FCDS hosted its 7th Annual Conference at the Melbourne Beach Hilton Oceanfront on August 14-15, 2000. This year’s meeting was once again held in conjunction with the Florida Cancer Registrar’s Association Annual Conference, which took place August 16-18, 2000. The hotel was great! The food was great! The beach was great! We were all very happy with the attendance at both conferences. These two important conferences seem to compliment each other more and more each year. Thanks to all who attended and special thanks to our program planners and administrative support staff, our speakers and moderators and our afternoon working session team. Congratulations to all on a job well done!

The Florida Cancer Data System (FCDS) Annual Conference is intended to provide professional registrars, contractors, vendors, and other healthcare provider representatives with timely information regarding Florida’s statewide cancer surveillance program. One focal objective of the FCDS Annual Conference is to assess program performance during the previous 12 months. Program achievements are reviewed and emphasis is placed on the many ways FCDS data are used. FCDS staff feel that among the more significant elements of the conference are inclusion of educational and informational sessions. Providing the most current information to registrars and healthcare professionals is an essential objective of the conference, as participation of these professionals in Florida’s cancer surveillance and control efforts is essential to the program’s success.

Of course, FCDS staff could not miss the opportunity to review a number of policies and procedures. The objective being to remind participants of the ever-present need for conformity and compliance in order for the program to generate a quality output. In addition, a hands-on training session was provided to emphasize abstracting techniques and enhance the skills of those participants responsible for abstracting and submitting cancer-related data to FCDS.

Overall, the two-day conference was quite rigorous, as evidenced by the participants’ dazed expressions at the conclusion of day two.

Continued on page 2
This is the fourth year that we have been fortunate enough to honor outstanding registrars and registries with the Jean Byers Memorial Award for Excellence in Cancer Registration. Over 60 registries were honored as award recipients this year. Next year FCDS is hoping to expand the Jean Byers Award by adding personal Certificates of Excellence. The proposed Certificates of Excellence will be awarded to individual registrars in order to recognize personal commitments to excellence in cancer registration. Specific details regarding both awards will be made available early next year.

The facilities which appear with an (*) next to the facility number met all of the Jean Byers Award Criteria except for submission of the application form. This year we are making an exception and giving each facility that met all of the award criteria except for submission of the application form an award. CONGRATULATIONS and THANK YOU for your commitment to excellence!!!

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<td>7446</td>
<td>Volusia Medical Center/Fish Memorial</td>
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<td>7447</td>
<td>Memorial Hospital Ormond Beach</td>
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* Awarded in the 2000 supplemental applicant review process

*1610 Memorial Hospital Pembroke
*1647 Cleveland Clinic Hospital
*1676 Plantation General Hospital
*1688 Memorial Hospital West
*1905 Citrus Memorial Hospital
*2359 Miami Children’s Hospital
*3701 Oak Hill Hospital
*3715 Spring Hill Regional Hospital
*3977 Memorial Hospital Tampa
*3978 Town & Country Hospital
*4206 Jackson Hospital
*4605 Lee Memorial Hospital
*5406 Lower Florida Keys Health Systems
*6007 Glades General Hospital
*6172 Bayonette Point Medical Center
*6707 Santa Rosa Medical Center
*6870 Doctors Hospital
The following is a brief overview of topics and information presented during this year’s FCDS Annual Conference.

On the first day, a broad overview of cancer surveillance and control efforts in Florida was provided. The conference agenda included presentations from a number of professional organizations; an attempt was made to provide an idea of the level of interaction between FCDS and these organizations. Among them were: The National Cancer Institute’s (NCI) Cancer Information Services (CIS), the Florida Cancer Control & Research Advisory Board (CCRAB), The Florida Comprehensive Cancer Control Initiative (which is a part of the new CDC National Comprehensive Cancer Control Program), The Florida Breast Cancer Early Detection Program (EDP), CDC’s National Program of Cancer Registries (NPCR), and the NCI’s Surveillance Epidemiology and End Results program (SEER).

The afternoon included FCDS data-driven presentations on Colorectal Cancer and Hispanic Liver Cancer and a Quality Control Update. See details below.

Dr. Lora Fleming gave two presentations on Day 1. The first was a review of findings from the Florida Breast Cancer Early Detection Program. The second was a study of Liver Cancer in South Florida Hispanics. Both of these informative talks provided the audience with a glimpse of how FCDS data (your data) is used collectively to study how cancer surveillance programs and cancer control programs work together. By joining forces both programs and patients benefit. The public is better informed about cancer, health professionals can identify anomalies in the occurrences of cancers among certain racial and ethnic populations and intervention programs can be better targeted towards high-risk populations to hopefully improve patient outcomes.

JoBeth Speyer, Director of the CIS which services Florida, Puerto Rico and the Spanish-speaking Eastern United States, presented an overview of the CIS. Information included how the CIS and FCDS work together to provide patients, physicians and family members with information specific to all types of cancer including: detection, diagnosis, staging and treatment options.

Jill MacKinnon provided a possible glimpse into the future of Florida cancer case reporting in the event that FCDS is awarded an National Cancer Institute contract to become a participant in the NCI’s SEER Program. This VERY informative session outlined potential strategies which FCDS has formally submitted to SEER in proposal form. If FCDS is awarded a contract with SEER you will be hearing a great deal more about SEER in the VERY near future. If you missed this session…you missed a lot !!!!!

Jill also outlined the new NPCR requirements for cancer reporting. The new requirements will be followed by every state in the country starting with 1/1/2001 patient encounters/admissions. There are lots of changes in the works… expect a new FCDS DAM, new education & training teleconferences and workshops and much, much more… Don’t Panic… DO STAY TUNED !

Steve Peace reviewed the DOH/FCDS Policies and Procedures regarding late reporting and showed the audience that over 14% of the 1998 cases reported to FCDS were submitted after the June 30, 1999 deadline.

FCDS used the 1998 reporting year so that we could include missed 1998 AHCA cases and 1998 Death Certificate Notification cases as well as identify the facilities and numbers of 1998 cases that were submitted after the deadline.

Lydia Voti presented a Quality Control Update and reviewed the methodology and findings for the QC activities undertaken over the past year.

The second day provided a variety of topics and included a 3 hour afternoon working session with plenty of ‘hands-on’ exercises.

Jill MacKinnon provided a thought-provoking look at Hispanic Prostate Cancer in the South Florida Hispanic Population. This interesting presentation showed a two year lag in rising incidence rates in the Florida Hispanic population. Reasons are still unclear for the two year lag behind Whites and African American populations, but numerous hypotheses have been entertained.

Joyce Allan gave us an update on activities, complaints, etc. that have Continued on page 4
been brought to her attention as the FCRA Liaison to FCDS.

Mayra Alvarez gave an update on the Ambulatory Centers Cancer Reporting Program which began 1/1/2000. Over 85% of the 1997 and 1998 cases have been reported to FCDS from these centers. Given that this is their first deadline, we are thrilled with the response.

Dr Lora Fleming presented a very interesting talk on Blue Green Algae and its effects on drinking water in Florida.

Steven Peace gave a presentation on the changing Ovarian Cancer scene as a result of changes in the classifications of papillary and mucinous tumors of the ovary over the past 5 years.

Dean Powell once again entertained the audience with his presentation “What did you Mean to download??!!”. Dean gave examples of the wide variety of packaging material used to ‘protect’ diskettes submitted to FCDS. He also gave examples of the number and types of non-cancer data files that are submitted to FCDS along with some facilities cancer cases.

Dan Thompson presented this year’s Jean Byers Award for Excellence in Cancer Registration to over 40 award recipients. Congratulations to Everyone!

The afternoon working session provided both didactic presentations and ‘hands-on’ exercises to further the abstracting and documentation skills of registrars. MANY THANKS to Mae Whitehead, Edith Alvin, Megsys Cuadra, Joy Houlahan, Ray Oviedo, Mayra Alvarez and Steve Peace for putting together an informative and timely afternoon.

FCDS hosted a ‘THANK YOU’ reception Tuesday evening and again, THANKS TO EVERYONE FOR A GREAT YEAR and FOR ALL OF YOUR HARD WORK!!

All-in-all, the conference was interesting, thought provoking, and full of information about the past, present and future of FCDS and state cancer reporting as they effect each and every one of us. FCDS hopes to see you next year for the 8th Annual FCDS Conference which will be held in Plantation, July 31 – August 1, 2001. The FCRA Annual Conference will be held immediately following on August 2 - 4, 2001, also in Plantation. Hope to see you there!

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**PARANEOPlastic NEurologic SYNDROMES**

Introduction:

Neoplasm can alter neurologic function in numerous ways, by direct invasion, metastatic invasion, and opportunistic infections in the course of neoplastic processes, complications of therapy and metabolic complications.

Concept:

Several neurologic syndromes have been delineated that are a consequence of a remotely located neoplasm but do not arise from direct involvement of the Nervous System by metastasis or any of the secondary complications cited above. These are the PARANEOPlastic NEurologic SYNDROMES.

Incidence:

Recent studies suggest lower than 7% of incidence, but it has been problematic because the syndromes are rare and classification vary among studies. Tumors that are more often associated with paraneoplastic neurologic syndromes are cancers of the lung (47%), stomach (12%), breast (12%), ovary (9%) and colon (6%).

Continued from page 3
Director’s Corner

By Jill MacKinnon

Comments received at our annual meeting combined with various e-mails and phone conversations about the Jean Byers Award prompted us to re-visit this year’s review and award process. On Wednesday, August 8, 2000, I met with selected FCDS staff to discuss the situation and to review the pre-award policies and procedures.

After a lengthy discussion we voted in favor of amending the award recipient list to include additional facilities. The additional facilities met all of the award requirements except one: they did not submit an award application.

The following is a summary of our discussion, which led to the vote:
The 2000 process was similar, but not identical to previous years. On July 6, 2000, the Affidavits of Completeness (Attachment 1) were mailed to all facilities with a review and submission deadline of July 31, 2000. The cover letter that accompanied the Affidavits of Completeness indicated the Jean Byers Award application would be ‘mailed out’ by July 15th. This statement was the heart of our decision.

The application and award criteria were indeed mailed to facilities, not as a separate piece of addressed correspondence but in our newsletter, Volume VIII, 2000 FCDS Register (mailed June 23, 2000). Additionally, the June 2000 FCDS Monthly Memo referred facilities to the Register and the FCDS Web site for the application.

In years past, the application was mailed in an addressed envelope. This is the only departure from previous practices.

Our decision to make an exception this year is based solely on what we have come to refer to as a ‘loophole’. We all left the meeting with conflicting feelings. First, we feel the correspondence was sufficient (evidenced by the fact that 40+ awards were handed out). However, we also feel the essence of Jean Byers Award is meant to reward facilities and registrars that do a good job. Should part of the process be the application? Is it right to withhold the award from facilities that did everything asked of them, but did not submit an award application in a timely fashion? Is that part of doing a ‘good job’? Also, what message are we sending to those 40+ facilities that did do a good job and complied with the process? We are quite adamant that we do not want to take anything away from them!

You will find a revised listing of the facilities that received the 2000 Jean Byers Award present in this copy of the Register. The list of supplemental awards includes only those facilities that submitted a complete Affidavit of Completeness and met all of the posted requirements and deadlines with the exception of submission of an award application, either in time (or at all).

We have already begun drafting a revised policy for next year (ironclad, clear, timely and unequivocal). There will be no separate application. Once the facility completes the Affidavit of Completeness there will be an additional line or two at the bottom in which they request the award and provide information about their facility.

Additionally, since the FCRA has moved their meeting to earlier in the Summer, we will not be making the Jean Byers award presentations at our annual meeting. This is both “good” and “bad” on several levels. First it will give us time (without rushing so much) to review the applications when they are submitted. Also, it will allow us time to see what additional records are being submitted by the facility after they attest their completeness (a situation that occurs quite often). The bad part of this is that we will make the presentation via the Register and not be able to recognize the recipients at our Annual Meeting.

Once again, we would like to CONGRATULATE ALL of the registrars and registries who received this year’s Jean Byers Award for Excellence in Cancer Registration.
**REMINDERS WHEN PROCESSING FORCES**

1) Please abstract cases so that ALL data presents an accurate reflection of what is documented in the medical record. Some records may fail FCDS edits but still give a true representation of the patient’s condition, treatment course, age, stage, etc. These cases will have to be “forced” into the FCDS database by overriding the FCDS edit. **DO NOT CHANGE YOUR DATA JUST SO IT WILL PASS FCDS EDITS.**

2) When a case fails an FCDS edit you need to verify that the data you submitted is correct. This does not mean that you just look in your computer and verify that the codes we received are the codes that you sent. You need to actually verify that the data you coded reflect the information gleaned from the case medical record. Again, you should never change your data just so it will pass FCDS edits.

Upon receipt of the FCDS Edit Check Discrepancy Journal you should:
1) review the edit that was failed, 2) review the medical record again in order to confirm that the case was abstracted accurately, and 3) review the abstracted data in order to verify that the data was coded correctly and that it accurately reflects the information in the medical record.

Following verification of record and abstract, you can then make changes to the abstracted case if necessary or you can make copies of medical record reports or other health record documents that support the data as originally submitted, so that they can be reviewed for edit override (force).

3) Documentation is required for any and every case needing to be ‘forced’ into the FCDS masterfile. Documentation **MUST** be copy(s) of medical record report(s) or other health record document(s) that confirm the coding of the data submitted as it relates to the edit that must be overridden (forced). Text documentation in the cancer abstract is not sufficient for any edit override (force).

The **ONLY** exception to the above policy involves cases requiring edit override for edit 0106 – Probable duplicate detected in master file – when the case involves bilateral organs (i.e., right and left breast cancers). Text documentation in the cancer abstract is sufficient for overriding edit 0106, only.

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**Breast Cancer Awareness**

*October Is Breast Cancer Awareness Month and the 3rd Friday in October each year is National Mammography Day, first proclaimed by President Clinton in 1993.*

*On this day, or throughout the month, radiologists provide discounted or free screening mammograms.*

*To learn more about the participating facilities in your area please call: the American Cancer Society at (800) 227-2345 or the National Cancer Institute at (800) 4-CANCER*
### Calendar of Events

**NAACCR 2000 E-Toolkit Workshop**
- **Date:** September 25 - 27, 2000
- **Place:** Double Tree Hotel Seattle, Washington
- **Contact:** Joellyn Hotes at 217-698-0800 ext.3
- **Website:** [www.naaccr.org/News/index.html](http://www.naaccr.org/News/index.html)

**Oncology Workshop**
- **Date:** October 13, 2000
- **Time:** 7:30 a.m. - 1:00 p.m.
- **Place:** Jackson Memorial Hospital Diagnostic Treatment Center Miami, Florida
- **Contact:** Lisette Acosta at 305-585-6533
- **CEU’s applied for**

**FCDS Incidence Training Workshop**
- **Date:** October 25 - 27, 2000
- **Place:** Holiday Inn - Coral Gables Miami, Florida
- **Contact:** Betty Fernandez or Bleu Herard at 305-243-4600
- **CEU’s awarded from AHIMA**

**Principles of Oncology for Cancer Registry Professionals**
- **Date:** December 4 - 8, 2000
- **Place:** Bolger Center For Leadership Development, Potomac, Maryland
- **Contact:** NCI 301-496-8510 or April Fritz, ART, CTR at 301-402-1625

**FCRA CTR Exam Review**
- **Date:** February 6 - 7, 2001
- **Place:** Mayo Clinic Jacksonville, Florida
- **Contact:** Mary O’Leary, RHIT, CTR at 305-243-4961

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**Pathologic Changes, Pathogenesis and Treatment:**

Two major pathologic changes occur, one is characterized by encephalomyelitis with perivascular lymphocytosis and inflammation in a second pathologic form severe degeneration or loss of neurons occurs without inflammation. In other paraneoplastic syndromes, the associated pathologic changes occur in the peripheral nervous system with demyelination, myonecrosis or ultrastructural changes.

Several mechanisms have been invoked to explain these disorders, including release by the tumor of neurotoxic substances, viral or retroviral infections of tumor, and/or neural tissues, and an autoimmune response directed against common antigenic determinants expressed by the tumor and the affected neural cells. Serum and CSF antibodies with specific patterns of reactivity with neural tissue or muscle are identified.

Treatment of the paraneoplastic neurologic syndromes is difficult and very often unsuccessful. Resection of the tumor is surprisingly ineffective. Immunosuppression is of little benefit; plasma exchange can ameliorate some symptoms. Otherwise therapy is largely symptomatic.

Following is a list of some Paraneoplastic Neurologic Syndromes:

1) Brain, cerebellum and spinal cord:
   - Visual Paraneoplastic Syndrome
   - Paraneoplastic Encephalomyelitis
   - Limbic Encephalitis

2) Peripheral Nerves:
   - Subacute Sensory Neuropathy
   - Acute Demyelinating Polyneuropathy
   - Sensorymotor Neuropathy

3) Neuromuscular Junction:
   - Lambert-Eaton Myasthenic Syndrome.

4) Muscle:
   - Polymyositis- Dermatomyositis
   - Necrotizing Myopathy.

Completeness Report

As of September 1, 2000 only 7% of the 2000 cases are in the FCDS database, 17% of 2000 cases should be in the FCDS database.

FCDS would like to extend an Invitation To All Healthcare Professionals interested in learning more about cancer surveillance and cancer case reporting in Florida...Please join the FCDS Training Staff October 25-27, 2000 at the Holiday Inn - Coral Gables, Miami, Florida and attend the FCDS Incidence Training Workshop. This intensive 2 ½ day workshop is designed to provide participants with tools, references and guidance necessary to become a successful abstractor. The cost is only $100, which covers materials and refreshments. Please contact either Betty Fernandez or Bleu Herard at FCDS for registration and travel information. 1-800-906-3034 or (305) 243-4600

Yet, Another Season Have Come and Gone...