necessary to ensure clean margins
A550	Gross total resection	Lobectomy



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Coming UP...

- Coding Pitfalls 2024
 - Janet Vogel, CTR




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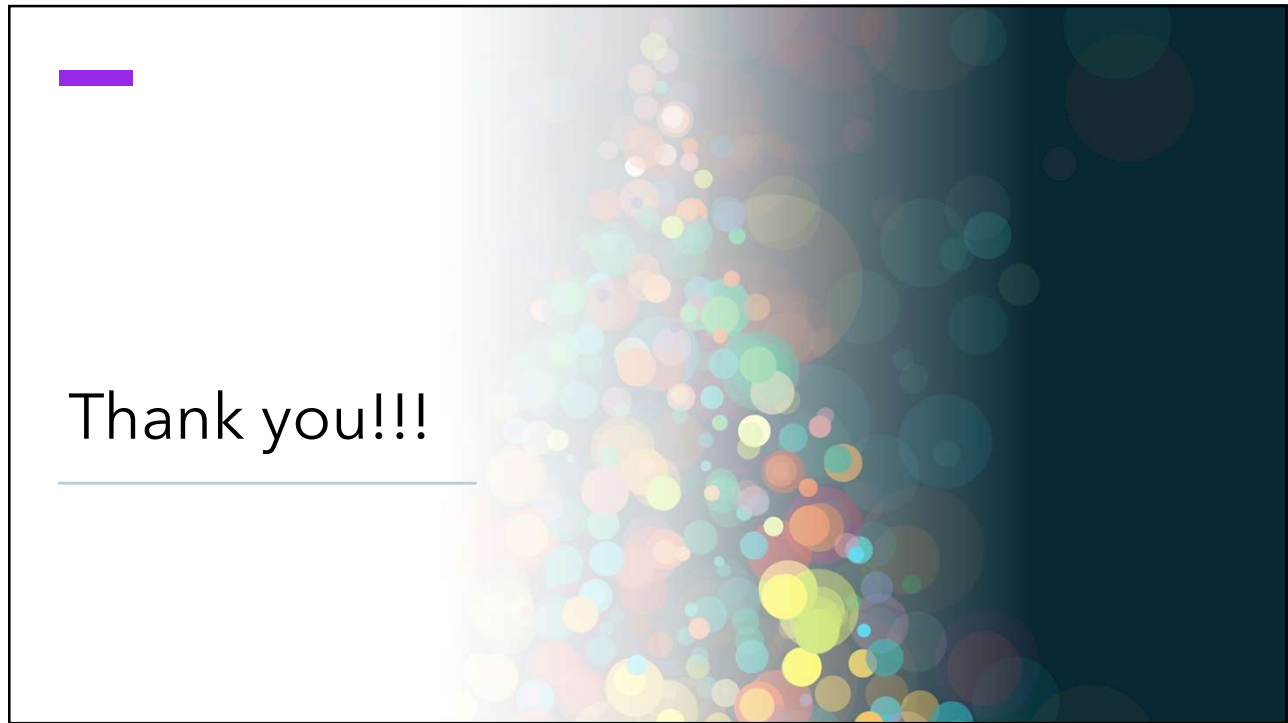
CE Certificate Quiz/Survey

CE Phrase

Link



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