GCCR Register

Georgia Comprehensive Cancer Registry Spring 2004

Benign Brain and Central Nervous System Tumors

By A. Rana Bayakly, GCCR Director

Based on NAACCR 2004 Implementation Guidelines www.naaccr.org

Benign brain and central nervous system tumors (CNS) are deadly because of their location and their impact on the brain. Although often removable, they may result in death, paralysis, blindness and other brain damage.

Malignant CNS tumors are the second most common cancer in children, accounting for 23% of all childhood cancers death in Georgia. They also are the third leading cancer cause of death in young adults aged 15-34 in the United States and Georgia.

The number of benign CNS tumors diagnosed in Georgia each year is unknown, but is thought to be similar to the number of malignant CNS tumors.

Meningioma, a "benign" brain tumor that accounts for one-fourth to one-third of all brain cancers, is more deadly than breast cancer. Thirty-one percent (31%) of patients with meningioma die within five years, compared to only sixteen percent (16%) for breast cancer.

Improvements in understanding the disease and its course, as well as advances in treatment, depend on accurate data collection. There are many reasons to collect data on benign tumors:

- Approximately half of all patients diagnosed with brain tumors are currently excluded from data collection efforts; it is not possible to monitor the impact of this condition on Georgia citizens.
- Some benign tumors become malignant over time;
- Due to their location and responsiveness to treatment, benign and malignant brain tumors have similar prognoses;
- Since causes of brain tumors are not well understood, studying the etiology of benign brain tumors will improve our understanding of malignant tumors;

The Benign Brain Tumor Cancer Registries Amendment Act was signed by the President in October 2002. Public Law 107-260 requires the collection of benign and central nervous system tumors by the National Program of Cancer Registries (NPCR). This law requires all cancer registries authorized by the Public Law and funded by the federal government (NPCR program) to collect both benign and malignant CNS tumors.

Commission on Cancer (COC) and the Surveillance Epidemiology and End Results (SEER) added benign CNS tumors to their case definition as of January 1, 2004. Georgia reporting mandate was changed to add benign CNS tumors to the reportable list for all cases diagnosed on January 1, 2004 and later.

In Georgia any tumor diagnosed on January 1, 2004 or later with a behavior code of '0' or '1' is reportable for the following Site Codes (ICD-O-3): Meninges C70.0 – C70.9; Brain C71.0 – C71.9; Spinal Cord, cranial nerves, and other parts of the Central nervous System C72.0 – C72.9; Pituitary gland C75.1; Craniopharyngeal duct C75.2; and Pineal gland C75.3. Histology codes are based on the ICD-O-3 book. Juvenile astrocytomas should continue to be reported as 9421/3.

Laterality- beginning with malignant and benign tumors diagnosed in 2004, the following sites require a laterality code of 1-4 or 9:

- Cerebral meninges, NOS C70.0
- Cerebrum C71.0
- Frontal lobe C71.1
- Temporal lobe C71.2
- Parietal lobe C71.3
- Occipital lobe C71.4
- Olfactory nerve C72.2
- Optic nerve C72.3
- Acoustic nerve C72.4
- Cranial nerve, NOS C72.5

The research community has indicated that the location and laterality for primary CNS tumors is of significant interest in determining causation and assessing the impact on quality of life.

Grade-The World Health Organization (WHO) grade should be recorded in Site Specific Factor 1 of the CS system, histological grade will continue to be collected as the morphology sixth digit 'Grade'.

Sequence Number- primary non-malignant tumors diagnosed on or after January 1, 2004 should be sequenced in the range of 60-87.

Site/Histology Validation List is available in the ICD-O-3 primary brain and CNS site histology list.

Casefinding- Hospital casefinding list should now include the following ICD-9-CM codes to identify all the potential cases:

- 225.0 Benign neoplasm of brain
- 225.1 Benign neoplasm of cranial nerves
- 225.2 Benign neoplasm of cerebral meninges; cerebral meningioma
- 225.3 Benign neoplasm of spinal cord, cauda equina
- 225.4 Benign neoplasm of spinal meninges; spinal meningioma
- 225.8 Benign neoplasm of other specified sites of nervous system
- 225.9 Benign neoplasm of nervous system, part unspecified
- 227.3 Benign neoplasm of pituitary, craniopharyngeal duct, craniobuccal pouch, hypophysis, Rathke's pouch, sella turcica
- 227.4 Benign neoplasm of pineal gland, pineal body
- 237.0 Neoplasm of uncertain behavior of pituitary gland and craniopharyngeal duct
- 237.1 Neoplasm of uncertain behavior of pineal gland
- 237.5 Neoplasm of uncertain behavior of brain and spinal cord
- 237.6 Neoplasm of uncertain behavior of meninges: NOS, cerebral, spinal
- 237.70 Neurofibromatosis, Unspecified von Recklinghausen's Disease
- 237.71* Neurofibromatosis, Type One von Recklinghausen's Disease
- 237.72 Neurofibromatosis, Type Two von Recklinghausen's Disease
- 237.9 Neoplasm of uncertain behavior of other and unspecified parts of nervous system; cranial nerves

It is estimated that reporting benign and CNS tumors are similar to the malignant CNS tumors approximately 1% of the total caseload at the central registry. However the hospital caseload will be dependent on the type of reporting facility, hospitals with small or no neurology service will likely experience a minimal increase, however hospitals with a large neurology service will likely experience a larger increase. Reporting facilities need (cont.)

Benign CNS Tumors (cont.)

to review the following casefinding sources for identifying these cases: Pathology, cytology; disease indices; surgery logs; diagnostic imaging; radiation oncology; neurology clinics; medical oncology and autopsy reports.

The GCCR is planning to conduct training on reporting benign brain and CNS tumors during our Spring Training April 28-30, 2004. You can also find training materials on the NAACCR website at www.naaccr.org or on SEER training web site at www.training.seer.cancer.gov.

Inquires regarding the collection of the benign and CNS tumors should be directed to your regional coordinator or you may go to the *Ask NAACCR* web site at www.naaccr.org/Standards/AskNAACCR.html. A panel, including representatives from each standard setting organization will review each question and provide an answer.

Welcome Wagon

The cancer registry profession has a new recruit in its ranks. Teri Carter of LaGrange accepted the offer as the new cancer registrar for West Georgia Health Systems.

Teri has lived in LaGrange for 46 years, her entire life. A former middle school teacher, she has worked in the medical field for 5 years coming from LaGrange Internal Medicine as a Certified Medical Assistant before moving to West Georgia Health System.

Teri's husband Perry is a Supervisor with the City of LaGrange Water Department and they are planning a trip to Canada next year to celebrate their 30th wedding anniversary.

More immediate celebrations include their only daughter's wedding which will take place in June.

Teri enjoys reading, cross-stitch and painting in her spare time. When asked whom she admired most, she said her mother. Her mother was the first female police officer in their town and retired 2 years ago after 25 years as Lieutenant over the Detective Division. Teri stated that her mother showed her "that no obstacle is insurmountable if you believe in yourself."

That is sound wisdom for all cancer registrars and we all welcome Teri Carter to the cancer registry profession.

Betty Gentry, RHIT, CTR
Central Regional Coordinator
Macon

Blue Ribbon Award

During the recent CDC/NPCR audit, Phoebe Putney Memorial Hospital in Albany and South Georgia Medical Center in Valdosta were two of the nine hospitals selected to be part of the audit process.

The Registrars and staff at both of these facilities deserve a blue ribbon for their efforts in having everything in place for the auditors, which made the audit process run vary smooth and efficiently.

The auditors commented on how impressed they were with both of these facilities and how much they appreciated their cooperation and hospitality. Both had a very nice conference room reserved for the auditor's use and had all the requested records available for their review.

The Pathology Department of both hospitals had hard copies of the path reports available rather than electronic files, which made the review much easier. The Medical Records Department at Phoebe retrieved records from storage for the audit and electronic medical records were printed out at South Georgia.

The Registry staff at both facilities coordinated the requests of documents and was responsible for all the data being available for the audit.

As the Southwest Regional Coordinator, I was very proud of these hospitals and along with GCCR, GCCS at Emory, and CDC would like to thank Phoebe Putney Memorial Hospital and South Georgia Medical Center and tell them how much we appreciate their work.

Carol Crosby, CTR
Southwest Regional Coordinator
Albany

HIPAA Corner

Adapted from: Hiatt, RA. HIPAA: The End of Epidemiology, or a New Social Contract? *Epidemiology*. 2003;14:637-639.

HIPAA was not intended to interfere with public health and medical research. However, what if there are genuinely deleterious effects? One positive step we can all take is to read and understand the new privacy regulations. We might need to press for changes in the regulation. In fact, there are already mechanisms in place to modify the rule annually. Whatever changes are needed, they must begin with documented examples of genuinely adverse impacts on research and public health.

The American Association of Medical Colleges (AAMC) has begun to collect such data. The AAMC "HIPAA Impact Survey" is currently collecting examples of ways in which HIPAA has interfered with the conduct of research.

Thus far, most responses have focused on problems with contacting and screening potential participants; the process of consent and authorization; and the general burden of time, cost, and diversion from primary research associated with the new procedures. Many respondents report patient confusion when confronted with new paperwork.

The data collection effort by the AAMC is a systematic and constructive effort to document the HIPAA-related problems for research that will be essential to future decision-making. It will help show the burden of compliance, and it could uncover new issues that were not considered in the formulation of the current Rule.

Most important, the data collection will help show whether the additional level of privacy achieved by HIPAA is worth the impact it could have on the production of epidemiologic and other medical research. Results of this survey will be made available to the US Department of Health and Human Services as they develop formal guidance for compliance with HIPAA.

HIPAA Regulation information and updates may be found on the following websites: Georgia Division of Public Health at www.ph.dhr.state.ga.us/phil; NAACCR at www.naaccr.org; US Department of Health and Human Services at www.hhs.gov; and ACoS at www.facs.org/dept/cancer/coc/. Please keep yourself updated on the latest HIPAA regulations.

FAQ's

Q: Is GCCR providing a collaborative staging manual for all the hospitals in the state?
A: Yes, GCCR will be providing one (1) manual per hospital. Your hospital representative may pick up their manual at the GCCR Spring Training, April 28-30, 2004.

Q: If a date of initial diagnosis is not clear, should the diagnosis date be estimated and if so what are the guidelines?
A: The diagnosis date should be approximated. GCCR recommends using the full date (month mm, day dd, year yyyy) that best describes the documentation in the medical record (rather than 9's for one or more segments of the date and rather than the date the patient was first seen at the reporting facility.) Please refer to the GCCR Policy and Procedure Manual, Section IV, pages 15 and 16.

- Example 1: Current admission date of 03/05/02. Medical record states that patient was diagnosed last month. Use 02/01/02 as the estimated diagnosis date and justify in text.
- Example 2: Current admission date of 04/20/01. Medical record state that patient was diagnosed last year. Use 01/01/00 as the estimated diagnosis date and justify in text.
- Example 3: Current admission patient status post biopsy for presumed new diagnosis, patient admitted for treatment. Estimate diagnosis date based on common practice.

You must indicate in the text that this is an estimated date. A reasonable estimated date is preferable to an unknown date. If there is absolutely no information regarding the date of diagnosis use all 9's (99/99/9999).

Mark Your Calendars…

GCCR Spring Training
April 28-30, 2004
Renaissance Concourse Hotel
Atlanta, Georgia

Educational opportunities will include: Collaborative Stage, Benign Brain Tumors, Improving Data Quality, and more…

NCRA's 30th Annual Educational Conference
On the Trail to New Horizons
April 20-23, 2004
Portland, Oregon

NAACCR 2004 Annual Meeting
New Frontiers in Cancer Surveillance
June 5-12, 2004
Salt Lake City, Utah

Georgia Comprehensive Cancer Registry
Georgia Department of Human Resources
2 Peachtree St NW 14th Floor
Atlanta, GA 30303-3142

Thank You Note from the Georgia Comprehensive Cancer Registry

GCCR thanks the following hospitals for submitting cancer data at least two months out of three (December 2003; January and February 2004).

Hospitals Reported Three Months Out of Three		
Augusta State Medical Prison	Floyd Medical Center	Peach Regional Medical Center
Bacon County Health System	Georgia Baptist Meriwether Hosp	Perry Hospital
Berrien County Hospital	Gordon Hospital	Phoebe Putney Memorial Hospital
Bleckley Memorial Hospital	Grady General Hospital	Phoebe Worth Medical Center
Brooks County Hospital	Grady Health System	Piedmont Hospital
Burke County Hospital	Gwinnett Health System	Polk Medical Center
Calhoun Memorial Hospital	Habersham County Medical Ctr	Redmond Regional Medical Ctr
Candler County Hospital	Hamilton Medical Center	Rockdale Hospital
Candler Health System	Hart County Hospital	Satilla Regional Medical Center
Cartersville Medical Center	Henry Medical Center	Screven County Hospital
Central State Hospital Med Surg	Houston Medical Center	SE Georgia Health Sys – B'wick
Charlton Memorial Hospital	Hutcheson Medical Center	SE Georgia Health Sys – Camden
Chatuge Regional Hospital	Irwin County Hospital	Smith Northview Hospital
Children's Healthcare of Atlanta	Jefferson County Hospital	South Fulton Medical Center
Clinch Memorial Hospital	Jenkins County Hospital	South Georgia Medical Center
Cobb Memorial Hospital	John D. Archbold Memorial Hosp	Southern Regional Medical Center
Coffee Regional Medical Center	Kindred Hospital	Southwest Hospital and Med Ctr
Coliseum Health System	Liberty Regional Medical Center	Spalding Regional Hospital
Colquitt Regional Medical Center	Louis Smith Memorial Hospital	St Joseph's Hospital – Augusta
Crisp Regional Hospital	Macon Northside Hospital	St Joseph's Candler Health Sys
DeKalb Medical Center	McDuffie Regional Medical Center	St Mary's Healthcare System
Doctor's Hospital Columbus	Memorial Health Univ Med Ctr	Sumter Regional Hospital
Donalsonville Hospital	Memorial Hospital and Manor	SW Georgia Regional Med Ctr
Dorminy Medical Center	Memorial Hospital of Adel	Tanner Health System
Early Memorial Hospital	Miller County Hospital	Telfair Regional Medical Center
East Georgia Regional Med Ctr	Mitchell County Hospital	The Medical Center
Effingham County Hospital	Monroe County Hospital	Tift General Hospital
Elbert Memorial Hospital	Morgan Memorial Hospital	Union General Hospital
Emory Adventist Hospital	Mountainside Medical Center	VA Medical Center – Atlanta
Emory Crawford W Long Hospital	Murray Medical Center	VA Medical Center – Dublin
Emory Dunwoody Medical Center	NE Georgia Medical Center	Walton Medical Center
Emory Eastside Medical Center	Newnan Hospital – East	Washington County Reg Med Ctr
Emory Northlake Reg Med Ctr	Newnan Hospital – West	Wayne Memorial Hospital
Emory University Hospital	North Fulton Regional Hospital	Wellstar Health System
Evans Memorial Hospital	Northside Hospital Cancer Center	West Georgia Health System
Fairview Park Hospital	Oconee Regional Medical Center	Wheeler County Hospital
Fayette Community Hospital	Palmyra Medical Center	Wills Memorial Hospital
Flint River Community Hospital		
Hospitals Reported Two Months Out of Three		
Appling Health Care System	Jeff Davis Hospital	St Joseph's Hospital – Atlanta
Athens Regional Medical Center	Meadows Regional Medical Ctr	Stewart Webster Hospital
Atlanta Medical Center	Medical Center of Central Georgia	Sylvan Grove Hospital
Decatur Medical Center	Northside Hospital – Cherokee	University Hospital
Doctor's Hospital Augusta	Rabun County Memorial Hospital	Upson Regional Medical Center
Dodge County Hospital	Select Specialty Hospital	Wesley Woods Geriatric Hospital
Fannin Regional Hospital	St Francis Hospital	Wildwood Lifestyle Center & Hosp
Jasper Memorial Hospital		

New CTRs

The following candidates successfully passed the 2003 CTR Exam on September 13, 2003 and formally became Certified Tumor Registrars:

- Diane B. Alligood – Dexter, GA
- Patricia A. Bodine – Columbus, GA
- Jennifer M. Davidson – Rentz, GA
- Alicia L. Gibson – Carrollton, GA
- Diane G. Small – Lithonia, GA
- Diane M. Wade – Lithonia, GA

Congratulations to you all!