Florida Cancer Data System

FLORIDA DEPARTMENT OF HEALTH

REGISTER

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

UMSylvester Comprehensive Cancer Center

University of Miami School of Medicine

Division of Cancer Prevention and Control

Volume VIII, 2000

Ambulatory Surgery Center & Radiation Therapy Center Update

Let me begin by welcoming the freestanding Ambulatory Surgical Centers and Radiation Therapy Facilities to the FCDS. I would also like to thank the administration and staff of the freestanding facilities for their efforts in making this a smooth implementation. Your data are a very important component of the Statewide Cancer Registry. In general, we are very pleased with the level of support and cooperation we have experienced with the freestanding facilities. The data began arriving on schedule. FCDS dedicated staff to coordinate the data gathering activities and address the needs of the freestanding facilities. It appears this has worked well.

The reporting deadline is June 30, 2000 which is after the deadline for this article. Unfortunately, I will not have any data to present here, but in the coming months we will update the 1997 and 1998 files to include the data obtained from the freestanding facilities. We expect the impact on some cancer sites to be significant. As the management of cancer has changed over the years to more and more outpatient settings, the impact of these changes can be seen in population based cancer data. I believe we will find that an accurate and complete population based registry will be impossible without the reporting from freestanding facilities.

The Agency for Health Care Administration (AHCA) has been very cooperative with FCDS. We expect to receive the 1999 and subsequent ambulatory data sets on an annual schedule. Just as we did this year, these data will clear against the FCDS master file and only those cases not reported to FCDS by other sources will be followed back to the freestanding facility for abstracting. Based on national trends, we expect the data from Florida's freestanding facilities to contribute greatly to the Florida Cancer Data System.

Again, thank you for your support and cooperation. I look forward to a long, professional relationship with you.

Jill A. MacKinnon, CTR
Administrative Director

Clarification of Carcinoma in Situ of the Cervix

Per April Fritz at the National Cancer Institute - Surveillance, Epidemiology, and End Results Registry (SEER), according to SEER rules, all in situ carcinomas of the cervix are non-reportable, including adeno- and squamous carcinoma.

In this Issue

Stat's Corner by Lydia Voti, MS
In collaboration with Joy Houlahan, CTR and Steve Peace, CTR

SPECIAL QC PROJECTS: CHILDHOOD CANCER

FCDS and the Florida Association of Pediatric Tumor Programs (FAPTP) have a long-standing relationship dating back to 1985. FCDS has been using FAPTP as a casefinding mechanism for a number of years. However, for the past 2 years, FCDS took the initiative of expanding the scope of this cooperation and has added new quality control components to the projects' scope.

In December 1999, FCDS was awarded a CDC grant devoted solely to special pediatric cancer projects. Under the auspices of the proposed activities, the FCDS database was matched with the FAPTP database, in order to ascertain and improve -if found necessary- the completeness and the quality of the pediatric cancer data collected**.** The objectives of this project went above and beyond fulfilling the former goals of the FCDS/FAPTP partnering agreement. Specifically, the objectives of this study were to:

1. Assess the completeness of the FCDS data base and enhance it if found incomplete
2. Assess the completeness of the FAPTP data base and provide FAPTP with information on the missed cancer records
3. Cross-reference the collected cancer information and quantify the two registries' agreement level.
4. Follow back the discrepancies found to the reporting facilities in order to obtain the most accurate information (reconciliation) for these cases
5. Provide FAPTP with feedback on the results of the cross-validation.

FAPTP- FCDS Database Linkage

Methods

The file received from FAPTP contained 1,010 records covering the diagnosis years 1996 and 1997. The fields included in the file were the following: FAPTP identification number; Last name; First name; Medical record number; Date of birth; Date of diagnosis; Date the patient was seen; Receipt date; Institution number; Primary site; Morphology; Sex; County of residence; State/Country of residence; Zip code of residence; Race; Ethnicity; Birth place; Children's Medical Services (CMS) sponsor; Pediatric Oncology Group (POG) protocol; Zip code of diagnosis; County of diagnosis. *The FAPTP data file did not contain social security number.*

The two databases were originally linked at the patient level and then at the tumor level.

At the patient level, the following fields were used to link the two databases: First name; Last name; Sex; County of residence; Year of birth; Month of birth and Day of birth. This part of the procedure was done using commercial software (Automatch) that performs probabilistic linkage.

At the tumor level, the Primary Site, the Morphology and the date of Diagnosis were used to assess if a tumor diagnosed for a patient that existed in both databases was the same. This procedure was done manually by the FCDS quality control staff.

Results

For comparative purposes, we are presenting the results from the previous linkage (1995) to the one performed on the 1996-1997 data.

Diagnosis year	Linked FAPTP cases	Unlinked FAPTP cases	Total
1995	405 (86%)	65 (14%)	470 (100%)
1996-1997	834 (83%)	170 (17%)	1010 (100%)

Initially, 834 FAPTP records matched with FCDS records. (Six of the FAPTP cases were duplicates themselves, i.e. a patient was listed more than once in the FAPTP file).

In turn, the **834 patients** were compared at the tumor level, to ensure that the referent tumors were the same. Only 2 new tumors (not previously identified by FCDS) were found with this exercise from the 834 patients that existed in both databases. For the rest of the cases, the tumors appeared to be the same, although there were often differences in the coding of the site and the morphology. All discrepancies found were followed back to the facilities to determine whether the FAPTP record or the FCDS record was accurate.

We used this opportunity to quality control the FCDS records, so we also followed back to the facilities those FCDS records for which there was a disagreement in the coding of the same tumor among different reporting facilities. The facilities were contacted by phone and mail and were requested to submit the relevant information.

For the **170 possibly missed patients** an additional effort was made to link them manually to the FCDS database, especially those with incomplete demographic information. In turn they were examined visually to determine if their diagnosed tumors were reportable to FCDS. The residual unlinked cases that were reportable were followed back to the facilities.

Linked records - Comparison:
Several discrepancies were found between FAPTP and FCDS on the **834 linked records**. They fell into 2 major categories, Primary Site and Morphology and they were distributed as follows:

Differences between FCDS and FAPTP	No of Cases	%
Primary Site	96	11.5
Morphology	83	4.6

Visual review of the above differences showed that they occurred for the following reasons:

- For 4 FAPTP records the primary site was missing and for one record the morphology was blank.
- There was an extensive usage of ill defined sites in the FAPTP database (C76.*), a coding usually avoided when reporting to FCDS since it conveys very little information about the specific tumor.
- Astrocytomas were incorrectly coded as juvenile astrocytomas in the FAPTP database, as the term "juvenile" refers to the maturity of the tumor cells and not the age of the patient.
- Discrepancies in the coding of the primary site and morphology were observed for sarcomas and lymphomas: Sub-classifications of sarcoma and lymphoma were often incorrectly coded in the FAPTP data and/or tumor types were generalized without coding of sub-classifications in important tumor sub-groups. These sub-classifications are often extremely important in determining appropriate therapies and treatment regiments.
- Several neuroblastomas were assigned wrong primary sites and there were discrepancies in the morphology subclass (4th digit of morphology).
- The staff reporting to FAPTP tended to use less specific coding for brain tumors than the registrars reporting to FCDS.

Interestingly enough, the discrepancies often occurred on cases abstracted and reported to FCDS and FAPTP from the same facility and had the same diagnosis date. (It should be noted that the individuals responsible for reporting cases to FAPTP are not necessarily the same individuals responsible for reporting cases to FCDS. This may account for the majority of the discrepancies.) Initially these cases were reviewed visually and for the vast majority the information from the FCDS database was considered more accurate. However, we did not limit ourselves to the visual inspection. Instead all these discrepancies were followed back to the hospitals for verification/correction (12/10/99).

Note that for most of the 834 records common to FCDS and FAPTP, there were several records for the same patient and the same tumor in the FCDS database. For those cases, we adopted a "majority rule" to determine if the case needed to be followed back to the facility in order to determine which coding was more accurate. That is, if 2 or more FCDS records agreed on the coding of the primary site and morphology but they did not agree with the FAPTP record, then we accepted the FCDS record as accurate and we did not follow back the case to the facility for verification.

Example:

Source	Facility	Diagnosis date	Primary Site	Morphology
FAPTP record :	XXXX	05/23/1996	71.0	9391 *
FCDS record :	XXXX	05/24/1996	71.0	9473
FCDS record :	YYYY	05/24/1996	71.0	9473

In the above example, the FCDS record was considered the most accurate, since 2 reporting facilities agreed on the morphology and disagreed with FAPTP. Cases of that type were not followed back to the facilities they originated from. Thus the number of cases that needed to be followed-back to the facilities was reduced to 90.

Our hypothesis is that this investigation will show that: Overall, the tumors abstracted for reporting to FCDS were coded more accurately and with more specificity, as there are differences in the training of the staff reporting to the two registries (CTRs versus non-CTRs) and/or differences in the source documents the information is obtained from (medical records versus physician's office records).

Unlinked records:
Of the **170 initially unmatched** cases, some were eventually found in the FCDS database. They were not successfully linked electronically due to the incomplete demographic information listed in the FAPTP file. One facility for example, only reports patient initials to FAPTP instead of the complete first and last name of the patient. In the absence of social security numbers and with only initials listed for the name, the electronic linkage was disabled. These cases were looked up manually and most of them were found in the FCDS database. The remaining of the unmatched cases were reviewed at the tumor level to determine if they were reportable to FCDS. After identifying those unmatched cases that on paper looked reportable to FCDS, only 69 of the 170 initially unmatched cases had to be followed back to the

Continued on page 4

Continued from page 3

facilities they were reported from. Upon return of the requested information on the 69 cases, we found that:

- 35 cases turned out to be non-reportable, according to the FCDS reportability criteria.
- 16 cases were previously reported to FCDS (the facility provided additional information that helped us in locating the cases in our database)
- 10 missed reportable cases were abstracted by the facilities and will be sent to FCDS.
- 8 cases seemed reportable on paper, but FCDS never received confirmation and/or an abstract from the facilities.

Although all facilities were requested to submit abstracts on the 18 potentially missed cases, unfortunately not all responded. So far, this exercise has contributed only 9 new records to the FCDS database.

Site Distribution for the 18 missed cases

Primary Site	No of Cases
Kaposi Sarcoma – Skin	1
Sarcoma – Skin	1
Leukemia- Bone Marrow	5
Glioma- Brain	2
Medulloblastoma- Brain	1
Neuroblastoma – Adrenals	1
Lymphoma – L/N	1
Teratoma – Ill defined site	1
Teratoma- Brain	1
Retinoblastoma – Eye	1
(Ki-1) Lymphoma – L/N	1
Bone – Ewings Sarcoma	1
Germinoma – Testicular	1

We contacted all the facilities that had missed more than 2 cases and reminded them that they need to send the cases to **both** registries, as this is a point of confusion very often. WHEN A FACILITY REPORTS A CASE TO FAPTP IT ALSO HAS TO REPORT IT TO FCDS AS LONG AS THE CASE SATISFIES THE FCDS REPORTABILITY CRITERIA. Summarizing the results, the maximum number of truly missed cases by FCDS did not exceed the 2.1% of the cases reported to FAPTP. Thus, for 1996 and 1997, FCDS is at least 97.9% complete in the pediatric cancers if FAPTP is used as the benchmark.

The final yield of this exercise is described in the table below:

Diagnosis year	Matched FAPTP cases	Maximum # of Potentially Missed cases by FCDS	Cases Non-reportable or found in the FCDS database	Total
1995	405 (86%)	18 (4%)	47 (10%)	470 (100%)
1996-1997	834 (82.5%)	18 (1.2%)	152 (15.1%)	1010 (100%)

Conversely, 1,882 (unduplicated) pediatric cancers were diagnosed and reported to FCDS in 1996 and 1997. These cases correspond to 1,427 children. Of them, 828 patients were found in the FAPTP data file. Therefore, 174 patients (14%) are potentially missing by the FAPTP database. This corresponds to at least the same number of tumors. A list of all these patients will be sent to FAPTP for possible inclusion in their database and/or for their internal QC purposes.

The purposes of the two registries are very different. FAPTP's primary goal is to identify new pediatric cancers for a select group of hospitals with the intent to enroll children in cancer protocols and to monitor the clinical care they are receiving. FCDS' primary goal is the complete and accurate registration of all newly diagnosed cancers in Florida (population-based cancer case reporting) and to monitor trends in cancer incidence statewide. One program focuses on pediatric cancer care and the other provides epidemiological information for all diagnosed tumors. Consequently, the data collection procedures followed by the two registries and the quality assurance mechanisms they have in place are very different and geared towards their respective missions. Despite these differences, there is room for beneficial collaboration between FAPTP and FCDS. Projects like this CDC-financed one help both registries assess and enhance the completeness of their databases and improve the quality of the collected information. They can also identify deficiencies that if fixed can assist both registries in fulfilling their respective goals better. Of tremendous value in the conduct of these studies is the collaboration of the CTRs across the state whose patience and diligence was detrimental on this study's success. We would like to thank all of you who contributed to this study!☙

Florida Cancer Data System
2000 Annual Meeting
Melbourne Beach, Florida
August 14th and 15th
Information and Registration

The Florida Cancer Data System invites you to participate in the Annual Meeting of the Statewide Central Cancer Registry. The meeting will be held two days prior to the FTRA Annual Meeting at the **Melbourne Beach Hilton Oceanfront – 3003 N. Highway A1A – Indialantic, Florida – Phone (321) 777-5000**. Special room rates of $89.00 (single/double) have been secured for the FCDS meeting. **The special room rates have been reserved until July 21, 2000**. Please make your hotel reservations directly with the Melbourne Beach Hilton.

Who Should Attend?

The **Florida Cancer Data System** invites all **data gathering professionals and administrators** at hospitals, ambulatory surgical centers, freestanding radiation facilities and pathology laboratories to our two-day annual meeting. General topics directed at data gathering professionals and facilities administrators and additional subject specific breakout sessions will be presented. The meeting has been designed to provide all participants, regardless of their level of experience, with multiple hands on working sessions.

The meeting will begin with registration and continental breakfast each morning at 7:30 a.m. and run from 8:30 a.m. until 5:00 p.m. on both days. *A "THANK YOU" reception is planned after the meeting on Tuesday at 6:00 p.m.*.

Registration Form

Registration fee: $25 You may register for the FCDS meeting by completing the registration form below and returning it to FCDS with your registration fee by July 30, 2000. For additional information please call Bleu Herard at (305) 243-4600

Please Complete and Return by July 30, 2000 to:
Florida Cancer Data System, University of Miami School of Medicine, P.O. Box 016960 (D4-11), Miami, Florida 33101

FCDS Annual Meeting August 14 and 15, 2000
Melbourne Beach Hilton Oceanfront
3003 N. Highway A1A
Phone (321) 777-5000

Name: _____ **Title:** _____

Organization: _____ **Phone: (____)** _____

Address: _____ **Fax: (____)** _____

_____

Additional topics I would like to have included: _____

Calendar of Events

Principles of Oncology for Cancer Registry Professional
(5 day training program)
Date: July 24-28, 2000 and December 4-8, 2000
Place: Bolger Center for Leadership Development; Potomac, MD
Contact: NCI at 301-496-8510
April Fritz, ART, CTR at 301-402-1625

♦ ♦ ♦

CTR Exam Dates
Application Deadline: August 1, 2000
Examination Date: September 16, 2000
Visit: www.nbcr.org

♦ ♦ ♦

Principles and Practice of Cancer Registration, Surveillance, and Control
Date: August 14-18, 2000 and Nov 6-10, 2000
Place: Emory University
Atlanta, Georgia
Contact: Steven Roffers, PA, CTR at 404-727-4535

♦ ♦ ♦

Florida Cancer Data System Annual Meeting
Date: August 14-15, 2000
Place: Melbourne Beach Hilton Oceanfront
Indialantic, Florida
Contact: Bleu Herard at 305-243-4600

♦ ♦ ♦

Florida Cancer Registrars Association Annual Meeting
Date: August 16-18, 2000
Place: Melbourne Beach Hilton Oceanfront
Indialantic, Florida
Contact: Lynn McGill at 321-799-7125

♦ ♦ ♦

Annual Town Hall Meeting
Date: September 29, 2000
Place: Jackson Memorial Hospital, Miami, FL
Contact: Alice Moody, CTR at (305)585-6038
CEU's will be applied for from: NCRA, AHIMA & Assoc. of Nurses

Jean Byers Memorial Award for Excellence In Cancer Registration

2000 Criteria

- ***Affidavit of Completeness Signed and Returned before July 31, 2000***
- ***Jean Byers Award Application Form Signed and Returned before July 31, 2000***

Awards are based on three general criteria:

- *Timeliness*
- *Completeness*
- *Quality*

Timeliness - All deadlines are met

Any FCDS Deadline: July 1, 1999 thru June 30, 2000

- ✓ *1997 Death Certificate Notification Deadline - August 31, 1999*
- ✓ *1997 AHCA In-Patient Follow-Back Deadline - November 30, 1999*
- ✓ *1998 AHCA In-Patient Follow-Back Deadline - May 15, 2000*
- ✓ *1999 Reporting Year - Annual Reporting Deadline - June 30, 2000*

Completeness – All cases are reported to FCDS

- ✓ *Annual Deadline - No More than 5% (or 35 cases whichever is greater) missed cases (No More than 5% of cases reported after deadline)*
- ✓ *AHCA In-Patient Missed Cases Findings – No More than 5% missed cases*

Quality – All data submitted are of high quality

- ✓ *Average Edit Failure Percentage – Fewer than 15% Cases Fail Edits*
- ✓ *Every 50th Case Review Findings – Cases Meet Quality Standards for Documentation*

FCDS/DOH STAFF UPDATE

FAREWELLS: ☹

Join us in wishing **Brad Wohler-Torres & Steve Schmidt** a fond farewell and best wishes in their new roles. Brad tranfered within the University of Miami. Steve transfered to another position within the Department of Health.

WELCOME ABOARD! ☺

Join us in welcoming **Anne Mulbach**. She has filled Steve Schmidts' position as Operations & Management Consultant at the State of Florida Department of Health.
Join us in welcoming the following staff at FCDS: **Raidel Oviedo,** Field Coordinator/Quality Control. He will be working closely with Lydia Voti and Joy Houlahan. **Anne Auguste**, **Kelly Friesmuth**, and **Beatriz Hallo**, Field Assitants, in the Hospital/Non-Hospital areas. They will be working closely with the Field Coordinators.

Application Form
for
Jean Byers Memorial Award For Excellence
In Cancer Registration
2000

This form serves as an application for consideration of receipt for the **2000 Jean Byers Memorial Award for Excellence in Cancer Registration**. Award applicants will be evaluated on a variety of factors, which collectively indicate excellence in cancer registration, including Timeliness, Completeness and Data Quality. Please see attached for the complete 2000 Jean Byers Award criteria. No award will be granted without an application. Application does not guarantee receipt of an award. Application Deadline is July 31, 2000.

Casefinding Sources *	**Yes**	**No**	**N/A**	**If No or N/A please explain**
Medical Record Disease Index				
Pathology Reports				
Radiation Therapy Department				
Outpatient Departments				
** As outlined in the FCDS DAM – Section I*				

I hereby apply for the Jean Byers Memorial Award for Excellence in Cancer Registration. I attest that I am the responsible party for the cancer registry and the above is an accurate representation of 1999 cancer casefinding and reporting as of June 30, 2000.

Facility Name:_____

Name of Medical Facility as you would like it engraved:_____

Signature:_____Date: _____

Printed Name:_____

Title: _____

Has your facility ever received a Jean Byers Award? (needed to determine whether or not you will receive a new award plaque or a new brass plate for your existing plaque)

____Yes ____No

Application Deadline is July 31, 2000.
Please mail to:

Florida Cancer Data System
University of Miami School of Medicine
P.O. Box 016960 (D4-11)
Miami, Florida 33101

Reporting Program Clarification for Freestanding Healthcare Facilities

Since beginning the new Ambulatory Care Centers Reporting Program early this year FCDS has received numerous requests for clarification regarding the reporting requirements, policies and procedures for reporting cancer cases seen in freestanding healthcare facilities. These requests have increased over the past month as new FCDS staff have been contacting the ambulatory care centers asking about the status of their 1997 and 1998 case reporting and confirming contact information for the FCDS mailfile.

FCDS does understand that there are many, many different reporting arrangements being made between ambulatory care centers, hospital systems, individual hospitals, hospital registrars and contract abstractors and that these arrangements are subject to change. So many, in fact that it is difficult for FCDS to keep track of them.

Please note that FCDS has no official information from the State regarding facility affiliations. Therefore, FCDS is making every attempt to keep track of the various arrangements as you present them to us. We do understand that in many cases hospital registrars or contract abstractors are performing the abstracting duties for these facilities. We also understand that in some cases ambulatory center cases are being reported along with hospital cases making the lines of distinction between reporting facilities even less clear.

Please bear with us while we incorporate the new Ambulatory Care Centers Program into the day-to-day FCDS activities. The first year of any new program is challenging to say the least. FCDS is always open to suggestions and comments. Please do not hesitate to contact us if you would like to discuss any issues regarding the Ambulatory Care Centers Reporting Program.
Thanks.

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

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COMPLETENESS REPORT

As of June 1, 2000 only 74% of the 1999 cases are in the FCDS database, 92% of 1999 cases should be in the FCDS database. **All 1999 cases are due June 30, 2000.**

FCDS Florida Cancer Data System
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FLORIDA DEPARTMENT OF HEALTH

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