

# Register

A joint project of the Sylvester Comprehensive Cancer and Center and the Florida Department of Health

Division of Cancer Prevention and Control

Volume 20, 2003

## Population-Based Disease Registration in Florida

By Jill A. MacKinnon, CTR

The following article presents an overview of the process required in creating a disease surveillance system and the ongoing disease control efforts in Florida

For health problems to be understood, they must be defined and measured. Their measurement is determined by the frequency with which they occur and their severity. A well-designed disease surveillance system is an invaluable research resource to public health professionals, providing this measurement by gathering and analyzing information about diseases with regard to person, place and time. The potential of any system is contingent upon three elements: completeness, timeliness and quality. The system must have mechanisms in place to insure: 1) all cases from a defined geographic area are included in the data base; 2) the timely collection of data and subsequent release of information to health professionals; 3) the collected data are of the highest quality possible in order for health professionals to utilize the data.

Epidemiologists gather data from a wide variety of sources in order to develop a comprehensive picture of

health problems around the world. These are the kinds of questions they address:

What parts of the community have the highest rates of disease or conditions of public health significance? Why?

What are the environmental, lifestyle, and genetic factors that increase a person's chance of developing a disease or condition?

What is the natural history of a disease? Does it develop rapidly? What are the chances of surviving the

*(Continued on page 2)*



### Inside this issue:

Population Disease in Florida	1-3
NAACCR Certification	4
Calendar of Events	5
Other News	5
FCDS Data Set Revisions	6-7
CTR Recipients	8

(Continued from page 1: Population-Based Disease Registration in Florida)

disease? What factors influence survival?

Are there any education, prevention or screening measures that can improve the disease outcome?

What data are needed to help shape public health policy aimed at regulating harmful substances in the environment? Are specific occupations at risk for toxic exposures? Are the current levels of chemicals in the air, water, or soil hazardous to human health?

Populations, not the individual, are the focus of epidemiology research. Studies involving cancer risk, for example, cannot predict whether an individual with a certain exposure or genetic alteration will develop cancer, but can estimate the likelihood that a certain proportion of people (e.g., one out of 100) will develop cancer.<sup>i</sup>

To that end, the responsibilities of public health agencies center around three core responsibilities: assessment, policy development and assurance.<sup>ii</sup> Assessment is the process of determining the health status and needs of the people in the jurisdiction. This is the function by which public health agencies regularly and systematically collect, assemble, analyze and make available information on the health of the community, including statistics on health status, community health needs and epidemiological and other studies of health problems. Policy Development is determining the extent to which the needs of the public are being met by effective measures currently available. That is, the function by which scientific knowledge and information gathered through the assessment process is utilized in



the development of comprehensive public health policies and specific strategies which will serve the public interest. Assurance allows the public health professionals to take steps to see that the unmet needs are satisfied, that is ensuring high quality services needed for the protection of public health in the community are available and accessible to all persons even when such services are not provided by the Public Health Department directly.

### Surveillance Systems in Florida

Health policy is formed, in part, on the basis of an evaluation of health problems. Diseases and injuries have to be defined, ascertained and counted. The tabulation of that data forms the body of health statistics.<sup>iii</sup> Florida currently maintains 16 separate disease/injury registries and nine surveys (see table on page 3).<sup>iv</sup>

The numerators and denominators used in public health are comprised of three types: survival data (births, deaths, diseases and a count of the population); health and socioeconomic status data; and data on health services resources and utilization.<sup>v</sup> The registries and surveys listed on page 3 provide the numerators for diseases of public health significance in Florida. The denominators used by all are obtained from the Bureau of Statistics and the Governor's office.

The registration of conditions of public health significance in Florida is legislatively mandated. The most successful disease/injury surveillance systems are legislatively mandated. Legislation facilitates cancer control while protecting individual privacy. The hurdle of confidentiality can be overcome by adequate legislation in the interests of public health. Additionally, legislation will free those concerned (vital statistics, medical agencies,

(Continued on page 3)

### Registries

### Surveys

Adult Protective Services (FAHIS)  
 Birth Defects Registry  
 Brain and Spinal Cord Injury Program  
 Florida Cancer Data System (FCDS)  
 Child Abuse Hotline (FAHIS)  
 Childhood Lead Poisoning Surveillance Program  
 Communicable Disease Surveillance (Merlin)  
 HIV/AIDS Reporting System (HARS)  
 Immunizations Registry Infant Screening for Metabolic Diseases  
 Organ and Tissue Donor Registry  
 Pesticide Exposure Surveillance System  
 Sexually Transmitted Disease  
 Teratogen Information Services (TIS)  
 Trauma Registry  
 Tuberculosis Control Data  
 Vital Statistics Data System

Behavioral Risk Factor Surveillance System (BRFSS)  
 Florida Health Insurance Study  
 Florida Young Adult Tobacco Survey (FYATS)  
 Florida Youth Substance Abuse Survey (FYAS)  
 Florida Youth Tobacco Survey (FYTS)  
 Health Insurance Market Data Call  
 Health Maintenance Organization Member Survey  
 Medicaid Utilization Review  
 Pregnancy Risk Assessment and Monitoring (PRAMS)

reporting facilities, general physicians, etc.) from the fear of litigation for breach of medical secrecy.<sup>vi</sup>

The legislation limits the registration of diseases/conditions to broad principles; responsibilities and penalties while the administrative rules provide the details of collection. In that rules are easier to revise than laws are, using administrative rules also allow for revisions to the collection system that result from changes in the diagnosis or management of the conditions of significance. If details of reporting and control appear in the law, further scientific advances will require constant changing of the law or the law will become outdated.

The Florida Cancer Data System (FCDS) is one of the successful surveillance systems in Florida. It was conceived in the mid 1970's by forward thinking public health professionals and legislators. The fact that FCDS has developed into one of the finest population-based, disease registration systems in the Nation is not an accident. Year after year, the dedicated health professionals in Florida's Department of

Health, at the University of Miami School of Medicine (contractors in charge of running the FCDS for the State of Florida) and the individual reporting facilities throughout the state continue to embrace and enhance the concepts envisioned in the 70's. ❧

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<sup>i</sup> Wilson N: Epidemiology in a Nutshell, [http://newscenter.cancer.gov/BenchMarks/archives/2002\\_07/related\\_article.html](http://newscenter.cancer.gov/BenchMarks/archives/2002_07/related_article.html) Archive Benchmarks July 2002.

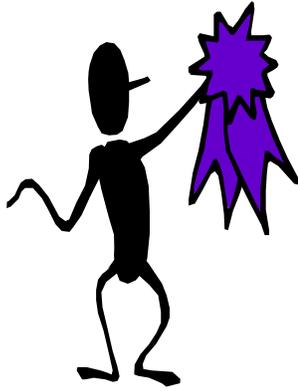
<sup>ii</sup> American Public Health Association: The role of official local health agencies, Am J Public Health 65:189, Feb 1975.

<sup>iii</sup> Pickett G, Hanlon JJ: Public Health Administration and Practice, Times Mirror/Mosby, 1990

<sup>iv</sup> Florida Health Stat [http://www.floridahealthstat.com/shdc\\_help.shtml#table4](http://www.floridahealthstat.com/shdc_help.shtml#table4) Disease/Injury Registries, 2002

<sup>v</sup> Murnaghan JH: Health indicators and information systems for the year 2000. In Breslow L, editor: Annual review of public health, vol 2, Palo Alto, CA. 1981.

<sup>vi</sup> MacLennan R, Muir C, Steinitz R, Winker A: Cancer Registration and its Techniques. International Agency for Research on Cancer, Lyon 1978.



## FCDS RECEIVES “ GOLD STATUS” ON NAACCR CERTIFICATION PROCESS



### NAACCR Awards Announced

By: Youjie Huang, MD, Dr.PH, MPH, Chronic Disease Surveillance & Epidemiology Section Administrator, Bureau of Epidemiology - Reprinted from the State of Florida 'Epi Update' Friday, May 16, 2003

The Florida Cancer Data System (FCDS) received a gold certification for *Quality, Completeness and Timeliness* for its 2000 data from the North American Association of Central Cancer Registries (NAACCR) in May 2003. Being awarded a gold certification indicates that the

FCDS achieved the highest standards of quality, completeness and timeliness defined by the NAACCR. The FCDS received silver certifications for outstanding quality of data during the past several years.

The NAACCR establishes quality measurements to increase the value and comparability of data. Member registries have been evaluated annually since 1998. Cancer registries with all indicators of quality, completeness and timeliness of data exceeding NAACCR's standards receive a gold certification from the NAACCR.

Florida has the highest crude incidence rate of cancer in the nation. Over 500 hospitals and freestanding facilities report approximately 135,000 cases annually, which when unduplicated, translate into more than 95,000 newly diagnosed cases per year. The FCDS is Florida's statewide, population-based cancer registry. Since 1981, the Bureau of Epidemiology has maintained a contract with the University of Miami School of Medicine to maintain the FCDS and collect incidence data. Currently, the FCDS database contains over 1,800,000 cancer incidence records. FCDS also maintains a cancer mortality data provided by the Department of Health. The FCDS data are widely used for cancer control programs and research.

**Florida Cancer Registry**

NAACCR Registry Certification on Quality, Completeness & Timeliness of 2000 Data Summary of Certification Measures					
Registry Element	Gold Standard	Silver Standard	Actual Measure*	Measurement Error Allowed	Standard Achieved
1. Completeness of case ascertainment	95%	90%	108.8%	1.0%	Gold
2. Completeness of information recorded					
▶ Missing/unknown "age at diagnosis"	<=2%	<=3%	0.0%	-0.4%	Gold
▶ Missing/unknown "sex"	<=2%	<=3%	0.0%	-0.4%	Gold
▶ Missing/unknown "race"	<=3%	<=5%	0.8%	-0.4%	Gold
▶ Missing/unknown "State/Province & county"	<=2%	<=3%	0.0%	-0.4%	Gold
3. Death certificate only cases	<=3%	<=5%	3.4%	-0.4%	Gold
4. Duplicate primary cases	<=1 per 1000	<=2 per 1000	0.0 per 1000	-0.4 per 1000	Gold
5. Passing EDITS	100%	97%	100.0%	Not applicable	Gold
6. Timeliness	Data submitted within 24 months of close of accession year.				Gold
<b>Certification Status</b>					<b>Gold</b>

\* Measures are truncated to one decimal place. The measure for completeness of case ascertainment includes an adjustment for unresolved duplicates.

*FCDS wishes to thank and congratulate all reporting facilities for helping us attain this status. This is as much your achievement as ours. Without your continued commitment in reporting quality, complete and timely data this would not be possible. It is this commitment to excellence that makes this award possible. Thank you! ☺*

# CALENDAR OF EVENTS

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## FCDS EDUCATIONAL TELECONFERENCES

**Topic:** Revisions to FCDS Data Set—NAACCR-V10

**Date:** June 27, 2003      **Time:** 2:00 p.m. - 3:00 p.m.

**Dial In Number:** (877) 322-9654 (Toll Free)

**Participant Code:** 715431

**Topic:** Coding Complex Morphologic Diagnoses

Presented by: April Fritz, RHIT, CTR

**Date:** July 9, 2003      **Time:** 2:00 p.m. - 4:00 p.m.

**Dial In Number:** (800) 486-2726 (Toll Free)

**Participant Code:** 182834

## ADVANCED CANCER REGISTRY TRAINING PROGRAM

**Dates:** July 16-18, 2003 and November 5-7, 2003

**Location:** Emory University, Atlanta, GA

**Website:** <http://cancer.sph.emory.edu>

**Contact:** Steven Roffers, PA, CTR at (404) 727-4535

## FCDS ANNUAL MEETING

**Date:** July 30<sup>th</sup> 2003

**Location:** Belleview Biltmore Resort & Spa, Clearwater, FL

**Registration Fee:** \$25.00

**Contact:** Betty Fernandez/Bleu Heard (305) 243-4600

**Website:** <http://fcds.med.miami.edu>

## FCRA ANNUAL MEETING

**Dates:** July 31 – August 1, 2003

**Location:** Belleview Biltmore Resort & Spa, Clearwater, FL

**Registration Fee:** \$100.00 (Members)

**Contact:** Denise Colburn (727) 518-2522

**Website:** <http://www.fcra.org>

## CTR EXAM DATES AND DEADLINES

**Application Deadline:** August 1, 2003

**Examination Date:** September 13, 2003

**Application Fees:** \$200.00 NCRA Members  
\$275.00 All other candidates

**NCRA website:** <http://www.ncra-usa.org>

## CDC'S 2003 CANCER CONFERENCE

*Comprehensive Approaches to Cancer Control:  
The Public Health Role*

**Dates:** September 15 – 18, 2003

**Location:** Marriott Marquis Hotel, Atlanta, GA

**Website:** <http://www.cdc.gov/cancer>



Brochures for the Florida Cancer Data System Annual meeting were mailed in March, 2003. If you have not received your copy please log on to the FCDS website <http://fcds.med.miami.edu> click on "What's New", and click on [FCDS 2003 Annual Meeting Brochure](#) to download a copy. See you there!



**FCDS Incidence Abstracting Workshop**  
**Dates:** October 29 – 31, 2003  
**Location:** DoubleTree Hotel  
Coconut Grove, FL  
**Reg. Fee:** \$100.00  
**Contact:** (305) 243-4600  
Betty Fernandez/Bleu Heard



## Revisions to FCDS Data Set - NAACCR Version 10 (Effective July 1, 2003)



In accordance with national standards, FCDS will begin collecting cancer data in NAACCR version 10 format. The date for this conversion is July 1, 2003. The new variables in the version 10 format are mandated for all cases diagnosed 1/1/2003 and greater. Therefore, no cases diagnosed in 2003 will be accepted prior to July 1, 2003 and any 2002 cases received after the June 30, 2003 deadline must contain the new variables and be in the version 10 format.

FCDS will host a teleconference on June 27, 2003 to discuss the new/revised variables. A PowerPoint presentation will soon be available at the FCDS website. The teleconference information is as follows:

**Date of Conference:** June 27, 2003  
**Time of Conference:** 2pm – 3pm EST  
**Name of Conference:** Revisions to FCDS Data Set – NAACCR-V10  
**Dial In Number:** 877-322-9654 (toll free)  
**Participant Code:** 715431

In order to convert the FCDS database from version 9 to version 10, you will not be able to access the FCDS IDEA on the web site between July 1, 2003 and July 15, 2003. No single entry abstracting or batch uploads can take place during that time.

As with previous conversions, no vendor submitted data may be uploaded until your field coordinator has reviewed and approved the version 10 layout. In order to obtain approval, please upload 10 abstracts as you normally do on or after July 15<sup>th</sup> and submit a paper copy of these 10 abstracts to your field coordinator (mail or fax). The paper copies must be printed from your computerized system. **DO NOT COMPLETE AN FCDS PAPER ABSTRACT, SIMPLY PRINT THE ABSTRACT FROM YOUR SYSTEM.** If the data are acceptable, your field coordinator will approve your future submissions, beginning with the 10 abstracts your approval was based upon.

The minimum data set FCDS will require is on the FCDS web site under “What’s New”. One paper copy of the 2003 FCDS Data Acquisition Manual will be sent to each facility by August, 2003. Copies of the DAM may be downloaded from the FCDS website by July 1<sup>st</sup>, 2003.

FCDS will continue to collect all the variables that are currently being collected. However, the NAACCR Version 10 format consists of changes in the coding of several data items, the addition of new data items, changes in the definitions of surgery data items, and a change in the electronic record layout. The following is an overview of the changes:

**CODING CHANGES FOR THE FOLLOWING FIELDS:**

<b>Abstracted By</b>	<b>Primary Payer at DX</b>	<b>Rx Summ – Chemo</b>
<b>Rx Summ- Hormone</b>	<b>Rx Summ – BRM/Immunotherapy</b>	

**ABSTRACTED BY**

Effective July 1, 2003 ‘abstractor initials’ will no longer be accepted on electronic abstract or abstract forms. All abstracts must have an approved ‘**Cancer Abstractor Code**’ in this field. The abstractor code will be part of the edit process, therefore, if a code is incorrect, the abstracts (or batch) will be returned unprocessed. This code may not be shared with other abstractors. Each abstractor that submits work to FCDS must have their own unique abstractor code.

Cancer Abstractor Code Request form must be completed and returned to your Field Coordinator. Once you receive your code you may begin using it. **However, on and after July 1, 2003, no records will be accepted with an incorrect abstractor code.**

**PRIMARY PAYER AT DX**

01 Not Insured	51 Medicare with supplement
02 Not insured, self pay	52 Medicare with Medicaid supplement
10 Insurance, NOS	53 TRICARE
20 Managed Care, HMO, PPO	54 Military
31 Medicaid	55 Veterans Affairs
35 Medicaid administered through a Managed Care plan	56 Indian/Public Health Service
36 Medicaid with Medicare supplement	99 Insurance status unknown
50 Medicare	

**Rx SUMM- CHEMO**

- 00 None, chemotherapy was not part of the first course of therapy; not customary therapy for this cancer
- 01 Chemotherapy, NOS
- 02 Chemotherapy, single agent
- 03 Chemotherapy, multiple agents (combination regimen)
- 82 Chemotherapy was not recommended/administered because it was contraindicated due to patient risk factors (comorbid conditions, advanced age, etc).
- 85 Chemotherapy was not administered because the patient died prior to planned or recommended therapy.
- 86 Chemotherapy was not administered; it was recommended by the patient's physician, but was not administered as part of first-course therapy. No reason was noted in the patient record
- 87 Chemotherapy was not administered; the patient's physician recommended it, but this treatment was refused by the patient, the patient's family member, or patient's guardian. The refusal was noted in the patient record
- 88 Chemotherapy was recommended, but it is unknown if it was administered
- 99 Unknown if chemotherapy was recommended or administered; death certificate- only cases

**Rx SUMM- HORMONE**

- 00 None, hormone therapy (including NOS and antihormones) was not part of the first course of therapy; not customary therapy for this cancer\*
- 01 Hormone therapy\*
- 82 Hormone therapy was not recommended/administered because it was contraindicated due to patient risk factors (comorbid conditions, advanced age, etc.)
- 85 Hormone was not administered because the patient died prior to planned or recommended therapy.
- 86 Hormone was not administered; it was recommended by the patient's physician, but was not administered as part of first-course therapy. No reason was noted in the patient record
- 87 Patient, the patient's family member, or the patient's guardian refused hormone therapy as part of first-course therapy. The refusal was noted in the patient record\*
- 88 Hormonal therapy recommended, but it is unknown if it was administered
- 99 Unknown if hormonal therapy was recommended or administered; death certificate-only cases

**Rx SUMM- BRM/IMMUNOTHERAPY**

- 00 None, Immunotherapy was not part of the first course of therapy; not customary therapy for this cancer
- 01 Immunotherapy
- 82 Immunotherapy was not recommended/administered because it was contraindicated due to patient risk factors (comorbid conditions, advanced age, etc.)
- 85 Immunotherapy was not administered because the patient died prior to planned or recommended therapy.
- 86 Immunotherapy was not administered; it was recommended by the patient's physician, but was not administered as part of first-course therapy. No reason was noted in the patient record
- 87 Immunotherapy was not administered; the patient's physician recommended it, but the patient, the patient's family member, or the patient's guardian refused this treatment. The refusal was noted in the patient record.
- 88 Immunotherapy was recommended, but it is unknown if it was administered
- 99 It is unknown if Immunotherapy was recommended or administered; death certificate-only cases.

**NEW DATA FIELDS:**

<b>Telephone Current</b>	<b>Rx Summ - Transplnt/Endocr</b>	<b>Rx Date - Transplnt/Endocr</b>
<b>Rx Summ – Surg Site 98-02</b>	<b>Rx Summ – Surg Oth/Dis 98-02</b>	<b>Rx Summ – Scope Reg LN Sur 98-02</b>

**CHANGES IN THE DEFINITIONS OF SURGERY DATA ITEMS**

**For Case Diagnosed on or after January 1, 2003, the following data items will apply:**

- Rx Summ – Surg Prim Site (*site-specific*)
- Rx Summ – Scope Reg LN Sur (*non site-specific*)
- Rx Summ – Sur Oth/Dis (*non site-specific*)

**For Case Diagnosed before January 1, 2003, the following data items will apply:**

- Rx Summ – Surg Site 98-02 (*site-specific*)
- Rx Summ – Surg Oth/Dis 98-02 (*site-specific*)
- Rx Summ – Scope Reg LN Sur 98-02 (*site-specific*)Rx Summ – Reg LN Examined/Removed (*site-specific, will not be required for cases diagnosed on or after January 1, 2003*)



Congratulations to  
the March, 2003  
CTR Recipients for  
the State of Florida:



Dana C. Antone  
Komal D. Balaney  
Julio C. Burunat  
Sharon B. Eley  
Karen M. Elia  
Beatriz Hallo  
Marylou Mason



### Register

A joint project of the Sylvester Comprehensive Cancer and Center and the Florida Department of Health

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### Completeness Report

As of May 31, 2003

Calendar Year 2002 Admissions  
84% Complete — 92% Expected



667369

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PO Box 016960 (D4-11)  
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