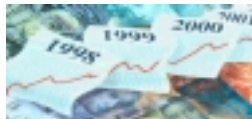


FCDS MONTHLY MEMO

DECEMBER 2000

It is hard to believe that November has already slipped away and the days are closing in on the new millennium. We always seem to be so busy that we sometimes forget the important things...

**HAPPY HOLIDAYS from the FCDS Staff to ALL of you,
and a Safe and HAPPY 2001**



Year 2001, not 2000, begins the new century (and in this case, also the new millennium). The famous year 2000 is actually the last year of the 20th century. This is a time of great change, new challenges and collective opportunity. Keeping this in mind FCDS will be updating some of our policies and procedures in order to bring Florida's cancer surveillance program into the new millennium. We were just informed that FCDS will not become a part of the SEER Program. Therefore, the changes we will be implementing January 1, 2001 will not be as far reaching as we had anticipated. FCDS will only be adding the new CDC/NPCR requirements for reporting. The FCDS Register, our quarterly newsletter, provides many of the details of the 2001 changes.

In the new millennium, FCDS will also be changing our case processing procedures. We will soon begin using the Internet for case submissions, performing edit checks and correcting cases failing edits. FCDS will begin phasing out diskette data submission early in 2001. **It is imperative that ALL facilities gain access to the Internet in order to meet the new case submission requirements.** Without Internet access, FCDS will not be able to process your data.

FCDS does understand that some facilities have policies against Internet access for their employees. FCDS plans to host a teleconference for facility administrators early in 2001 to help explain FCDS Policies and Procedures as well as formal correspondence with administrators explaining the new Florida cancer reporting requirements.

Additionally, FCDS will begin using a new FCDS Internet Abstracting and Case Extracting Module before March 31, 2001. Registrars and contractors who are currently using the FCDS Comprehensive Incidence Software will need to have Internet access if they are going to use the updated FCDS Internet abstracting tool. More information will be forthcoming in the very near future. This abstracting and case submission tool will be free of charge. (*Special Note: No 2001 cases will be accepted using the current version of the FCDS Comprehensive Incidence Software. Any 2001 cases submitted to FCDS in the incorrect format and without the new required data items will be rejected.*)

Announcements: FCDS will be holding an **Incidence Abstracting Workshop** in Miami from March 28-30, 2001. The three-day training will cover the basics of what is required to complete casefinding, abstracting and reporting cases to meet the minimum FCDS requirements including the new guidelines for casefinding. The cost is \$100.00. Please contact Betty Fernandez at FCDS for more information or to register. Also, please register early. We had to cancel the last workshop because we only had 3 registrants.

ICD-O-3 SATELLITE BROADCAST SCHEDULED

FCDS will host the ICD-O-3 live two hour Satellite Training program (2:00 p.m. - 4:00 p.m. ET) on **January 9, 2001**. The program will be broadcast from the 8th Floor Auditorium of the Mailman Center for Child Development Building at the University of Miami Medical Campus Complex (1601 N.W. 12 Avenue).

This live, two-hour program will be videotaped for use in educational sessions and individual training. The satellite broadcast will cover what is new and what has changed in ICD-O-3. There is no fee to downlink to this broadcast; however, local fees may be charged for use of facilities.

Lecture notes will be available for downloading from the SEER training web site, <http://www.training.seer.cancer.gov> beginning approximately two weeks before the broadcast.

Exercises and answer sheets, which can be used in conjunction with the satellite broadcast/video when ICD-O-3 books are available, may also be downloaded from the training web site at that time.

Any facility interested in hosting a location can downlink via the facility satellite network and/or many household satellite dishes can capture the conference. Please contact FCRA Education Chairman for more information and registration, Mary O'Leary, RHIT, CTR at (305) 243-4961, Fax (305) 243-5885 or e-mail her at moleary@med.miami.edu. FCRA can disseminate the information if they know who wants to host the satellite conference.

The following is the satellite information and coordinates:

Satellite Information

Date: Tuesday, January 9, 2001
Test: 1:30 p.m. to 2:30 p.m.
Time Broadcast Starts: 2:00 Eastern Time
Length: 2 hours

Coordinates

KU Band
Galaxy 11 Transponder 13
Downlink Frequency: 11960
Audio: 6.2 and 6.8
Polarity: Horizontal
91 West Degrees West

For technical information please call: Jonathan Bennett, NIH Television Operation Center at 301 435-8278

ICD-O-3 ARTICLE PUBLISHED IN JOURNAL OF REGISTRY MANAGEMENT

The November issue of the National Cancer Registrars Association's Journal of Registry Management will include a detailed article describing what is new and what is different in ICD-O-3. This article is eligible for one (1) continuing education unit upon completion of a quiz and payment of \$15 for NCRA members and \$25 for non-members. Requests for

reprints should be directed to Amy Fremgen, PhD, CTR, Editor, Journal of Registry Management, W 192 Hilltop Drive, Genoa City, WI 53128. Telephone: (262) 279-0173; e-mail: afremgen@worldnet.att.net. If possible, please request the article by E-mail first. Please note that the content of these various ICD-O training modalities does overlap, but reinforcement of new information is encouraged.

WEB BASED TRAINING MODULE AVAILABLE

The SEER Program of the National Cancer Institute is pleased to announce the availability of a web-based training module in preparation for the implementation of ICD-O-3 (International Classification of Diseases for Oncology, Third Edition) for cases diagnosed on or after January 1, 2001. The web site address is <http://www.training.seer.cancer.gov>.

The module includes a quiz on the educational content, coding exercises, learning games, and an ICD-9 casefinding reference list, in addition to information about the revisions to ICD-O.

The ICD-O-3 web-based training module is the first of a series of free Internet training courses developed by the SEER Program. The National Cancer Registrars Association has granted three (3) continuing education hours to Certified Tumor Registrars who complete the module, and who have filled in the attestation of completion and requested a certificate of completion. However, all persons involved with ICD-O coding are encouraged to complete this training.

Any questions about the ICD-O-3 web-based training module should be addressed to Steven Roffers, PA, CTR, Rollins School of Public Health, Emory University, 1462 Clifton Road NE, Fifth Floor, Atlanta, GA 30322 or by e-mail to sroffers@emory.edu.

QC REMINDER

We have recently received a number of abstracted cases with cancers that documented bone marrow involvement staged as local and regional which should be coded to distant. Please be careful when abstracting and staging cases and always refer to your reference manuals if you have questions or call us.

NEW TEST IMPROVES THE DETECTION OF RECURRENT THYROID CANCER

The presence of thyroglobulin mRNA in peripheral blood is a more sensitive marker of recurrent disease in thyroid cancer patients than either serum levels of the hormone or a whole body scan with radioiodine. <http://oncology.medscape.com/29986.rhtml?srcmp=onc-111700>

ADENOCARCINOMA OF UNKNOWN PRIMARY SITE

Explore the clinical features and therapies available for each of the clinically defined subgroups of AUP patients. UpToDate (C) 2000.

<http://oncology.medscape.com/29657.rhtml?srcmp=onc-111000>

ELECTRONIC ACCESS TO COURT FILES

The Judicial Conference of the US Subcommittee on Privacy and Electronic Access to Court Files has raised an important question that could affect the privacy and confidentiality of patient records. The Subcommittee seeks comment on its potential policies addressing "issues of privacy and security concerns related to the electronic availability of court case files". In the November 8 Federal Register (65FR67017-67019) these policies were published. The Privacy and Electronic Access recommendations do not carry a clear message that information such as medical records should always be private. Rather, the guidelines suggest that the court could either define different levels of electronic access, or decide--on a case by case basis--what records will be made public. In addition, the recommendations note that there must be a balance between access and privacy interests in making such decisions. Comments are due by January 26, 2001. The Federal Register can be accessed at <http://www.access.gpo.gov/nara/>. Posted to e-alert@www.ahima.org from e-alert@AHIMA.org on Tue Nov 21 15:29:05 2000

CASEFINDING

FCDS has received numerous questions regarding the new casefinding terminology especially with Myelodysplastic Syndrome (MDS). Therefore, we contacted April Fritz regarding the following question:

Q: What will be the date of diagnosis if a Myelodysplastic Syndrome (MDS) was diagnosed in 1973, but is now reportable starting with January 1, 2001 cases? Would the diagnosis date be 1/1/2001 and the class of case 0 or 1 or would the diagnosis date be 6/15 /73 and a class of case 3?

A A: April Fritz: The diagnosis date is 1973 and the behavior for MDS diagnosed in 1973 was/ 1 (borderline malignancy). Therefore, the case would NOT be reportable in 2001 to FCDS.

WHAT ARE MYELODYSPLASTIC SYNDROMES (MDS)? NCI –CancerNet Website
Myelodysplastic syndromes, also called pre-leukemia or "smoldering" leukemia, are diseases in which the bone marrow does not function normally and not enough normal blood cells are made. The bone marrow is the spongy tissue inside the large bones in the body. The bone marrow makes red blood cells (which carry oxygen and other materials to all tissues of the body), white blood cells (which fight infection), and platelets (which make the blood clot). Normally, bone marrow cells called blasts develop (mature) into several different types of blood cells that have specific jobs in the body.

Myelodysplastic syndromes occur most often in older people, but they can occur in younger people. The most common sign is anemia, which means there are too few mature red blood cells to carry oxygen. There may also be too few white blood cells in the blood to fight infections. If the number of platelets in the blood is lower than normal, this may cause people to bleed or bruise more easily. A doctor should be seen if a person bleeds without any reason, bruises more easily than normal, has an infection that won't go away, or feels tired all the time.

If there are symptoms, a doctor may order blood tests to count the number of each kind of blood cell. If the results of the blood test are not normal, the doctor may do a bone marrow biopsy. During this test, a needle is inserted into a bone and a small amount of bone marrow is taken out and looked at under the microscope. The doctor can then determine the kind of disease and plan the best treatment.

A myelodysplastic syndrome may develop following treatment with drugs or radiation therapy for other diseases, or it may develop without any known cause. The myelodysplastic syndromes may change into acute myeloid leukemia, a form of cancer in which too many white blood cells are made.

Myelodysplastic syndromes are grouped together based on how the bone marrow cells and blood cells look under a microscope. There are five types of myelodysplastic syndromes: refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, refractory anemia with excess blasts in transformation, and chronic myelomonocytic leukemia.

Stages of myelodysplastic syndromes

AJCC has no staging for the myelodysplastic syndromes. SEER Summary stage 1977 and 2000 for myelodysplastic syndrome is 7. Treatment depends on whether or not the disease developed following other treatments, or whether the patient has been treated for the myelodysplastic syndrome.

Myelodysplastic syndromes are grouped as follows:

De novo myelodysplastic syndromes

De novo myelodysplastic syndromes develop without any known cause. The patient has not received radiation therapy or chemotherapy for other diseases.

Secondary myelodysplastic syndromes

Secondary myelodysplastic syndromes develop following treatment with radiation therapy or chemotherapy for other diseases.

- Previously treated myelodysplastic syndromes
- Previously treated myelodysplastic syndrome means the disease has been treated but has gotten worse.

How myelodysplastic syndromes are treated?

There are treatments for all patients with myelodysplastic syndromes. Often the main treatment is giving red blood cells or platelets by a needle in a vein (transfusion) to control anemia or bleeding. Vitamins or other drugs may also be given to treat anemia.

Chemotherapy and biological therapy are being tested in clinical trials. Chemotherapy uses drugs to treat disease. Chemotherapy may be taken by pill, or it may be put into the body by a needle in the vein or muscle. Chemotherapy is called a systemic treatment because the drug enters the bloodstream, travels through the body, and affects cells throughout the body. Biological therapy tries to get the body to fight disease. It uses materials made by the body or made in a laboratory to boost, direct, or restore the body's natural defenses against disease. Biological therapy is sometimes called biological response modifier (BRM) therapy or immunotherapy.

Bone marrow transplantation is a newer type of treatment that uses high doses of chemotherapy and/or radiation therapy (high doses of x-rays or other high-energy rays) to destroy all of the bone marrow in the body, then transplants healthy bone marrow back into the body. Healthy marrow is then taken from another person (a donor) whose tissue is the same or almost the same as the patient's. The donor may be a twin (the best match), a brother, sister, or other relative, or another person not related. The healthy marrow is given to the patient through a needle in the vein, and the marrow replaces the marrow that was destroyed. A bone marrow transplant using marrow from a relative or person not related to the patient is called an allogeneic bone marrow transplant.

MDS treatment

The choice of treatment depends on the type of myelodysplastic syndrome, and the patient's age and general health. Standard treatment may be considered because of its effectiveness in patients in past studies, or participation in a clinical trial may be considered. Most patients with myelodysplastic syndromes are not cured with standard therapy and some standard treatments may have more side effects than are desired.

For these reasons, clinical trials are designed to find better ways to treat cancer patients and are based on the most up-to-date information. Clinical trials are ongoing in most parts of the country for patients with myelodysplastic syndromes. To learn more about clinical trials, call the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237); TTY at 1-800-332-8615.

De Novo Myelodysplastic Syndrome

Treatment may be one of the following:

1. Treatment to relieve symptoms of the disease, such as anemia or bleeding.
2. Allogeneic bone marrow transplantation.
3. Clinical trials of chemotherapy or biological therapy.

Secondary Myelodysplastic Syndrome

Patients will probably receive treatment to relieve symptoms of the disease, such as anemia or bleeding. They may also choose to take part in a clinical trial of chemotherapy or biological therapy.

Previously Treated Myelodysplastic Syndrome

Patients will probably receive treatment to relieve symptoms of the disease, such as anemia or bleeding. They may also choose to take part in a clinical trial of chemotherapy or biological therapy.

For more information, call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237); TTY at 1-800-332-8615. The call is free and a trained information specialist is available to answer your questions. Visit the WebSite at http://cancernet.nci.nih.gov/cgi-bin/srchcgi.exe?DBID=pdq&TYPE=search&UID=208+02495&ZFILE=patient&SFMT=pdq_treatment/1/0/0. The National Cancer Institute has booklets and other materials for patients, health professionals, and the public. These publications discuss types of cancer, methods of cancer treatment, coping with cancer, and clinical trials. Some publications provide information on tests for cancer, cancer causes and prevention, cancer statistics, and NCI research activities. NCI materials on these and other topics may be ordered online from the NCI Publications Locator Service at <http://publications.nci.nih.gov> or by telephone from the Cancer Information Service toll free at 1-800-4-CANCER.

EDUCATION

January 9, 2001, The SEER program will sponsor a satellite teleconference on **ICD-O-3** scheduled for January 9, 2001 and will be broadcast through the hospital satellite network. This broadcast will also be videotaped for future use in training data collectors.

February 5-6, 2001, The Florida Cancer Registrars Association will conduct a **CTR Exam Review Workshop** at the at Mayo Clinic in Jacksonville, FL. The cost is \$100. Please contact FCRA Education Chairman for more information and registration, Mary O'Leary, RHIT, CTR at (305) 243-4961, Fax (305) 243-5885 or e-mail: moleary@med.miami.edu.

March 5-9, 2001, 2001 Commission on Cancer, American College of Surgeons **BASIC CANCER REGISTRY TRAINING** in Chicago. Registration for the program will begin January 2, 2001 and the fee for the five-day course is \$500. For more information and details, contact Pat Tary at tary@facs.org.

May 21-26, 2001-[National Cancer Registrars Association](http://www.ncra-usa.org) -**NCRA Annual Conference** will be held at the Hilton in the Walt Disney World Village, Orlando, Florida. Carol Johnson, president-elect is looking for Florida Registrars and Central Registry volunteers to help staff the hospitality & registration booths as well as the cocktail reception. Any suggestions for local speakers, and volunteers are welcomed. Contact Carol Johnson, 301-402-6226, carol.johnson@NIH.gov or contact Edie Kutlus (302) 798-3978, email at Ekutlus@cppsinc.com. NCRA (913) 438-6272 or email NCRA at: ncra-info@goamp.com. WebSite: www.ncra-usa.org. For hotel information visit WebSite: <http://www.hilton.com/groups/ncr/index.html> or 1-800-782-4414

EDUCATION, continued

June 5-7, 2001, North American Association of Central Cancer Registries (NAACCR) Annual Conference & workshops will be hosted by FCDS at the Sheraton Bal Harbour Beach Resort. For more information contact Megsys Cuadra at 305-243-2625 or 1-800-906-3034.

HAPPY HOLIDAYS TO EVERYONE FROM FCDS !!!

DEADLINES

HOSPITALS

Hospitals should now be reporting June 2000 cases.

AMBULATORY CANCER CARE REPORTING PROGRAM (AACRP)

1999 Case Identification has been delayed due to changes in AHCA.

FCDS will keep you informed regarding upcoming deadlines and possible changes in the ACCRP reporting requirements resulting from these delays.

