



## MANY CONGRATULATIONS



Please join us in wishing Steve Peace the best on his move to Washington, D.C., where he has relocated to join Westat in Rockville, Maryland as a Medical Information Research Specialist. He was a part of FCDS for 8 years and will be greatly missed by his colleagues, peers, and the Florida registrars.



### 2002 FCDS EDUCATIONAL TELEPHONE CONFERENCE, Number 5

#### UPDATE ON THE NEW CLINICAL LABORATORY CANCER IDENTIFICATION PROGRAM.

**OBJECTIVE:** The telephone conference provided an update to the clinical pathology laboratory administrators, registrars, abstractors, and contractors with an overview of the new Clinical Laboratory Cancer Identification Program. The conference covered reporting legislation, reporting requirements, details for case identification, details for the data elements required for case submission, details for data submission via the FCDS IDEA (Internet data transmission protocol), and other related subjects.

The following are the questions and answers and caller concerns discussed during the call. Please refer to the PowerPoint slide presentation and full notes available on the FCDS website for background and additional clarification for each question.

#### Q & A SESSION:

**Q.** Re: pg. 42, the 800 word string search has many words containing the term carcinoma"; can we use the word "carcinoma" alone to pull all these carcinoma cases instead of using adenoid squamous cell carcinoma, etc. etc.? Can we use broader search terms such as "malignant"?

**A.** Yes, you can use carcinoma alone and it will pull any subtype of carcinoma.

**Q.** Is there a way that the lab can avoid picking up cases that have already been picked up by the registry, to avoid duplicates?

**A.** The CLIP program is a Case finding tool and not an incident record. FCDS will unduplicate the pathology report against the FCDS master file before doing any follow-back to the physician offices.

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# FCDS Q & A

*(Continued from page 1)*

**Q.** If a patient has several different specimens with a diagnosis of cancer on the same day, do all of them have to be reported?

**A.** Yes, if there are several different pathology reports, with several specimens and there is a diagnosis of cancer on the same day FCDS wants each of those reports.

**Q.** Re: ICD-9 codes, we note that there are no leukemia or lymphomas on our list of codes

**A.** Leukemia and lymphomas are included in the range 140.0-208.9. *(Pg. 5: Y2001 Case finding List)*

**Q.** Do we report Pap smears?

**A.** No, pap smears are cytology, which are not reportable to FCDS.

**Q.** The pathologist at our hospital-based lab also reads pathology for physicians' offices as a separate part of his business. Does he have to report the cancer cases from the doctors' offices as well as from the hospital?

**A.** Yes, all reportable cancer cases are to be transmitted electronically to FCDS.

**Q.** Can a facility submit the user ID form to get a password even though we are not ready to send cases?

**A.** Yes, a facility can submit a user ID form and test the data online.

**Q.** Does our test file have to be limited to 10 cases?

**A.** No, test files do not have to be limited to the 10 cases and they can be

tested via the Internet.

**Q.** If we use the word string, would we be in trouble if we pick up cases that are negative for cancer? Examples "no residual cancer," "lymph nodes negative for cancer."

**A.** No, FCDS also has the word string search at upload pathology reports that are not in the word string search will be placed in a separate holding area for review. The CLIP program cancer cases will be stored in a separate area from the FCDS database. Once a field staff reviews the pathology report and it is found to be non-reportable to FCDS, we will delete the pathology report from our system.

**Q.** From an independent lab: If a hospital sends us a slide for special stains, and our diagnosis differs from theirs due to these tests, they may change their original diagnosis. What effect does this have regarding the difference in the two diagnoses?

**A.** FCDS is aware that there will be different interpretations on a pathology report and field staff will resolve those issues.

**Q.** Is this program for Florida patients only?

**A.** The CLIP program is for only FL residents, but there are other states doing the same. Since this is an NPCR requirement, other, states are also breaking ground with the Pathology identification programs. NAACCR has set standards for pathology reporting and FCDS is following those standards.

**Q.** Regarding the word string search: What if a report mentions a disease that the patient does not definitely have? Examples: "cells like this sometimes are present in Adult T-Cell Lymphoma," and certain cancer "can't be ruled out," and "hematologic neoplasia."

**A.** The word string search does include false positive words and those

will be placed in a separate location for review. We will not penalize any labs for sending us any false positive cases.

**Q.** Pg. 35 Do we want bronchial washings, pleural fluid, paracentesis fluid?

**A.** If the reports from the bronchial washing and pleural fluid or paracentesis are reportable with the word string search FCDS wants that case, but no cytology reports from pap-smears are required.

**Q.** Will it be acceptable to submit a file that includes more than one hospital (more than 1 CLIA number)?

**A.** If a laboratory has multiple facilities with different CLIA numbers FCDS will accept them upon upload.

**Q.** Does each facility have to submit a separate test file.

**A.** Every facility laboratory will have to submit a test file but if this a vendor such as Meditech who is developing a standard program for all facilities they will be checked upon upload.

In complying with the Cancer Identification program, we are requesting information on the actual Florida statute or rule (or FCDS determination) listing the kinds of cancer cases that must be reported. Publications from FCDS have indicated exclusions of CIS, CIN III, and PIN III, and basal cell, squamous cell carcinoma of the skin. This clarification will assist in providing complete and accurate data.

The FCDS Data acquisition manual that is online has all of the information you need on reporting. Also, our website has a

*(Continued on page 7)*

# CANCER REPORTING AND HIPAA



*.Note: The implementation of HIPAA is a lengthy process; in fact, most provisions do not take effect until 2003. While this article represents our best understanding of the current issues at this time, future events and interpretations may occur.*

**HIPAA.** Health Insurance Portability and Accountability Act. A federal law passed in 1996 to help protect the insurability of Americans. How could that have anything to do with cancer registries?



## Who Is Covered?

It depends on the cancer registry. For instance, hospital cancer registries are covered by HIPAA while state registries are not. HIPAA clearly defines what are “covered entities.” They are **health care providers** (hospitals, doctors, laboratories, etc.), **health plans** (insurance companies) and **clearinghouses** (firms that process data for health care providers and health plans). Thus, hospital cancer registries are covered entities, while state registries are not.

Most of the provisions of HIPAA have nothing to do with cancer registries. HIPAA is written in two parts. Title I, Health Insurance Reform addresses the health-insurance issues. Title 2, Administrative Simplification deals with technical issues of privacy and security. It is the privacy regulations that most directly impact cancer registries.

## What Is Covered?

The privacy regulations establish a general rule that **Protected Health Information (PHI)** may not be disclosed without the written, informed consent of the patient. It specifically defines PHI as 18 items including name, address information more specific than the state, dates more specific than year, telephone number, social security number, medical record numbers as well as other identifiers. All of the above are reportable data items under many state’s cancer reporting regula-

tions. So how can hospitals continue with state reporting? The privacy regulations made 11 exceptions to the general rule for “uses and disclosures for which consent, an authorization, or opportunity to agree or object is not required.” One of these is for public health activities. It states, “A covered entity may disclose PHI... to a public health authority that is authorized by law to collect or receive such information.” Since states may mandate cancer reporting, hospitals will continue to report cancer cases to the state registry as they do currently.



## Accounting of Disclosure

Cancer reporting facilities will be held to one new requirement, however. The law states that the facility must provide an **accounting of disclosure** of any disclosure of PHI that was made without patient consent. This would include reporting cancer patient information to the state registry. It would also include merely reviewing records by non-hospital personnel. Such as a case finding audit by the state registry. This accounting of disclosure must be provided to patients upon request and include disclosures for the previous 6 years. The information to be provided includes:

- Date of the disclosure
- Name of the entity or person who receive the PHI
- Brief description of the PHI disclosed
- Brief statement of the purpose of the disclosure

## Receipt of Information from Other Hospitals and Physicians

While HIPAA does not restrict hospitals and physicians from reporting cancer cases as required by state law, no allowance was made for hospitals and physicians to share PHI among themselves, except for the treatment of the patients.

Specifically, HIPAA does not allow an out-of-hospital physician to provide patient treatment or follow-up to the hospital registrar without patient consent. Either this will require that consent be requested from cancer patients or a significant portion of treatment and follow-up information will no longer be available to the registry.

## Proposed Amendments

In March 2002, the federal government proposed several modifications to HIPAA. Among them is language that may permit hospitals and physicians to exchange PHI without consent for cancer registry purposes. “The department proposes to permit a covered entity to disclose protected health information about an individual to another covered entity for certain health care operations purposes of the covered entity that received the information.” The activities include quality assessment and improvement activities, and population-bases activities relating to improving health or reducing health care cost. This provision is intended to allow information to flow from one covered entity to another for activities important to providing quality and effective health care. It is unknown when a decision will be made on these proposed modifications.



## Where Do We Go From Here?

It is important to remember that the privacy regulations do not go into effect until April 14, 2003, despite reports that some individuals are already stating that they may or may not do something “because of HIPAA.” A California Cancer Reporting HIPAA Task Force has been created made up of cancer registry professionals from hospitals, registry services vendors, Regional Registries, the California Cancer Registry, the California Cancer Registrars Association, and the American College of Surgeons. The task force will identify issues relevant to hospital and state-based cancer registries in performing cancer reporting in compliance with these HIPAA standards. Progress will be reported in future issues of the NAACCR Narrative.

*Excerpt from NAACCR Narrative Summer 2002 Edition*



# EDUCATION AND TRAINING

## EAST NPCR INSTITUTE

A basic registry training institute for registry staff, will be held at the Bolger Center in Potomac, Maryland on March 17-20, 2003. The Institute will cover fundamental issues that are integral to central registry operations. Some of the topics that are covered are: ICD-03, SEER Summary Stage 2000, Multiple Primaries, Death Clearance, and Descriptive Statistics. Training is both didactic and interactive with cases to abstract and code.

## NAACCR Cancer Surveillance Institute (CSI)

NAACCR will be offering a new four-day Cancer Surveillance Institute (CSI). The Institute will be held in San Jose, California from January 28-31, 2003. The goal is to prepare professionals to address appropriate uses, data interpretation, and questions, about cancer surveillance data.

*Further information and registration forms for both the NPCR East Institute and the Cancer Surveillance Institute are available on the NAACCR website at [www.naaccr.org](http://www.naaccr.org).*

*You may also contact Kay Gebhard, Program Manager for Education and Training, at [kgebhard@naaccr.org](mailto:kgebhard@naaccr.org) or (505) 332-0470.*

## NATIONAL CANCER REGISTRARS ASSOCIATION (NCRA) 2003 ANNUAL CONFERENCE

The NCRA Annual Conference will be held at the innovative new David L. Lawrence Convention Center in Pittsburgh, Pennsylvania on May 13-16, 2003.



## MARK YOUR CALENDAR

- **NAACCR Cancer Surveillance Institute, January 28-31, 2003**
- **NCRA Annual Conference Scholarship, Deadline for Application: February 28, 2003**
- **NPCR Institute East, March 17-20, 2003**
- **NCRA 2003 Annual Conference, May 13-16, 2003**

## NCRA ANNUAL CONFERENCE SCHOLARSHIP

NCRA is offering the Annual Conference scholarship to allow members who have no other available funding to attend the NCRA 2003 Annual Conference to be held in Pittsburgh, PA. The scholarship will cover the registration fee, airfare, and hotel for 3 nights. The individual will have been an active NCRA member for at least one year and can not be a member of the Board of Directors or the Advisory Committee.

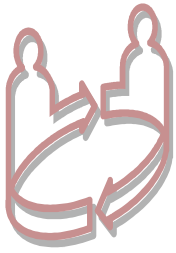
*Further information and scholarship application is available on the NCRA website at [www.ncra-usa.org](http://www.ncra-usa.org).*

## CASE ASCERTAINMENT CD-ROMS—MADE AVAILABLE FALL 2002

Early Fall 2002, the first of a series of educational CD-ROMs covering all aspects of Case Ascertainment for the U.S. and Canada, was made available. The CD module includes articles to read, tutorials with questions for Canada and the U.S., and a comprehensive test. The content for the second CD on Principles of Abstracting is almost complete. This CD covers abstracting techniques and has three cases to abstract and code.

*For additional information on the CD-ROMs, contact:*

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**Program Manager, Education and Training**  
**NAACCR**  
**[kgebhard@naaccr.org](mailto:kgebhard@naaccr.org)**  
**Phone: (505) 332-0470**



## Y2001 Case finding List

Cancer registries and cancer surveillance programs typically describe the reportable neoplasms as any neoplasm with a behavior code (fifth digit in a complete six-digit morphology code) of '2' (in situ) or '3' (invasive). FCDS does not collect and any benign ('0') and borderline ('1') neoplasms.

The following list is intended to assist in reportable neoplasm case finding activities that are performed in case finding sources that use ICD-9-CM\* codes to codify the diagnoses. Codes and/or terms that have new malignant behavior codes in ICD-O-3 are underlined and the ICD-O-3 code is placed in parentheses following the terms.

### ICD-9-CM Codes Diagnosis (in preferred ICD-O-3 terminology)

042	AIDS (review cases for AIDS-related malignancies)
140.0 - 208.9	Malignant neoplasms
203.1	Plasma cell leukemia (9733/3)
205.1	Chronic neutrophilic leukemia (9963/3)
210.0 - 229.9	Benign neoplasms
230.0 - 234.9	Carcinoma in situ
235.0 - 238.9	Neoplasms of uncertain behavior
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.7	Chronic myeloproliferative disease (9960/3)
238.7	Myelosclerosis with myeloid metaplasia (9961/3)
238.7	Essential thrombocythemia (9962/3)
238.7	Refractory cytopenia with multilineage dysplasia (9985/3)
238.7	Myelodysplastic syndrome with 5q- syndrome (9986/3)
238.7	Therapy-related myelodysplastic syndrome (9987/3)
239.0 - 239.9	Neoplasms of unspecified behavior
273.2	Gamma heavy chain disease; Franklin's disease
273.3	Waldenstrom's macroglobulinemia
273.9	Unspecified disorder of plasma protein metabolism (screen for potential 273.3 miscodes)
284.9	Refractory anemia (9980/3)
285.0	Refractory anemia with ringed sideroblasts (9982/3)
285.0	Refractory anemia with excess blasts (9983/3)
285.0	Refractory anemia with excess blasts in transformation (9984/3)
288.3	Hypereosinophilic syndrome (9964/3)
289.8	Acute myelofibrosis (9932/3)
V07.3	Other prophylactic chemotherapy (screen carefully for miscoded malignancies)
V07.8	Other specified prophylactic measure
V10.0 - V10.9	Personal history of malignancy (review these for recurrences, subsequent primaries, and/or subsequent treatment)
V58.0	Admission for radiotherapy
V58.1	Admission for chemotherapy
V66.1	Convalescence following radiotherapy

V66.2	Convalescence following chemotherapy
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up
V71.1	Observation for suspected malignant neoplasm
V76.0 - V76.9	Special screening for malignant neoplasm

### Please note:

Prostatic Intraepithelial Neoplasia (PIN III) M-8148/2 will NOT be collected by FCDS or the SEER registries.

Pilocytic/juvenile astrocytoma M-9421 which moves from /3 to /1 will CONTINUE to be collected as a /3 by FCDS and SEER registries.

Borderline cystadenomas M-8442, 8451, 8462, 8472, 8473, of the ovaries which move from /3 to /1 will NOT be collected as of 1/1/2001 and previous cases will continue to have to be submitted to FCDS or SEER registries.

The World Health Organization (WHO) diagnosis "B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma" is coded as 9823/3, and cross-referenced to 9670/3, malignant lymphoma, small B lymphocytic. If this WHO term is diagnosed in blood or bone marrow, code 9823/3; if diagnosed in tissue, lymph nodes or any organ in combination with blood or bone marrow, code 9670/3.



### New Clarifications and Corrections to FORDS Online

Clarifications have been added and corrections made to the following FORDS pages: 8, 46, 53, 69, 73, 100, 101, 139, 150, 153, 158, 163, 164, and 189.

We have revised the appropriate PDF files found on our Web site at: <http://www.facs.org/dept/cancer/coc/fordsmanual.html>. There is also an individual PDF that holds just the corrected pages called "Individual Page Corrections #2" and the revision date of 9/18/02. If you have already printed or purchased a copy of the FORDS manual, we encourage you to replace the current pages with just the corrected pages found in the PDF.

For those who have downloaded the manual from the Web to your computer desktop, we suggest that you replace your current files with the revised PDFs for Section One and the individual sections of Patient Identification, Cancer Identification, and First Course of Treatment or the single, large FORDS file.



## Quality Control

By: Joy Houlahan

Just wanted to let you know that the first quarter 2002 visual review of every 25th

abstract has just been completed and will be coming your way soon. Any abstracts with "Please Verify With Reply" stamped on them, must be returned to us within 6 weeks.

Mary and I are also starting to set up our Site visits for the 2001 reporting year. If your facility has been randomly selected to be audited, we will be contacting you soon.

Remember, if you have any questions while you are abstracting and you can't find where it is in the FCDS DAM, Summary Stage 2000 or ICD-O3, instead of guessing, call your field coordinator.



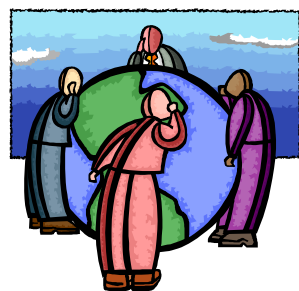
**SEER: WEBSITE UNDER HORMONES AND ANTI-HORMONES**

## Hormones

Hormones help regulate body mechanism such as growth, metabolism, and reproduction.

Hormones can be used to alter the growth of cancer. Cancer therapy which achieves its anti-tumor effect through changes in hormonal balance is also called endocrine therapy. Some tissues, such as prostate or breast, depend on hormones to develop. When a malignancy arises in these tissues, it is usually hormone responsive. Other primaries and histologic types may be hormone responsive, such as melanoma and hypernephroma. Hormonal therapy may effect a long-term control of the cancer growth.

Prednisone is a common hormone that is administered to cancer patients, especially in combination with multi-agent chemotherapy regimens .



*(Continued from page 3)*

## HIPAA Update:

Dennis Deapen has been charged by the NAACCR Board with taking the lead to review HIPAA issues and their impact on state registries. Current interpretations of the privacy rule and its impact on state registries were posted on the NAACCR web site in September, 2001. Dennis and NAACCR staff met in Washington, DC in January, 2002 with Health and Human Services Department staff to review NAACCR's interpretation of HIPAA. Collection and transmission of patient follow-up information between hospitals and physicians appeared to be the outlying issue.

NAACCR membership was surveyed to assess if follow-up activities are mandated at the state level. Dennis was going to be presenting the survey results during the annual meeting. Proposed modifications to the privacy rule currently being considered would accommodate the ability for collection of follow-up data. NAACCR is going to take a "wait and see" position related to this issue and expects that the final rule, to released later this summer, will have little or no impact on current reporting. Mary McBride reported on similar activity taking place in Canada. A common set of guidelines are being developed for Canadian registries which would result in a privacy policy covering issues related to data access and use, data collection, and a privacy impact review. These policies were discussed at the NAACCR North of the Border Workshop and will be made available in a few months.

# FCDS Q & A

(Continued from page 2)

wealth of information regarding FCDS. See [FCDS.med.miami.edu](http://FCDS.med.miami.edu). I have inserted the Data Acquisition manual that facilities such as hospital, freestanding, and physician offices use. Please see page I-2 and the table I-5, which helps explain what is inclusive and exclusive for reporting. Here is also the link to the section pertaining to the FL statute <http://fcds.med.miami.edu/inc/lawsrules.shtml>.

All cancers are reportable with the exception of basal and squamous cell carcinoma of the SKIN only and carcinoma insitu of the cervix CIS, CIN III, PIN III.

**QUESTION:** COC #2113

*How is splenectomy coded as treatment for chronic lymphocytic leukemia if it is the 3rd course of treatment with 1st no treatment and 2nd Prednisone?*

**ANSWER:** In this scenario there was no 1st course of treatment. For FCDS the Prednisone would NOT be coded since it is SUBSEQUENT therapy. If the splenectomy was first course of therapy then use the surgery codes under "All Other Sites" use code 20, "Local Tumor Excision" and in this case the splenectomy was 3rd course of treatment which is subsequent therapy.

**QUESTION:** COC # 2999

*When do we use Prednisone as treatment?*

If I have a the combination of Adriamycin/Cytoxan/Prednisone as one entry. Since the Prednisone is intended for symptoms when given in combination with Adria/Cytoxan in breast cancer, we do not code this as a hormone treatment. Should we pick this combination when we list chemo treatment or should we individually pick Adria and then pick Cytoxan as the two drugs of treatment?

**ANSWER:**

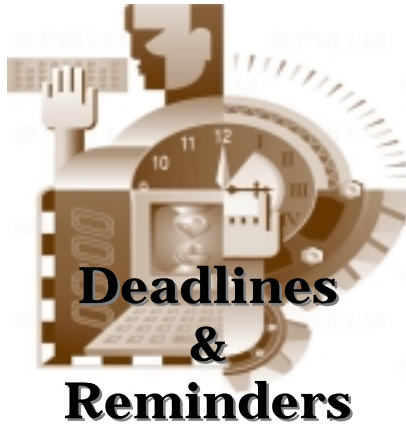
It is acceptable to pick up a combination of chemotherapy agents, but please make sure to code the hormone separately when necessary for treatment



## What is CHOP?

**Dr. Gribben:** <http://www.healthtalk.com/cllen/toc/drug/09.html>

CHOP stands for four drugs: the C is for Cytoxan, the H is for the proper name of Adriamycin; the O is for Oncovin, which is a drug called vincristine, and P is for prednisone. This drug is the mainstay of treatment for patients with diffuse large cell non-Hodgkin's lymphoma (NHL). This was the first combination of drugs put together by researchers at the NCI that demonstrated that NHL could potentially be cured by chemotherapy. CHOP's role in chronic lymphocytic leukemia has certainly been much more controversial for a period of time. In the days before fludarabine was around, and many patients were treated with CHOP, particularly those patients who had the more aggressive forms of the disease. Some studies, particularly from Europe, suggested there were some subgroups of patients who may benefit from this approach.



#### REMINDER

50% of the 2002 Cancer Admissions are due by December 31, 2002.

#### COMPLETENESS REPORT

The number of new cases added to the FCDS Master- file in November 2002 was 10,313.

As of November 30, 2002, 25% of the 2002 Cancer Admissions have been reported to FCDS. 42% is expected.

#### DEATH CERTIFICATE NOTIFICATION

FCDS will mail the Death Certificate Request Forms for 2001 the first week of December. All forms must be completed and returned to FCDS no later than January 15, 2003. The information on the forms was obtained from the official Florida Vital Statistics Death Certificate. Each form identifies a Florida resident who expired with a cancer-related cause of death and does not match with any record already in the FCDS database. **If you have any questions, please contact your Field Coordinator at (305) 243-4600 or 1-800-906-3034.**

#### AMBULATORY CARE CENTERS CANCER REPORTING PROGRAM

On June 18, 2002, FCDS mailed out the "AHCA Ambi Unmatched Cancer Records Request" lists for 2000 to the Florida Ambulatory Care Centers. The 2000 listings included patient encounters between January 1, 2000 and December 31, 2000. **The deadline for submission of copies of medical records or full case abstracts was August 31, 2002. If you have not responded as of yet, please contact Megsys C. Cuadra at (305) 243-2625 or DOH will be notified of any facility that did not comply.**

#### PATH LABS

Every anatomic pathology laboratory that reads biopsy and surgical resection specimens collected from patient encounters within the state of Florida **MUST** electronically submit the specified data for every malignant cancer case. **Specimens read between January 1, 2002 and June 30, 2002 must be submitted to FCDS on or before December 31, 2002.**

(July 1, 2002 through December 31, 2002 data are due June 30, 2003.)



FLORIDA CANCER DATA SYSTEM

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**FCDS** Florida Cancer Data System  
A Joint Project of the Sylvester Comprehensive Cancer Center and the Florida Department of Health

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