The Florida Cancer Data System

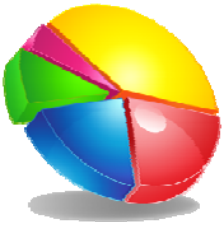
MonthlyMemo

Monthly Journal of Updates and Information

OCTOBER 11

Florida's Participation in "Enhancing Cancer Registry Data for Comparative Effectiveness Research"

In December of 2010 Florida was selected to participate in a Centers for Disease Control-sponsored National Program of Cancer Registries (NPCR) project entitled; "Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER)." As described by the Agency for Healthcare Research and Quality, "Comparative effectiveness research is designed to inform health-care decisions by providing evidence of effectiveness, benefits, and harms of different treatment options." The CER project gives the Florida Cancer Data System (FCDS) the opportunity to contribute to important cancer surveillance and disease monitoring enhancements along with nine other states. Funded by the American Recovery and Reinvestment Act, the project addresses specific CER questions targeting colon, rectum, breast and chronic myeloid leukemia cases diagnosed in 2011. In addition to routinely collected data, the FCDS will enhance existing first course treatment information with data on tumor marker, genetic, laboratory data and systemic treatment regimens. The FCDS has identified a five-county catchment area to be included in this project: Miami-Dade, Broward, Palm Beach, Orange, and Hillsborough Counties.



The impact of the CER enhancement project on FCDS has resulted in an expanded workforce for CER project management, development, and implementation. Together with core staff, the project objectives and responsibilities will be carried out almost entirely by the FCDS. Specifically, the FCDS has been fortunate

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WHAT'S NEW:

The following information is currently available on the FCDS website.

FCDS 2011 EDUCATIONAL WEBCAST SERIES: MYELOID NEOPLASMS (CML/AML/MDS) - MPH RULES/CSV02.03/SITE SPECIFIC FACTORS AND TREATMENT REGISTER

FCDS/NAACCR EDITs Metafile - compatible with NAACCR 12.1B version - 10/06/2011, 12.1B Metafile changes.

FCDS/NAACCR WEBINAR SERIES: COLLECTING CANCER DATA: OVARY, 11/03/2011, BEING HELD AT 7 FLORIDA FACILITIES AND requires registration.

The Florida Cancer Data System (FCDS) is Florida's statewide, population-based cancer registry and has been collecting incidence data since 1981.

Job Opportunities with the Florida Cancer Data System

FLORIDA CENTRAL CANCER REGISTRY SPECIALIST

The University of Miami, Miller School of Medicine has two opportunities available for a Central Cancer Registry Specialist located on our Medical Campus in Miami, Florida. This individual will be responsible to be the primary point of contact between the Florida Cancer Data System (FCDS), Florida's statewide population based cancer registry, and our reporting sources (hospitals, physician offices, radiation treatment centers and surgery centers). Primary duties include the processing, review and correction of submitted cancer abstracts by the reporting sources, developing relationships with each assigned facility and being the primary contact for questions and issues.

Position requirements are:

1. A minimum of two years experience in a cancer registry;
2. NCRA certification as a Certified Tumor Registrar (CTR) or CTR eligible with cancer abstracting.

Send resumes to mthiry@med.miami.edu or call 305-243-2639 for more information.

Calling All Florida CTRs Interested in Collaborative Stage Data Collection and Quality Control Activities at FCDS

FCDS recognizes the added value when using Florida peer-to-peer CTRs to conduct re-abstracting field audits and other FCDS QC activities. CTRs who abstract on a daily basis are our best resource for providing peer-to-peer feedback on data quality and recommendations to improve our data statewide. At this time FCDS is in need of several highly skilled abstractors willing to participate in the next FCDS Re-Abstracting Field Audit. This audit will take place in mid-winter (December-February), will include 80 or more facilities, and will focus on Collaborative Stage Core Data Elements and Site Specific Factor Coding for Cases Diagnosed in 2010. The actual data collection will take place during a 6-week window as yet defined but at some time during the in-the-field study window of December-February. FCDS needs registrars from across the state to visit hospitals either in person or via remote access to "re-abstract" key data elements: *patient demographics, primary site, histology and collaborative stage data items*. No treatment data will be collected. Thank you for your support and interest. Please contact Steven Peace, CTR directly with your resume and letter of interest.

You may contact Steven Peace via email at speace@med.miami.edu.

The Florida Cancer Data System Staff *Update*

We are pleased to welcome Susan K. Smith-Pierce, CTR to FCDS. Susan started her career in the Cancer Registry field in the early 1980's becoming a CTR in March 1984. She then worked three years in the mid -80's as a Field Coordinator here at the Florida Cancer Data System. When H. Lee Moffitt Cancer Center opened in late 1986, Susan, as manager, was responsible for development of the Cancer Registry. Susan was at Moffitt until forming, in February 1996, Cancer Reporting Services, Inc which contracted with non in-house cancer programs to do incidence cancer reporting to FCDS.

Susan has re-joined FCDS as a Senior Regulatory Analyst and will be part of the Comparative Effectiveness Research (CER) project.

Florida's Participation in "Enhancing Cancer Registry Data for Comparative Effectiveness Research"

(Continued from page 1)

to have hired three very experienced Florida hospital-based Certified Tumor Registrars that will act as our CER outreach and QC coordinators for the data gathering portion of the project. Little effort will actually be required of hospital and physician staff in the five CER counties, apart from navigational support and access to select facility patient records. Registrars and abstractors can provide additional support by prioritizing the reporting of the four CER cancer sites.

In addition to the collection of enhanced treatment information, the CER dataset will be linked to vital statistics records, area-based socioeconomic indicators, and area-based health indicators. Linked data sources include the National Death Index, 2010 U.S. Census, and Medicare and Medicaid databases. The project timeline extends to September 2013, at which time all relevant data will be submitted by FCDS, as well as the other nine states, to the CDC. The final dataset will reside at the Research Data Center of the National Center for Health Statistics, where access to data for research will be reviewed via a strict proposal process.

It is important to note that all CER project activities fall under the existing Florida Department of Health authority to capture and report cancer data. Current Florida statutes exempt DOH and FCDS from HIPPA restrictions as registry activities are in direct line with the legislatively mandated surveillance of cancer. As such, participation from healthcare facilities in the five CER counties is not voluntary. However, as previously mentioned, FCDS will assume almost all of the data collection responsibilities for the project.

More information on the Florida CER project, participating NPCR registries, and CER targeted questions can be found on our website: http://fcds.med.miami.edu/welcome.html . For specific questions and additional information please contact the FCDS CER Project Manager, Monique Hernandez, at mhernandez5@med.miami.edu.

Deadlines, Updates, & Reminders

The deadline for the FCDS Death Clearance Follow Back processing was Monday, October 24, 2011. Please remember to clear all of your cases by the deadline.

FCDS 2011 Annual Meeting NCRA Recognized CE Hours

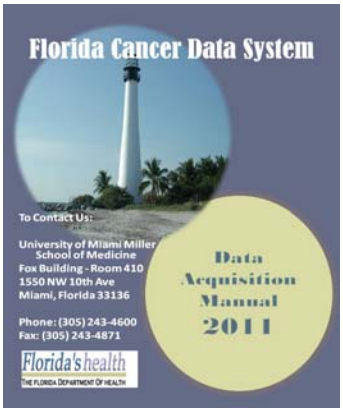
Please fill-in the following continuing education hours on your Certificate of Attendance for the FCDS Annual Meeting held in Tampa, FL on July 28th – 29th, 2011.

CE Hours: 9.25

5.75 CE Hours - *If you only attended day 1 of the meeting*
3.5 CE Hours - *If you only attended day 2 of the meeting*

NCRA Program Recognition Number: 2011-143

THE REVISED 2011 FCDS DAM IS AVAILABLE ON THE FCDS WEBSITE.



The *revised* 2011 FCDS Data Acquisition Manual (FCDS DAM) is available on the FCDS website. The manual includes important information about Florida cancer reporting requirements for 2011, instructions for coding new and changed data items, and has links to references and resources used daily when abstracting cancer cases.

Download a copy to your computer desktop for easy reference or for printing at : http://fcds.med.miami.edu under Downloads.

2011 FCDS Educational Webcast Series

FCDS is pleased to see the great interest and attendance in reference to our 8-part educational series. The webcasts have been tailored to the Florida cancer registrar and cancer case abstractor with emphasis on the 2011 Florida Cancer Reporting Requirements. The first webcast presented in mid August focused on 2011 FCDS Cancer Reporting Requirements (including enhanced text requirements and new CS Site Specific Factors), QC Visual Editing for 2011, and an Introduction to CSv02.03.02. The series will continue with concentration on specific cancer sites or site groups. Webcasts are held on Thursdays from 9am-11am. Please review the dates below.

DATE	TITLE	NCRA Program Recognition Number
*8/18/11	FCDS 2011 Text Documentation/Visual Editing and Introduction to CSv02.03.02	2011-162
*9/15/11	Colon/Rectum Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-167
*9/29/11	Breast Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-168
11/02/11	Myeloid Neoplasms (CML/AML/MDS) - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-169
11/17/11	Lung Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-170
12/15/11	Genitourinary (Kidney, Bladder, Prostate) - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-171
1/19/12	Brain and CNS Tumors - 2012 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-172
2/16/12	Head and Neck Cancers - 2012 MPH Rules/CSv02.03/Site Specific Factors and Treatment	2011-173

Each webcast will provide background and instruction sufficient for registrars to understand the anatomy and surrounding structures for each cancer site/site group, risk factors associated with cancers of each site/site group, CSv02.03.02 coding for each site/site group, and ASCO/NCCN Clinical Practice Guidelines for Treatment of each site/site group. This series builds upon information presented at the 2011 FCDS Annual Meeting in Tampa, Florida in July. There is no fee and each 2-hour webcast will be recorded and available on the FCDS website, http://fcds.med.miami.edu/inc/teleconferences.shtml . **NCRA approved CEUs (2 each)**, note the program recognition numbers in the above chart.

CSv02.03 FAQs

The following report summarizes FAQs. Coding guidance is provided where appropriate.

REFERENCE #	SCHEMA NAME	CS FIELD(S)	DESCRIPTION
#351	Part I		Lymph-Vascular Invasion code 8, not applicable, is only used for those histologies where lymph vascular invasion is not possible or the standard-setter does not require collection for the schema. These histologies are noted in Part I, Section 1, and include the lymphomas, leukemias and the myelodysplastic syndromes. If your standard-setter does not require collection of this data item for particular schemas, use code 8. For those cases where there is no information/documentation from the pathology report or other sources, use code 9. 6/30/11 - Revised 8/29/11
#45	Part I , KidneyParenchyma	CS Site-Specific Factor 3	For Kidney Parenchyma SSF 3, code 998 for "No histologic examination to determine ipsilateral adrenal gland involvement," will be added. In the meantime, code 999 should be used for cases without histologic examination that determines ipsilateral adrenal gland involvement. 6/10/11
#251	Colon, Rectum	CS Extension	We will modify the notes in v0204 to clarify that code "050" may be used when there are tumor deposits without lymph node metastasis in T1, T2, T3 and T4 cases. Previously, the v0203 instructions stated that you could only use this code for T1 and T2 cases. 6/3/2011
#423	Colon, Rectum	CS Site-Specific Factor 2, Extra Table	Code 030 is not relevant for SSF2 and we will be making it obsolete in the next version. This is because tumor deposits are identified histologically and SSF2 is used to code the clinical assessment of regional lymph nodes. We are not supposed to include information from surgical observation or lymph node biopsies in this SSF. Cases that were abstracted with this code will need to be reviewed and corrected. 6/3/2011
#268	CorpusCarcinoma, CorpusSarcoma	Schema Page	For corpus uterine/uterus NOS primaries, histology codes 8950 and 8951 should have been included in the CorpusCarcinoma schema. This will be fixed in CSv0204. Do NOT try to fix these cases before CSv0204. 6/3/2011
#531	EsophagusGEJunction	CS Extension	Esophagus GE Junction Extension: For extension to transverse colon (including flexures), previously coded 600, use code 605. This description was left off in v02.03 and will be added back at a later date. (8/9/11)
#353	Lung	CS Extension , Extra Table	A tumor involving the carina, regardless of size, should be a T4, per AJCC. If you code 250, for confined to carina, you will derive ased on tumor size. "Confined to carina" will be moved to a T4 (in a future version.) For now, the best code to use is code 700, which includes the description extension to carina and will derive a T4. In your abstract you can note this situation. The confusion arises since Summary Stage focuses strictly on how big or how many structures are involved, making a tumor strictly in the carina a localized tumor. Whereas AJCC assign stage based on treatment guidelines and prognosis (survival). We know that a tumor in the carina, even if it is small and strictly confined to the carina, will be unresectable and will have poor outcome, since the tumor can easily spread to both lungs due to the location (tumor can spread from the carina down BOTH mainstem bronchus into both lungs) it has a very poor prognosis (survival). 6/30/11
#271	Testis	CS Site-Specific Factor 8, CS Site-Specific Factor 14	The measurements in SSFs 8 & 14 were incorrectly entered as ng/ml and will be updated to mIU/ml in v0204. 6/3/2011

CS Manual V0203 in Online Help Format Available

The Collaborative Stage Data Collection System User Documentation and Coding Instructions, also known as the CS Manual, (version 0203) has been released in an online help format, available as a free download from the CS website, http://cancerstaging.org/cstage/manuals/coding0203.html. This release combines Part I of the manual, both sections 1 and 2, with Part II, the schemas, into a single online help system with combined index and robust navigation. The content of Part I is identical to the content of the PDF version. The content of Part II (the schemas) is expanded to include additional extra tables not included in the PDF format, especially useful for those who do CS training or perform quality control of CS data. The HTML online help system combines an index for Parts I and II, includes full text searching capability, and has multiple navigation methods. HTML online help systems are familiar to most users. Online help appears in a browser window using the standard Microsoft® HTML Help interface, with selected features enabled by third-party tools.

The 2011 edition of the SEER manual is now available on the SEER website.
http://www.seer.cancer.gov/tools/codingmanuals/index.html

2011 SEER Manual available on SEER website

This is a very limited revision of the 2010 manual. Changes were made only to data items with new codes.

These are:

- SEER Coding System Original
- SEER Coding System Current
- Marital Status
- Multiplicity Counter
- Surgery of Primary Site, Breast

The MP/H manual has also been updated to include the new codes for Multiplicity Counter.
http://www.seer.cancer.gov/tools/mphrules/index.html

NAACCR 2011-2012 Webinar Series

The Florida Cancer Data System is happy to announce that for another year we will be presenting the NAACCR Cancer Registry and Surveillance Webinar, 2011-2012 series at seven locations throughout Florida:

- **Boca Raton Regional Hospital (Boca Raton)**
- **Moffitt Cancer Center (Tampa)**
- **M.D. Anderson Cancer Center Orlando (Orlando)**
- **Shands University of Florida (Gainesville)**
- **Gulf Coast Medical Center (Panama City)**
- **Baptist Regional Cancer Center (Jacksonville)**
- **Florida Cancer Data System (Miami)**

DATE/TIME	TOPIC
10/06/2011	Collecting Cancer Data: Larynx Including Mucosal Melanoma of Larynx
11/03/2011	Collecting Cancer Data: Ovary
12/01/2011	Collecting Cancer Data: Thyroid and Adrenal Gland
01/05/2012	Collecting Cancer Data: Pancreas
02/02/2012	Collecting Cancer Data: Lung
03/01/2012	Abstracting and Coding Boot Camp: Cancer Case Scenarios
04/05/2012	Collecting Cancer Data: Lower Digestive System
05/03/2012	Collecting Cancer Data: Hematopoietic
06/14/2012	Using and Interpreting Data Quality Indicators
07/12/2012	ICD-10-CM and Cancer Surveillance
08/02/2012	Collecting Cancer Data: Melanoma of Skin
09/06/2012	Coding Pitfalls

Special thanks to the hosting facilities for their participation and support. For a complete description of the webinars, click here: https://fcds.med.miami.edu/scripts/naaccr_webinar.pl

Please go to the FCDS website to register online for your location of choice. Registration link is: https://fcds.med.miami.edu/scripts/naaccr_webinar.pl. A separate registration will be required for each webinar. The number of participants allowed to be registered for each webinar will be dependent on space availability. For more information, please contact Steve Peace at 305-243-4601 or speace@med.miami.edu.

NAACCR CANCER REGISTRY AND SURVEILLANCE WEBINAR SERIES

Seven Florida facilities will host the 2011-2012 webinar series, *registration is required*

REGISTER FOR THE NEXT WEBINAR

FCDS *is now the host site for Miami , FL with space for 25-30 participants.*

Links to each of the webinars within the 2010-2011 NAACCR Webinar series is now available on the FCDS website. You may access the recording, copy of the slides, Q&A, and CE Certificate for each webinar from the series. A CE Certificate has been provided for those viewing the recording of the webinars.

QUESTIONS? ANSWERS.

09/29/2011 FCDS Educational Webcast: Breast Cancer

QUESTION:
One of our breast surgeon does 'bone marrow ' BX for his study/trial on his surgery. We don't know whether he collects DTC or result information. Is it safe for us to code SSF 18 as 998?

ANSWER:
FCDS does not require the collection of SSF18 for breast cases. When the "bone marrow" is done it is checked for DTCs whether they use that terminology or not. You can either report the results as positive/ negative or code 997 test ordered, results not in chart.

QUESTION:
SSF 8. IHC value.

In the webcast, nothing was said about 'borderline = equivocal'

Today's presentation said, 0 : neg. 1+ :NEG. 2+ : POS, 3+: POS.

For my abstract, they order FISH, if it is 1+(always order FISH), or 2+ (sometimes).
How should I code 1+ ? as 'borderline' or NEG?
For 2+ ? as 'borderline' or POS?

ANSWER:
1+ is usually interpreted as negative and not all institutions will order FISH as follow-up test. Our research has indicated these are to be considered negative but if you institution reports as borderline then report as borderline. This is one reason why we collect this in two fields…the value and the interpretation since some facilities interpret the same value differently. 2+ can also be interpreted differently depending on how testing was read and how the institution reading the result interprets this finding, but is usually considered positive. The 1+ and 2+ since they are not strongly negative (0) or strongly positive (3+) some facilities err on the side of caution and do the next confirmatory test (FISH) to ensure they have an accurate and reliable test result to base treatment decisions. Yes, these are often deemed "borderline" with recommendation to follow-up with FISH for confirmation. That said, if FISH is not done, these patients will usually be offered Herceptin treatment because the result was not negative…just as with ER/PR borderline malignancies – if any suggestion that this was possibly positive and is borderline – patients will be offered hormonal treatment as though it was positive to cover all bases in treatment regimen option toolkit.

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QUESTION:
Paget's disease. Does the pathologist have to say that it is Paget's disease, or is it understood, if the nipple is positive for cancer. Because I have seen a staging form where the doctor very thoroughly fills it out and says that there is Paget's disease, but it is not staged in the path report, specifically, although the nipple was involved w/ ductal carcinoma.

ANSWER:
The nipple could be involved by invasive duct carcinoma and/or Paget's disease. Paget's disease of the nipple is usually clinically described as crusty nipple. If not stated in pathology report do not include it in coding histology.

QUESTION:
On Her2neu by IHC - Mayra mentioned that a score of 2+ was positive. I thought that a 2+ was borderline, and could be coded as such on SSF9. Normally, what I have seen is if the IHC is 2+, they will do a FISH study.

ANSWER:
2+ can be interpreted differently depending on how testing was read and how the institution reading the result interprets this finding. Yes, these are often deemed "borderline" with recommendation to follow-up with FISH for confirmation. That said, if FISH is not done, these patients will usually be offered Herceptin treatment because the result was not negative…just as with ER/PR borderline malignancies – if any suggestion tat this was possibly positive and is borderline – patients will be offered hormonal treatment as though it was positive to cover all bases in treatment regimen option toolkit.

QUESTION:
Colon cancer with the tumor being described as circumferential on colonoscopy, when there is no surgery at my facility, and all I have is the scope, and it says that it is a circumferential tumor, can I assign a T stage by that statement? Would that be a clinical T3?

ANSWER:
Great question – Yes, this can be assigned Clinical Stage T3 – we would also receive the case from a hospital that later performed resection as this case would definitely have a resection performed. We would get the complete staging from that facility based on the resected specimen. But, for your purposes at your facility Clinical T3 is appropriate.

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QUESTION:

Non-invasive papillary transitional cell carcinoma, high-grade, with focal necrosis and calcifications and focal extension into von Brunn's nests. Is that considered extension to lamina propria?

ANSWER:

Great question with a not so easy answer. But the answer is probably "NO" it does imply invasion through lamina.

von Brunn's Nests

The term 'von Brunn's nests' refers to the presence of groups of transitional cells in the lamina propria, detached from the overlying urothelium (Figure 1). The nests arise by a process of invagination from the overlying urothelium and the term von Brunn's buds can be used when an attachment to the urothelium is still present. It is the detachment from the overlying epithelium seen in von Brunn's nests that can be problematic, particularly if the nests lie relatively deep in the lamina propria, and are numerous. The cystoscopic impression may be of a tumor,[3] which may enhance diagnostic problems. Although the nests of this process are generally rounded and smoothly contoured they may be somewhat irregular.[3] The depth of 'penetration' into the lamina propria is usually to a uniform depth, often giving a somewhat band-like appearance. Even when invasive carcinoma has relatively bland cytologic features, the cell nests generally have a more disorderly arrangement and more variation in size and shape than von Brunn's nests and sometimes single cells are seen, or at least tiny clusters contrasting with the more numerous cells in the typical von Brunn's nest. Although the bland cytology of the cells in von Brunn's nests in most cases contrasts with the significant atypia seen in most invasive bladder cancers, the epithelium in von Brunn's nests, similar to the surface epithelium, may exhibit hyperplasia and reactive atypia including prominent nucleoli and mitotic activity.

LYMPH-VASCULAR INVASION

Description

This field records the absence or presence of tumor cells in lymphatic channels (not lymph nodes) or blood vessels within the primary tumor as noted microscopically by the pathologist. The presence of lymph-vascular invasion may affect the patient's prognosis.

Note: This data item is separate from the CS data items but is included in this manual because of its relationship to the Collaborative Stage Data Collection System. Lymph-vascular invasion is an item of interest to both pathologists and clinicians and is mentioned in many chapters of the AJCC Cancer Staging Manual, seventh edition.

Note: This field is required for mapping of T in some sites, such as testis and penis.

Code Description

0 Lymph-vascular invasion not present (absent)/Not identified
1 Lymph-vascular invasion present/Identified
8 Not applicable
9 Unknown if lymph-vascular invasion present Indeterminate

Definition

Lymph-vascular invasion is defined as the presence of tumor cells found inside small blood vessels or lymphatic channels within the tumor and surrounding tissues in the primary site. The tumor cells have broken free of the primary tumor and now have the capability to float throughout the body. Other names for lymph-vascular invasion are LVI, lymphovascular invasion, vascular invasion, blood vessel invasion, and lymphatic

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invasion. Vascular invasion is not the same as direct tumor extension from the primary tumor into adjacent blood vessels; LVI cells are not attached to or growing into the wall of the blood vessel. Lymphatic invasion is not the same as involvement of regional lymph nodes. Lymph-vascular

invasion does not include perineural invasion.

Instructions for Coding

1. **Code from pathology report(s).** Code the absence or presence of lymph-vascular invasion as described in the medical record.

    a. The primary sources of information about lymph-vascular invasion are the pathology check lists (synoptic reports) developed by the College of American Pathologists. If the case does not have a checklist or synoptic report, code from the pathology report or a physician's statement, in that order.

    b. Do not code perineural invasion in this field.

    c. Information to code this field can be taken from any specimen from the primary tumor.

    d. If lymph-vascular invasion is identified anywhere in the resected specimen, it should be coded as present/identified.

2. **Use of codes.**

    a. Use code 0 when the pathology report indicates that there is no lymph-vascular invasion. This includes cases of purely in situ carcinoma, which biologically have no access to lymphatic or vascular channels below the basement membrane.

    b. Use code 1 when the pathology report or a physician's statement indicates that lymph-vascular invasion (or one of its synonyms) is present in the specimen.

    c. Use code 8 for the following primary sites.

    - Hodgkin and Non-Hodgkin lymphoma
    - Leukemias
    - Hematopoietic and reticuloendothelial disorders
    - Myelodysplastic syndromes including refractory anemias and refractory cytopenias
    - Myeloproliferative disorders

    d. Use code 9 when

    i. there is no microscopic examination of a primary tissue specimen

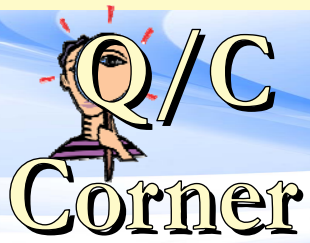
    ii. the primary site specimen is cytology only or a fine needle aspiration

    iii. the biopsy is only a very small tissue sample

    iv. it is not possible to determine whether lymph-vascular invasion is present

    v. the pathologist indicates the specimen is insufficient to determine lymph-vascular invasion

    vi. lymph-vascular invasion is not mentioned in the pathology report



QUESTIONS? ANSWERS. and CLARIFICATION

Neurofibromatosis – Is it reportable?

Neurofibromatosis – What is it? When is it Reportable?

The neurofibromatoses are a group of three genetically distinct disorders that cause tumors to grow in the nervous system. Tumors begin in the supporting cells that make up the nerve and the myelin sheath (the thin membrane that envelops and protects the nerves), rather than the cells that actually transmit information. The type of tumor that develops depends on the type of supporting cells involved.

Scientists have classified the disorders as **neurofibromatosis type 1** (NF1, also called von Recklinghaus disease), **neurofibromatosis type 2** (NF2), and a type that was once considered to be a variation of NF2 but is now called **schwannomatosis**. An estimated 100,000 Americans have a neurofibromatosis disorder, which occurs in both sexes and in all races and ethnic groups.

The most common nerve-associated tumors in NF1 are neurofibromas (tumors of the peripheral nerves), whereas schwannomas (tumors that begin in Schwann cells that help form the myelin sheath) are most common in NF2 and schwannomatosis. Most tumors are benign, although occasionally they may become cancerous.

REPORTABLE? When neurofibromas occur in the central nervous system and/or brain they are reportable. Neurofibromas occurring elsewhere in the body even though they may be numerous are not reportable - behavior of /1. When a patient is diagnosed with schwannoma, meningioma, or glioma related to their neurofibromatosis, record the histology that represents the actual tumor (schwannoma, glioma, etc.) and not the disorder or generalized term for the condition of neurofibromatosis.

Florida Cancer Data System
Cancer Reporting Completeness Report

TOTAL NUMBER OF CASES IN THE FCDS MASTERFILE AS OF OCTOBER 31, 2011

Total number of *New Cases* added to the FCDS Master file in October, 2011: **16,757**

The figures shown below reflect initial patient encounters (admissions) for cancer by year.

Admission Year	Hospital	Radiation	Ambi/Surg	Physician Office	Derm Path	DCO	Total Cases	New Cases
2011	17,194	214	36	3,057	0	**Pending**	20,501	**9,392**
2010	154,332	3.603	103	1,361	57	**Pending**	159,456	**7,118**
2009	171,986	9,963	3,376	3,143	73	**Pending**	188,541	**247**

		Actual	Expected
% Complete for:	**2011**	**12%**	**33%**
	2010	97%	100%
	2009	100%	100%

Expected % based on 165,000 reported cases/year

The Florida Cancer Data System (FCDS) is Florida's statewide, population-based cancer registry and has been collecting incidence data since 1981 when it was contracted by the State of Florida Department of Health in 1978 to design and implement the registry. The University of Miami Miller School of Medicine has been maintaining FCDS (http://fcds.med.miami.edu) since that time.

The FCDS is wholly supported by the State of Florida Department of Health, the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC) and the Sylvester Comprehensive Cancer Center at the University of Miami Miller School of Medicine.

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