

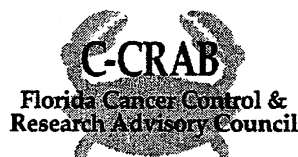
Florida Cancer Control and Research Advisory Council

1998 ANNUAL REPORT

Submitted to the Governor and Legislature
pursuant to Section 240.5121, Florida Statutes

February 15, 1999

W. Jarrard Goodwin, Jr. M.D., Chair
Dorothy F. Parker, M.H.S., Executive Director



C-CRAB Office:
H. Lee Moffitt Cancer Center & Research Institute
12902 Magnolia Dr., Tampa, FL 33612
(813) 632-1339

Cancer Control and Research Advisory Council (C-CRAB) Annual Report

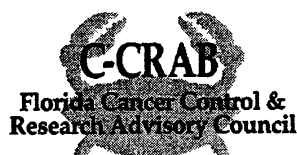
Executive Summary: Highlights from 1998

- ◆ In 1998, the C-CRAB statute was amended, adding a mandate to develop prostate cancer educational material, appropriating \$50,000 for breast cancer and \$50,000 for prostate cancer educational material, and adding three new organizational members to the Council (see Page 1 and Appendix 1).
- ◆ The Prostate Cancer Task Force was created (see Page 1 and Appendix 1).
- ◆ The C-CRAB Breast Cancer Technical Advisory Group worked on revising the treatment options pamphlet produced in 1996 (see Page 6 and Appendix 5).
- ◆ The *1998-1999 Florida Cancer Plan* was distributed (see Page 5).
- ◆ Governor Chiles issued a proclamation designating September 1998 as Prostate Cancer Awareness Month (see Appendix 4).
- ◆ Charles L. Gruder, Ph.D., Executive Director of the Special Research Programs Office at the University of California, addressed the Council at its June 11 meeting, presenting information on California's state-funded cancer programs and the role of advocates (see Page 4 and Appendix 3A).
- ◆ C-CRAB began planning for a public forum, to be held June 17, 1999. The purpose of the forum is to get input from the public and cancer advocacy groups on ways to improve cancer control and prevention programs in Florida (see Page 6 and Appendix 6).
- ◆ W. Jarrard Goodwin, M.D., Director of the Sylvester Comprehensive Cancer Center, was appointed Chair.
- ◆ Several C-CRAB members met with the Secretary of Health to discuss ways in which C-CRAB and the Department of Health could work together on cancer control programs (see Page 6).
- ◆ Three issues of the C-CRAB Newsletter were published (see Page 7).
- ◆ C-CRAB continues to work with other state cancer programs, such as the Florida Comprehensive Breast and Cervical Cancer Early Detection Program and the Florida Leadership Council for Tobacco Control (see Page 8).

For more information, please contact:

W. Jarrard Goodwin, Jr., M.D.
C-CRAB Chair

or Dorothy F. Parker, M.H.S.
C-CRAB Executive Director



Address: Cancer Control and Research Advisory Council
H. Lee Moffitt Cancer Center & Research Institute
12902 Magnolia Dr., Tampa, FL 33612
Phone: (813) 632-1339
E-mail: parkerdf@moffitt.usf.edu
Web page: <http://www/moffitt.usf.edu/ccrab>

Cancer Control and Research Advisory Council 1998 Annual Report

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SECTION 1: ADMINISTRATIVE UPDATE

1. APPROPRIATIONS AND CHANGES TO THE C-CRAB STATUTE

In 1998, the Legislature passed House Bill 1213, which became Chapter 98-305, Florida Laws (see **Appendix 1**). The bill accomplished four things:

- amended the C-CRAB statute (Section 240.5121), adding a mandate to produce educational material on prostate cancer
- appropriated to C-CRAB \$50,000 for breast cancer educational material and \$50,000 for prostate cancer educational material
- amended the C-CRAB statute adding three more organizations: the Cancer Information Service, Florida Agricultural and Mechanical University Institute of Public Health, and the Florida Society of Oncology Social Workers
- created the Prostate Cancer Task Force

2. MEMBERSHIP

Governor Chiles made the following appointments in 1998:

New Members:

Sandra Blank, a General Public Representative
Kari Barcome, M.S.W., representing the Florida Society of Oncology Social Workers
James Fiorica, M.D., representing the Florida Society of Clinical Oncology
James Lynch, M.D., representing the University of Florida Shands Cancer Center
JoBeth Speyer, representing the Cancer Information Service
Kurt Stonesifer, M.D., representing the Florida Society of Pathologists

Members Reappointed:

Kerry Chamberlain, D.O., representing the Florida Osteopathic Medical Association
Edward Trapido, Sc.D., representing the Sylvester Comprehensive Cancer Center

A complete list of current members can be found in **Appendix 2**.

3. OFFICERS AND BYLAWS

W. Jarrard Goodwin, M.D., Director of the Sylvester Comprehensive Cancer Center, was appointed by Governor Chiles as C-CRAB Chair. His term will be for 1998 and 1999.

There were no changes to the Council's bylaws.

4. MEETINGS

Two council meetings were held in 1998: June 11 and November 23. The Executive Committee had two conference calls, one on April 29 and one on August 26.

Highlights of June 11 Meeting: Charles Gruder, Ph.D., Executive Director of the Special Research Programs Office at the University of California, was invited to speak about California's state-funded cancer programs. He described how cancer advocates were instrumental in getting the California legislature to fund programs, and their ongoing role in making decisions about the use of the funds. He also explained the process of allocating money for projects to researchers throughout the state. His presentation was followed by a discussion on how to apply California's experience in Florida and how to involve cancer advocates.

The meeting also included discussions of the following topics: ways to improve the relationship between C-CRAB and the Department of Health; the C-CRAB breast cancer treatment options pamphlet; the Prostate Cancer Task Force and its role in helping C-CRAB develop prostate cancer education material; and the Department of Health's grant proposal for a comprehensive cancer control program. See **Appendix 3A** for meeting minutes.

Highlights of November 23 Meeting: Much of the meeting involved a discussion on revising the C-CRAB breast cancer pamphlet vs. using a similar brochure produced by the National Cancer Institute. The Council decided to revise the C-CRAB booklet.

Other issues that were discussed include: plans for a public forum in which cancer advocates, survivors, and other interested individuals and health care professionals could offer suggestions for ways to improve Florida's cancer control programs and to increase state funding; collaborating with the American College of Surgeons' efforts to promote cancer programs in Florida; and encouraging school districts to support efforts to reduce sun exposure among Florida's school children. See **Appendix 3B** for meeting minutes.

Executive Committee Conference Calls: The C-CRAB Executive Committee met via conference call on April 29 and August 26. The purpose of the April call was to plan for the June meeting. The August call focussed on plans for an advocacy meeting/public forum (see **Appendices 3C & 3D**).

SECTION 2: SUMMARY OF ACTIVITIES

1. FLORIDA CANCER PLAN

The *1998-1999 Florida Cancer Plan* was distributed in January 1998. Copies were sent to the following: the governor, state senators and representatives, cabinet members, staff at the Department of Health and the Agency for Health Care Administration, Area Health Education Centers, health planning councils, hospitals that report to the Florida Cancer Data System, Florida's federal congressional delegation, organizations represented on C-CRAB, members of the Florida Breast and Cervical Cancer Coalition and the Tobacco-Free Florida Coalition, and others. The Executive Summary was included in the 1997 C-CRAB Annual Report.

The *1998-1999 Florida Cancer Plan* is available on the Internet, and can be accessed from the C-CRAB web page (<http://www.moffitt.usf.edu/ccrab>).

2. PROSTATE CANCER

Educational Material and the Prostate Cancer Task Force: In 1997, the C-CRAB Prostate Cancer Technical Advisory Group (TAG) developed recommendations for increasing public awareness about prostate cancer. Some of the recommendations were addressed in the 1998 legislation, Chapter 98-305, Florida Laws (see page 1 and Appendix 1).

One of the TAG's recommendations that was accepted and funded was to develop educational material to increase awareness about prostate cancer. Since the Legislature created a Prostate Cancer Task Force (separate from C-CRAB), the Council decided to wait for the Task Force to develop recommendations as to what educational material is needed. However, there has been a delay in this process because, as of the publication of this report, not all appointments to the 18-member Task Force have been made. It is anticipated that the Task Force will convene by March 1999. In preparation for the Task Force, the C-CRAB Director has collected information on the issues that will be addressed:

- Insurance coverage for prostate cancer screening
- Ways to increase public awareness about prostate cancer
- Ways to coordinate services
- Ways to increase research and state funding

The \$50,000 appropriated to C-CRAB for the prostate cancer education material went to the Department of Health. Therefore, a contract between the H. Lee Moffitt Cancer Center and the Department was negotiated to enable C-CRAB to get the funds by June 30, 1999.

Prostate Cancer Awareness Month Proclamation: Governor Chiles issued a proclamation designating September 1998 as Prostate Cancer Awareness Month (**see Appendix 4**). C-CRAB staff provided background information for the proclamation, and the Council sent a letter to Governor Chiles endorsing it.

3. BREAST CANCER

Breast Cancer Treatment Options Pamphlet: An appropriation to C-CRAB of \$50,000 was approved for FY 1998-99 to revise and redistribute the breast cancer pamphlet. The C-CRAB Breast Cancer Technical Advisory Group (**see Appendix 5**) and staff worked on updating and revising the pamphlet that was produced in 1996. Since the \$50,000 appropriated for the pamphlet went to the Department of Health, a contract between the H. Lee Moffitt Cancer Center and the Department was negotiated to enable C-CRAB to get the funds by June 30, 1999.

After the text is revised and reviewed by breast cancer survivors, it will be printed and distributed to physicians and other health care providers, and will be made available upon demand until the supply is depleted. The text of the 1996 booklet is on the Internet, and can be accessed from the C-CRAB web page (<http://www.moffitt.usf.edu/ccrab>).

4. LEGISLATIVE ACTIVITIES

C-CRAB focused on two pieces of legislation in 1998:

- Breast and Prostate Cancer - House Bill 1213 and Senate Bill 94 (see page 1 and Appendix 3): C-CRAB provided background information to House and Senate committees.
- Clean Indoor Air revisions to remove the preemption clause giving more authority to local governments to regulate smoking in public places (House Bill 3379 and Senate Bill 148): Letters of support were sent to all senators and representatives.

5. PLANING FOR A PUBLIC FORUM

Based on the information presented by Dr. Larry Gruder at the June 11th meeting, C-CRAB decided that it would benefit from having public support to help promote efforts to expand Florida's cancer control programs and to seek state funding. As a first step, the Council decided to plan a forum to get input from the public, cancer advocacy groups, and health care professions to determine their priorities for cancer control programs. A public forum is planned for June 17, 1999 in Tampa, in conjunction with the next C-CRAB meeting (see **Appendix 6**). Plans are being developed to advertise and promote the forum. Depending on the results, plans will be made for further action.

6. THE DEPARTMENT OF HEALTH

Meeting with Dr. Howell: As a first step in helping C-CRAB work more closely with the Department of Health, a meeting was held on March 6, 1998, to explore ways in which the two can work together to address unmet cancer control needs in Florida. The meeting included the C-CRAB Chair (Dr. Goodwin), the past Chair (Dr. Ruckdeschel), C-CRAB Director (Dorothy Parker), the Secretary of Health (Dr. Howell), the Director of the Division of Disease Control (Dr. Crockett), and the Department's representative on C-CRAB (Dr. Hopkins). The discussion included several issues:

- How C-CRAB could serve in an advisory capacity if the Department gets federal funding to develop a comprehensive cancer control program.
- How C-CRAB could work with the Department in three priority areas -- epidemiology, environmental health, and health education.
- How C-CRAB could work with the Department on education and prevention programs resulting from the state's tobacco settlement.
- How the university-based C-CRAB members could help with cancer control research, particularly behavioral research.

The workshop discussion at the June 11 C-CRAB meeting provided an opportunity to expand on this discussion.

Communication with the New Administration: In late November, information about C-CRAB was sent to Governor Bush, and to the head of his health transition team, Dr. Susan MacManus. After the elections in November, the C-CRAB Chair, Dr. Goodwin, extended an offer to Governor Bush to assist with cancer-related issues that arise during his

administration. A similar offer will be extended to the new Secretary of Health, Dr. Robert Brooks.

7. COMMUNICATIONS AND PROMOTION

C-CRAB Newsletter: Three issues of the C-CRAB Newsletter were published in 1998: Winter, Spring and Fall. The newsletters are sent to the governor, senators and representatives, health care committee staff, and approximately 300 other individuals, agencies and organizations interested in cancer control. Copies of the newsletter can be viewed on the C-CRAB web page.

C-CRAB Web Page: The URL for the C-CRAB web page (see **Appendix 7**) is:
<http://www.moffitt.usf.edu/ccrab>

The main page includes a description of C-CRAB and its activities, with links to the following:

- a list of organizations represented on C-CRAB (with links to their respective home pages),
- the *1998-1999 Florida Cancer Plan*,
- the text of C-CRAB's the breast cancer pamphlet, *If You Have Breast Cancer. . . Information About Breast Cancer Treatment Options*.
- C-CRAB newsletters, and
- a description of the Prostate Cancer Task Force.

The site will continue to be developed and promoted during 1999.

Exhibit at Joint Cancer Conference: C-CRAB had an exhibit at the 2nd Annual Joint Cancer Conference of the Universities of Florida in February 1998. The exhibit included information about the Council, highlights from the *1998-1999 Florida Cancer Plan*, and information on cancer-related laws in Florida.

8. OTHER STATE CANCER PROGRAMS

Breast and Cervical Cancer Early Detection Program: C-CRAB continues to follow the progress of the Florida Comprehensive Breast and Cervical Cancer Early Detection Program (BCCEDP). The program is funded by the federal Centers for Disease Control and Prevention, and is administered by the Florida Department of Health's Family Services Department. It provides screening and diagnostic services to uninsured women in selected Florida counties, and includes outreach and educational programs. BCCEDP staff attend C-CRAB meetings, and several C-CRAB members are members of the BCCEDP's advisory group, the Florida Breast and Cervical Cancer Coalition. The C-CRAB Executive Director serves as Chair of the Coalition's Steering Committee.

A Legislative Budget Request for funding to expand the BCCEDP was developed by staff in the Department of Health. C-CRAB sent letters to Dr. Howell and then Governor-Elect Bush to express support for state funding to expand the breast and cervical cancer early detection program.

Tobacco-Free Florida Coalition: C-CRAB was a member of the Tobacco-Free Florida Coalition until the group disbanded this past year. The Council remains as a "network partner" to the Florida Leadership Council for Tobacco Control.

SECTION 3: PLANS FOR 1999

1. Hold a public forum on June 17, in conjunction with the regular semi-annual C-CRAB meeting, to solicit comments and suggestions on ways to improve Florida's cancer control programs. The goals of the public forum are to:
 - solicit public input for cancer control planning at the state level,
 - get ideas for expanding the objectives and strategies in *the 1998-1999 Florida Cancer Plan*,
 - translate ideas and suggestions into legislative or program initiatives, and
 - form a group of health care professionals and other concerned individuals to plan and organize future advocacy efforts.

The forum will be promoted and advertised statewide through the media and through groups and organizations. Activities will be planned to implement the ideas and suggestions that emerge.

2. Revise, reprint, distribute, and promote the C-CRAB breast cancer treatment options pamphlet in English and Spanish.
3. In conjunction with the Prostate Cancer Task Force, develop educational material on prostate cancer as well as a plan for distribution and promotion.
4. Promote skin cancer prevention efforts in Florida's schools.
5. Improve the working relationship with the Florida Department of Health and support efforts to expand the Department's cancer control and prevention initiatives.
6. Continue to support, and collaborate with where appropriate, statewide cancer control activities, e.g., the Breast and Cervical Cancer Early Detection Program and the Leadership Council for Tobacco-Free Florida.
7. Continue to monitor and develop position statements on legislation that relates to cancer, specifically the issues highlighted in the *1998-1999 Florida Cancer Plan*.
8. Continue to analyze cancer incidence and mortality data to assist with analysis of policy issues.

LIST OF APPENDICES

- 1 Chapter 98-305, Florida Laws**
- 2 C-CRAB Membership List**
- 3 Minutes**
 - 3A Council Meeting, June 11
 - 3B Council Meeting, November 23
 - 3C Executive Committee Conference Call, April 29
 - 3D Executive Committee Conference Call, August 26
- 4 Prostate Cancer Awareness Month Declaration**
- 5 Breast Cancer Technical Advisory Group**
- 6 Public Forum Announcement**
- 7 C-CRAB Web Page**

CHAPTER 98-305

Committee Substitute for House Bill No. 1213

An act relating to health care; establishing the Prostate Cancer Task Force; providing for representation on the task force; providing responsibilities; requiring a report to the Governor and the Legislature; providing for future repeal; amending s. 240.5121, F.S.; increasing membership of the Florida Cancer Control and Research Advisory Council; requiring the council to purchase or develop a written summary of cancer treatment alternatives for prostate cancer; providing appropriations for developing or purchasing and for distributing bilingual pamphlets, and for developing and implementing education programs, on prostate cancer and breast cancer; providing an effective date.

WHEREAS, the Legislature finds that prostate cancer accounts for 32 percent of all cancer cases in males, and 14 percent of all cancer deaths in males, and

WHEREAS, the Legislature also finds that an estimated 21,538 men in this state will have developed prostate cancer in 1995 and that prostate cancer is the most common form of cancer for men in Florida and that prostate cancer will have accounted for 14 percent of all cancer related deaths in males in 1995, and

WHEREAS, the Legislature finds that for men diagnosed with prostate cancer between 1986-1993 early detection resulted in significant improvement of survival rates, and that the key to treatment of prostate cancer is the early detection of its existence, and

WHEREAS, through the establishment of a state task force on prostate cancer, the Legislature intends to decrease the number of deaths due to prostate cancer by increasing public awareness of prostate cancer and by increasing, through public education, the percentage of men who seek examinations by physicians, and obtain prostate-specific antigen blood tests, and by increasing research and coordination at Florida institutions studying the causes, methods of prevention, and treatment of prostate cancer with private, state, and federal dollars, NOW, THEREFORE,

Be It Enacted by the Legislature of the State of Florida:

Section 1. Prostate Cancer Task Force.—

(1) There is created within the H. Lee Moffitt Cancer Center and Research Institute at the University of South Florida, the Prostate Cancer Task Force to identify where public awareness, public education, research, and coordination about prostate cancer are lacking and to prepare recommendations to increase research on prostate cancer and the public's awareness of the importance of the early detection and treatment of prostate cancer.

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(2) The task force is composed of 18 members to be appointed by July 15, 1998. The Governor shall appoint one representative of the University of Miami School of Medicine, one representative of the public who is a consumer advocate and who has been diagnosed with prostate cancer, one representative of the Florida Cancer Control and Research Advisory Council, one representative of the H. Lee Moffitt Cancer Center and Research Institute, one representative from a statutory teaching hospital affiliated with a community-based cancer center, one representative of the NOVA Southeastern University of Osteopathic Medicine, the Secretary of Health or a designee, and the Insurance Commissioner or a designee. At least two members appointed by the Governor shall be members of an ethnic or racial minority group. The President of the Senate shall appoint one representative of a business that has fewer than 100 employees, one representative of the University of Florida College of Medicine, one representative of the American Cancer Society, one representative of the public who is a consumer advocate and who has been diagnosed with prostate cancer, and one representative of a health maintenance organization. At least one member appointed by the President of the Senate shall be a member of an ethnic or racial minority group. The Speaker of the House of Representatives shall appoint one representative of a business that has more than 300 employees, one representative of the University of South Florida College of Medicine, one representative of the Association of Community Cancer Centers, one representative of the public who is a consumer advocate, and one representative of the insurance industry. At least one member appointed by the Speaker of the House of Representatives shall be a member of an ethnic or racial minority group.

(3) The task force shall exist for 2 years and shall meet as often as necessary to carry out its duties and responsibilities. Within existing resources, the H. Lee Moffitt Cancer Center and Research Institute shall provide support services to the task force.

(4) The members of the task force shall serve without compensation.

(5) The task force may obtain information and assistance from any state agency. All state agencies must give the task force all relevant information and reasonable assistance on matters related to prostate cancer.

(6) The task force shall collect research and information on prostate cancer and shall prepare recommendations for reducing the incidence and the number of deaths related to prostate cancer in this state, in a report submitted to the Governor and the Legislature by January 15, 2000. The task force must review and report on:

(a) The Florida Insurance Code as it relates to coverage for prostate cancer screening and treatment options. The task force shall include in its report recommended changes to the Florida Insurance Code, including specific statutory language, if the task force determines such changes are necessary to ensure that policyholders have coverage for appropriate and necessary prostate cancer prevention, screening, and treatment. If any legislative changes are recommended which would mandate a health coverage or the offering of a health coverage, the task force must assess the impact of the proposal as specified in s. 624.215, Florida Statutes.

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(b) Approaches to be used by state and local governments to increase public awareness of prostate cancer.

(c) Approaches to improving coordination of agencies and institutions involved in research and treatment of prostate cancer.

(d) A plan for reducing the number of deaths related to prostate cancer in this state, including:

1. The best methods to ensure that the percentage of men in this state who receive the prostate-specific antigen blood test increases.

2. The best methods to ensure that the percentage of men in this state who seek examinations from physicians increases.

(e) A plan for increasing research and appropriate funding at Florida institutions studying cancer.

(f) A program to monitor the implementation and effectiveness of task force recommendations.

(7) This section is repealed effective July 1, 2000.

Section 2. Paragraphs (a) and (m) of subsection (4) of section 240.5121, Florida Statutes, are amended to read:

240.5121 Cancer control and research.—

(4) FLORIDA CANCER CONTROL AND RESEARCH ADVISORY COUNCIL; CREATION; COMPOSITION.—

(a) There is created within the H. Lee Moffitt Cancer Center and Research Institute, Inc., the Florida Cancer Control and Research Advisory Council. The council shall consist of 35 ~~32~~ members, which includes the chairperson, all of whom must be residents of this state. All members, except those appointed by the Speaker of the House of Representatives and the President of the Senate, must be appointed by the Governor. At least one of the members appointed by the Governor must be 60 years of age or older. One member must be a representative of the American Cancer Society; one member must be a representative of the Florida Tumor Registrars Association; one member must be a representative of the Sylvester Comprehensive Cancer Center of the University of Miami; one member must be a representative of the Department of Health ~~and Rehabilitative Services~~; one member must be a representative of the University of Florida Shands Cancer Center; one member must be a representative of the Agency for Health Care Administration; one member must be a representative of the Florida Nurses Association; one member must be a representative of the Florida Osteopathic Medical Association; one member must be a representative of the American College of Surgeons; one member must be a representative of the School of Medicine of the University of Miami; one member must be a representative of the College of Medicine of the University of Florida; one member must be a representative of NOVA Southeastern College of Osteopathic Medicine; one member must be a representative of the College of Medicine of the

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University of South Florida; one member must be a representative of the College of Public Health of the University of South Florida; one member must be a representative of the Florida Society of Clinical Oncology; one member must be a representative of the Florida Obstetric and Gynecologic Society who has had training in the specialty of gynecologic oncology; one member must be a representative of the Florida Medical Association; one member must be a member of the Florida Pediatric Society; one member must be a representative of the Florida Radiological Society; one member must be a representative of the Florida Society of Pathologists; one member must be a representative of the H. Lee Moffitt Cancer Center and Research Institute, Inc.; three members must be representatives of the general public acting as consumer advocates; one member must be a member of the House of Representatives appointed by the Speaker of the House; one member must be a member of the Senate appointed by the President of the Senate; one member must be a representative of the Department of Education; one member must be a representative of the Florida Dental Association; one member must be a representative of the Florida Hospital Association; one member must be a representative of the Association of Community Cancer Centers; one member shall be a representative from a statutory teaching hospital affiliated with a community-based cancer center; ~~and one member must be a representative of the Florida Association of Pediatric Tumor Programs, Inc.; one member must be a representative of the Cancer Information Service; one member must be a representative of the Florida Agricultural and Mechanical University Institute of Public Health; and one member must be a representative of the Florida Society of Oncology Social Workers.~~ Of the members of the council appointed by the Governor, at least 10 must be individuals who are minority persons as defined by s. 288.703(3).

(m) If funds are specifically appropriated by the Legislature, the council shall develop or purchase a standardized written ~~summaries~~ summary, written in layperson's terms and in language easily understood by the average adult patient, informing actual and high-risk breast cancer patients, prostate cancer patients, and men who are considering prostate cancer screening of the medically viable treatment alternatives available to them in the effective management of breast cancer and prostate cancer; describing such treatment alternatives; and explaining the relative advantages, disadvantages, and risks associated therewith. ~~The breast cancer~~ Such summary, upon its completion, shall be printed in the form of a pamphlet or booklet and made continuously available to physicians and surgeons in this state for their use in accordance with s. 458.324 and to osteopathic physicians in this state for their use in accordance with s. 459.0125. The council shall periodically update ~~both summaries the pamphlet~~ to reflect current standards of medical practice in the treatment of breast cancer and prostate cancer. The council shall develop and implement ~~an~~ educational programs ~~program~~, including distribution of the ~~summaries pamphlet or booklet~~ developed or purchased under this paragraph, to inform citizen groups, associations, and voluntary organizations about early detection and treatment of breast cancer and prostate cancer.

Section 3. There is hereby appropriated from the General Revenue Fund to the H. Lee Moffitt Cancer Center and Research Institute at the University of South Florida the sum of \$50,000 for fiscal year 1998-1999 to be used by

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the Cancer Control and Research Advisory Council to produce or purchase and to distribute pamphlets, in English and in Spanish, that inform patients about treatment alternatives for prostate cancer and to develop and implement an educational program that includes the distribution of the pamphlets, as required by s. 240.5121, Florida Statutes.

Section 4. There is hereby appropriated from the General Revenue Fund to the H. Lee Moffitt Cancer Center and Research Institute at the University of South Florida the sum of \$50,000 for fiscal year 1998-1999 to be used by the Cancer Control and Research Advisory Council to produce or purchase and to distribute pamphlets, in English and in Spanish, that inform patients about treatment alternatives for breast cancer and to develop and implement an educational program that includes the distribution of the pamphlets, as required by s. 240.5121, Florida Statutes.

Section 5. This act shall take effect July 1 of the year in which enacted.

Approved by the Governor May 29, 1998.

Filed in Office Secretary of State May 29, 1998.

Florida Cancer Control and Research Advisory Council

Membership List

(* Executive Committee Members)

Name, Affiliation (if different from organization represented) and City	Dates of Term	Organization Represented
Joyce A. Allan, M.P.H., C.T.R. St. Petersburg	12/7/97-12/1/01	Florida Tumor Registrars Association
Kari Barcome, M.S.W. Largo	12/98 - 12/02	Florida Society of Oncology Social Workers
Sandra Blank Florida Breast Cancer Resource Network, Deerfield Beach	2/10/98-12/31/99	General Public
Representative Mary Brennan Pinellas Park	9/6/96-10/12/99	Florida House of Representatives
Clarence H. Brown, III, M.D. * M. D. Anderson Cancer Center Orlando	12/7/97-12/1/01	Statutory teaching hospital affiliated with a community cancer center
Linda C. Casey, A.R.N.P. James A. Haley V.A. Hospital, Tampa	4/25/97-12/1/00	Florida Nurses Association
Denis Cavanagh, M.D. Tampa	1/30/97-1/30/01	University of South Florida College of Medicine
Kerry E. Chamberlain, D.O. Largo	1/30/98-12/1/02	Florida Osteopathic Medical Association
Edward M. Copeland, M.D. Gainesville	12/7/97-12/1/01	University of Florida College of Medicine
Marcia W. DeSonier, R.N., L.C.S.W. * Baptist Hospital, Pensacola	12/7/97-12/1/01	Florida Hospital Association
James V. Fiorica, M.D. H. Lee Moffitt Cancer Center, Tampa	4/8/98-12/1/01	Florida Society of Clinical Oncology
W. Jarrard Goodwin, Jr., M.D. (Chair)* Miami	1/31/96-12/31/99	University of Miami School of Medicine
Cynthia M. Harris, Ph.D. Tallahassee	Appointment pending	Florida Agricultural & Mechanical University, Institute of Public Health
Richard S. Hopkins, M.D., M.S.P.H. * Tallahassee	1/31/96-12/31/99	Florida Department of Health
Senator Jim Sebesta St. Petersburg	1/2/99-1/1/01	Florida Senate
Jeffrey P. Krischer, Ph.D. * H. Lee Moffitt Cancer Center, Tampa	1/31/96-12/31/99	Florida Association of Pediatric Tumor Programs
Jerry M. Layne, D.D.S., M.D. Miami	1/30/97-1/30/01	Florida Dental Association
James W. Lynch, Jr., M.D. Gainesville	12/98 - 12/02	University of Florida Shands Cancer Center
Donna Malvey, Ph.D. Tampa	12/17/97-9/19/01	University of South Florida College of Public Health
Gretchen McCall Tallahassee	7/31/96-12/31/99	Department of Education

Name, Affiliation (if different from organization represented) and City	Dates of Term	Organization Represented
Robert L. McGuire, M.D. * Plantation	1/31/96-12/31/99	American Cancer Society
George R. McSwain, M.D. Bradenton	1/30/95-12/1/99	American College of Surgeons
Morton J. Morris, D.O., J.D. Davie	7/30/97-7/1/99	Nova Southeastern University
James W. Orr, M.D. Patty Berg Cancer Center, Ft. Myers	1/31/96-12/1/99	Florida Obstetric and Gynecologic Society
Janet Patten Tallahassee	1/30/95-12/1/99	General Public
John C. Ruckdeschel, M.D. * Tampa	12/17/97-12/1/01	H. Lee Moffitt Cancer Center & Research Institute
Alvin E. Smith, M.D. Herbert D. Kerman Regional Oncology Center, Daytona Beach	12/17/97-12/31/01	Association of Community Cancer Centers
Ann E. Spangler, M.D. Herbert D. Kerman Regional Oncology Center, Daytona Beach	2/1/96-12/31/99	Florida Medical Association
JoBeth Speyer, M.S.W. * Miami	12/98 - 12/02	Cancer Information Service
Kurt J. Stonesifer, M.D. University Community Hospital, Tampa	4/23/98-12/1/02	Florida Society of Pathologists
Frances Sykes Tampa	1/30/97-1/30/01	Consumer/general public
Stuart R. Toledano, M.D. University of Miami School of Medicine, Miami	12/17/97-12/1/01	Florida Pediatric Society
Edward J. Trapido, Sc.D. * Miami	1/30/95-12/1/98	Sylvester Comprehensive Cancer Center
Debby Walters Tallahassee	12/4/97-9/19/01	Florida Agency for Health Care Administration
Vacant		Florida Radiological Society

MINUTES

Cancer Control and Research Advisory Council (C-CRAB)

June 11, 1998

Tampa Airport Marriott Hotel

10:00 a.m. – 4:00 p.m.

Members Present:

Sandra Blank
General Public
Mary Brennan
Florida House of Representatives
Clarence Brown, M.D.
MD Anderson Cancer Center, Orlando
Kerry Chamberlain, D.O.
Florida Osteopathic Medical Association
Marcia DeSonier, R.N., L.C.S.W.
Florida Hospital Association
James Fiorica, M.D.
Florida Society of Clinical Oncology
W. Jarrard Goodwin, M.D., Chair
University of Miami School of Medicine
Jeffrey Krischer, Ph.D.
Florida Assn. of Pediatric Tumor Programs
Jerry Layne, M.D., D.D.S.
Florida Dental Association
Gretchen McCall
Department of Education
Robert McGuire, M.D.
American Cancer Society
Morton Morris, D.O.
Nova Southeastern University
Janet Patten
General Public
John Ruckdeschel, M.D.
H. Lee Moffitt Cancer Center
Frances Sykes
General Public
Edward Trapido, Sc.D.
Sylvester Cancer Center
Stuart Toledano, M.D.
Florida Pediatric Society

STAFF:

Dorothy Parker

Attending for Members:

Dan Thompson for Dr. Hopkins, Dept. of Health
Gail Zavelson for Dr. Copeland, Univ. of Florida
College of Medicine, and Dr. Lynch, nominee from
Univ. of Florida Shands Cancer Center

Members Absent:

Joyce Allan
Florida Tumor Registrars Association
Linda Casey, A.R.N.P.
Florida Nurses Association
Denis Cavanagh, M.D.
Univ. of South Florida College of Medicine
George Kirkpatrick
Florida Senate
Donna Malvey, Ph.D.
Univ. of South Florida College of Public Health
George McSwain, M.D.
American College of Surgeons
James Orr, M.D.
Florida OB/GYN Society
Alvin Smith, M.D.
Association of Community Cancer Centers
Ann Spangler, M.D.
Florida Medical Association
Kurt Stonesifer, M.D.
Florida Society of Pathologists
Debby Walters
Agency for Health Care Administration

Guests:

Nina Entrekin, American Cancer Society
Adrienne Hollis, Ph.D., FAMU Institute of
Public Health
Christine Hunt, Suncoast Health Planning Council
JoAnn Green, Dept. of Health
Bob Powell, Sylvester Cancer Center
Bob Samuels, Prostate Cancer Action Network
JoBeth Speyer, Cancer Information Service

Introductions and Approval of Minutes

Dr. Goodwin opened the meeting with introductions. Minutes from the November 3, 1997 meeting were reviewed.

✓ A motion to accept the minutes was made, seconded, and approved.

Copies of the minutes from the November 3rd Executive Committee meeting and the April 29th conference call were distributed with the handouts.

Guest Speaker: Dr. Charles Gruder

Charles (Larry) Gruder, Ph.D., Executive Director of the Special Research Programs Office at the University of California, was invited to give a presentation on state-funded cancer control programs in California (see attached – copy of slides). Information about California's experience will be helpful to C-CRAB in its efforts to get state funding for cancer programs in Florida.

The Office of Special Research Programs, which is part of the Office of the President of the University of California, administers state-funded research programs in tobacco, breast cancer, and AIDS. Other cancer control programs are located in the California Department of Health Services. State cigarette tax revenues fund the research programs. The tobacco program receives 5% of a 25¢/pack tax as stipulated in a constitutional amendment. The breast cancer research program receives 45% of a 2¢/pack tax that also provides funding for the cancer registry (5%) and a breast and cervical cancer screening program (50%). In addition, there is an AIDS research program funded from general revenue. The Office of the President currently receives ~ \$50 million for its three programs, and the state health department receives ~ \$25 million for cancer control programs. In FY 98-99, 199 grants were awarded to 50 institutions in California: 84 for tobacco, 66 for breast cancer, and 49 for AIDS projects.

Dr. Gruder described California's process for reviewing and awarding research grants, including the composition of the scientific review committees, and examples of the funded projects. He also talked about cancer survivors as advocates for getting state funding and their role in the grant review process. In addition, he mentioned some of the lessons learned in the public and political arena, as well as in the scientific process.

Questions and discussion followed his presentation. There was a question about a decrease in funding if smoking rates declined, since funding is linked to tobacco tax revenues. Dr. Gruder mentioned that although smoking rates in California are relatively low among adults, and have declined in recent years, total revenues from cigarette taxes represent a large amount of money. He also mentioned that teen smoking rates have not declined. There was another question about funds going mainly to the larger research institutions, making money less available to smaller organizations. Dr. Gruder replied that, although the large research universities received much of the money initially, there were now 50 institutions that receive grants, including smaller organizations and hospitals.

Implementing the “C-CRAB Bill”

Dr. Goodwin announced that the Governor signed HB 1213 on June 10 in a bill-signing ceremony at the Moffitt Cancer Center. The bill gives C-CRAB money for breast and prostate cancer education material, and it creates a Prostate Cancer Task Force under Moffitt.

1. **Breast cancer treatment options pamphlet:** C-CRAB received a \$50,000 appropriation for FY 98-99. A list of Technical Advisory Group (TAG) members who helped develop the pamphlet in 1996 was reviewed, and suggestions were made for changes to the group. In addition, a plan for revising and reprinting the pamphlet was distributed, which included a plan for printing it in Spanish.

There was a question about using the money for something other than reproducing the brochure since there are many brochures already. Although no formal evaluation of the brochure was conducted, there is indirect evidence of its popularity. For example, we received more orders than could be filled, we received many unsolicited compliments from patients and providers, and requests for the pamphlet continue to come in even though there is no promotion because the supply is almost depleted.

- ✓ A motion was made to reconvene the TAG with new members, and ask the TAG to approve a plan for spending the money. The motion was seconded and approved unanimously. It was suggested that an osteopath and Hispanic person(s) be added to the group.

2. **Prostate Cancer Task Force:** Dr. Goodwin asked for nominees or volunteers for the C-CRAB representative on the task force. Dr. Brown was nominated, and his nomination was approved. This will be conveyed to the Governor in a letter.
3. **Prostate cancer education material:** It was agreed that direction for this project should come from the Prostate Cancer Task Force, and therefore funds appropriated to C-CRAB should be used by the task force to assess the need for education and to make recommendations to C-CRAB. Dorothy Parker will be providing staff support for the task force, and will keep C-CRAB informed as to their activities.
4. **New organizations on C-CRAB:** The bill also added three organizations to C-CRAB: (1) the Cancer Information Service, (2) the Florida Agricultural and Mechanical University (FAMU) Institute of Public Health, and (3) the Florida Society of Oncology Social Workers. Dorothy Parker will work with these organizations to facilitate the nomination and appointment process.

Dr. Goodwin mentioned that although C-CRAB has several cancer survivors among its members, survivor groups are not specifically represented on the Council. Ms. Blank mentioned that she is a cancer survivor and heads a breast cancer survivor group in Florida. However, her appointment is as a consumer/general public representative. It was suggested that, in the future, the C-CRAB membership list be amended to include specific cancer survivor and/or advocacy groups.

Sundown Review: In past meetings, the question about C-CRAB's 10-year "sundown" review was raised. Dorothy Parker reported that the statute requiring legislative review of all councils and boards every 10 years was repealed in 1993. Therefore, there will be no such review of C-CRAB in 1999.

September 26 March on Washington

Bob Samuels, President of the National Prostate Cancer Coalition and founder of the Florida Prostate Cancer Action Network, provided information about the nationwide effort to request more funds for cancer research. There will be a march and rally in Washington, D.C. on September 26, to bring attention to this issue to the President and Congress. For those that cannot go to Washington, a rally is being planned for Florida, to be held in Tampa on the same day. Mr. Samuels asked C-CRAB members to encourage the organization they represent, and others in their community, to support and participate in this effort.

It was suggested that C-CRAB write letters to Florida's federal legislators to encourage their participation and support. Mr. Samuels mentioned that they have already sought the endorsement of Florida's elected officials, as well as gubernatorial candidates. He also mentioned that the ACS, Florida Division, has offered its support.

- ✓ A motion was made that C-CRAB take a formal position in support of the March, and that we ask the Florida legislature and the governor to support the effort. The motion was seconded and approved. Dr. Goodwin urged C-CRAB members to take this message back to the organizations that they represent and to get involved at the regional, state, and/or national level.

Department of Health – Comprehensive Cancer Control Grant Application

JoAnn Green reported on a proposal being submitting to CDC on July 1 to develop a comprehensive cancer control program within the Department of Health. C-CRAB staff and the Executive Committee were sent a copy of the first draft to review, and their comments were incorporated into the final draft, which is currently being reviewed within the Department.

Funding decisions will be made in September. The proposal calls for a large coalition that would include C-CRAB, the Breast and Cervical Cancer Coalition, and the Tobacco-Free Florida Coalition. The Florida Cancer Plan is being submitted with the grant as a baseline that will be expanded to include time-phased goals and objectives.

Topics for Discussion Workgroups – Dr. Goodwin asked that we divide into two groups during lunch for discussion of two topics: (1) How can C-CRAB and the Department of Health work together to enhance cancer control programs in Florida? (refer to summary of March 6 meeting with Dr. Howell), and (2) How we can work with cancer survivor groups to promote cancer control programs in Florida and to get state funding?

Department of Health Workgroup: Dr. Trapido reported on the discussion regarding C-CRAB and the Department of Health (DOH). The following suggestions were made:

1. Hold quarterly meetings with key health department officials, e.g., Drs. Howell, Crockett, Beitsch, and Hopkins. The discussion could include budget issues as well as small projects or global issues.
2. Create a liaison committee to meet with DOH on regular basis.
3. Look at the language in the administrative rules of the DOH to see where we could strengthen our involvement.
4. Be more proactive and give DOH a specific proposal about what our role will be.
5. Although action is needed now, there may be new DOH leadership after election.
6. C-CRAB could function as an external advisory council the DOH to help with planning rather than react to specific proposal in short period of time.
7. Additional C-CRAB staff will be needed if activities increase.

Discussion:

- There was a question about funds in the DOH budget for research. Neither the Department nor C-CRAB has been funded for cancer research.
- It was suggested that Dr. Eric Handler, head of CMS, be added to list of people to meet with.
- Will C-CRAB have any influence over how the CDC grant money will be spent? Details have not been worked out, but C-CRAB will be part of the proposed advisory council.
- The key issue is that in the past, C-CRAB has been asked for comment on a post-hoc basis, but we want to be proactive.

Proposed Action Plan:

1. The C-CRAB Chair should appoint a committee to formulate a proposal that describes where we think C-CRAB could work collaboratively with the DOH. The proposal should be presented to DOH officials for comment and approval.
2. C-CRAB could serve as a council of external advisors to the DOH for cancer issues, and review plans for cancer programs in advance.
3. C-CRAB could review the department's LBRs and assist in planning as needed. C-CRAB can also provide public and scientific support for the department's budget requests.
4. C-CRAB's advisory role to the Legislature and Governor could be linked with, and be channeled through, the health department.

Dr. Goodwin asked if the Executive Committee should work on this, or if a subcommittee should be appointed. Dr. Ruckdeschel suggested that the Executive Committee set up the proposal, then appoint a subcommittee to carry out the plan.

- ✓ A motion was made that the C-CRAB Executive Committee, in consultation with the Department of Health, form a subcommittee to serve as a proactive external advisory committee to the Department on cancer issues. First, however, the Executive Committee

should prepare a proposal, and present it to key DOH officials for comment and approval. The motion was seconded and approved.

Survivors Workgroup: Sandy Blank reported on the group's discussion. They propose the following:

1. Identify cancer survivor groups in Florida (need to decide how to do it).
2. Based on the activities of Mr. Samuels and the prostate cancer group, we need to put together a portfolio and develop a comprehensive plan for promoting cancer control programs in Florida.
3. C-CRAB could hold a summit with cancer survivor and advocacy groups to identify an action plan to take to legislature for funding, programs, education, research, etc.

Discussion:

- Since the Breast and Cervical Cancer Coalition wants to lobby for state funding to supplement the CDC early detection grant for expanding screening and treatment services, they would be invited to participate in the summit.
- There was a question about the feasibility of requesting funding for education and research when the State has not funded these areas in the past. Dr. Goodwin commented the state legislature has not funded any cancer research, and they have funded cancer education and early detection very modestly. Therefore, our challenge is to figure out how to be more effective to get the legislature to fund these areas. These issues could be discussed at the proposed "summit."
- Dr. Gruder commented that we need to agree on priorities to ensure that the group is focussed on the same issues. In California, survivors and the advisory committee were key in getting legislators to support funding. Florida already has the infrastructure with C-CRAB and the agencies represented, and we need to let the State know that they are not meeting their own commitment for cancer control programs.
- External support for the summit could be solicited, e.g. from pharmaceutical companies, the university-based cancer centers, or the ACS.
- The "summit" should be held before, or in conjunction with, the next C-CRAB meeting.
 - ✓ A motion was made to pursue the potential for a "summit" of C-CRAB and leaders of cancer survivor and advocacy groups to develop a plan for getting state funding. The motion was seconded, and approved.

It was agreed that the Executive Committee should come up with a format and funding ideas. The Executive Committee should also put together a group of about 10 members to meet with a group of leaders of survivor organizations.

Update from State Programs

Breast and Cervical Cancer Early Detection Program, Department of Health: JoAnn Green reported that an application has been submitted for the last year of the initial five-year grant. At this time, they can only request level funding, but next year they can ask for more. Ms. Green reviewed the data on number of women screened, and reported on the social marketing pilot program developed by the University of South Florida. The Bureau of Epidemiology is currently working on evaluation of the social marketing pilot project. The next coalition meeting will be in November.

Bureau of Epidemiology: Dan Thompson reported on the following activities:

1. Contract renewal for operation of the Florida Cancer Data System (FCDS).
2. Revising the administrative rule for cancer reporting to reflect changes to the law that requires free standing clinics to report new cancer cases to FCDS. The rule should be final by the end of June.
3. Grant renewal for National Cancer Registry Program (CDC). The renewal, which is for the 5th year of the grant, asks for \$145,000 more than last year, and last year's grant was \$103,000 more than the previous year.
4. The 1995 Florida Annual Cancer Report is completed. Copies will be mailed to C-CRAB members with minutes from this meeting. The report will also be available on the FCDS web site.
5. A copy of the 1996 Smoking Attributable Mortality Report was also distributed.

Florida Tobacco Pilot Program: Dan Thompson provided an brief overview of the program, and reported that the Epidemiology Bureau is involved in the evaluation component.

Dr. Trapido provided more details about the funding and goals of the program. There will be RFAs (requests for application) or ITNs (invitations to negotiate) issued for the various program areas. Information will be posted on the Internet at the following address: <http://nosmoking.scri.fsu.edu/>. Evaluations are being conducted by six universities and the Department of Health, and coordinated by the University of Miami.

Gretchen McCall reported that the Department of Education has not been given any money for tobacco education; the money is going through the Department of Health. She provided a handout on the distribution of funds in the Tobacco Pilot Program, and copies of the questions and results from the Youth Tobacco Survey. Money is available for train-the-trainers for the tobacco school curriculum, but it is available through the county partnerships, not the school system.

Dr. Goodwin asked if there were any areas in which C-CRAB would like to be involved? Dr. Trapido pointed out that the program is moving at a very fast pace due to the nature of the settlement and the requirements to spend money in a short period of time. Therefore, if C-CRAB were to be involved, it would have to work at a fast pace. No issues were raised.

ACS Report on Prostate Cancer in Florida – Nina Entrekin presented the ACS Florida Division's second report on prostate cancer, which uses 1996 FCDS data. The report is organized by state, region and county, and has data on incidence, mortality data, and stage. Ms. Entrekin presented slides that highlighted the findings of the report. Encouraging trends are observed, e.g., increase in the percent of cases diagnosed at early stage, and decrease in deaths. However, rates for African American men are much higher than for White men.

Cancer Information Service: JoBeth Speyer reported that there is a RFA available from the National Cancer Institute on health communications and cancer control, focussing on cultural, economic and ethnic diversity. She encouraged organizations in Florida to apply, and offered to work with any institution that is interested.

There was no further new business, and meeting was adjourned at 3:30 p.m.

Minutes submitted by Dorothy Parker, 6/23/98 (revised 6/29/98)

MINUTES

Cancer Control and Research Advisory Council (C-CRAB) Meeting

November 23, 1998
Tampa Airport Marriott Hotel
1:30 p.m. - 4:30 p.m.

Members Present:

Joyce Allan
Florida Tumor Registrars Association
Kari Barcome (*nominee*)
Florida Society of Oncology Social Workers
Sandra Blank
General Public
Linda Casey
Florida Nurses Association
Kerry Chamberlain, D.O.
Florida Osteopathic Medical Association
Marcia DeSonier
Florida Hospital Association
James Fiorica, M.D.
Florida Society of Clinical Oncology
W. Jarrard Goodwin, M.D., Chair
University of Miami School of Medicine
Richard S. Hopkins, M.D.
Florida Department of Health
Jerry Layne, M.D., D.D.S.
Florida Dental Association
Donna Malvey, Ph.D.
Univ. of South Florida College of Public Health
Robert McGuire, M.D.
American Cancer Society
George McSwain, M.D.
American College of Surgeons
Morton Morris, D.O.
Nova Southeastern University
James Orr, M.D.
Florida OB/GYN Society
John Ruckdeschel, M.D.
H. Lee Moffitt Cancer Center
Alvin Smith, M.D.
Association of Community Cancer Centers
JoBeth Speyer (*nominee*)
Cancer Information Service
Kurt Stonesifer, M.D.
Florida Society of Pathologists
Edward Trapido, Sc.D.
Sylvester Comprehensive Cancer Center

Members Absent:

Mary Brennan
Florida House of Representatives
Clarence Brown, M.D.
MD Anderson Cancer Center, Orlando
Denis Cavanagh, M.D.
Univ. of South Florida College of Medicine
Edward Copeland, M.D.
University of Florida College of Medicine
George Kirkpatrick
Florida Senate
Jeffrey Krischer, Ph.D.
Florida Association of Pediatric Tumor Programs
James Lynch, M.D. (*nominee*)
University of Florida Shands Cancer Center
Gretchen McCall
Department of Education
Janet Patten
General Public
Ann Spangler, M.D.
Florida Medical Association
Frances Sykes
General Public
Stuart Toledano, M.D.
Florida Pediatric Society
Debby Walters
Agency for Health Care Administration

Guests:

Ralph DeVitto, American Cancer Society
Tom Coleman, M.D., American Cancer Society
Bob Powell, Sylvester Comprehensive Cancer Center
Robert Reichert, M.D., Florida Liaison Program,
Commission on Cancer

STAFF:

Dorothy Parker

INTRODUCTIONS AND APPROVAL OF MINUTES

Dr. Goodwin opened the meeting with introductions. Minutes from the June 11 meeting were reviewed. A motion to accept the minutes was made, seconded, and approved.

Dr. Goodwin mentioned that the Executive Committee met at noon to review the agenda. He also announced that there are two new members on the Executive Committee: Marcia DeSonier and JoBeth Speyer (pending her appointment by the Governor).

BREAST CANCER TREATMENT OPTIONS BROCHURE

Funding: Dorothy Parker reported that the money appropriated to CCRAB for the breast cancer brochure went to the Family Health division of the Department of Health, and that a contract between Moffitt and the Department is being prepared to disburse the funds.

Breast Cancer Technical Advisory Group (TAG) Report: Dorothy Parker reported that the TAG has been working on revising the brochure since July, via conference calls and E-mail/fax messages. The first conference call (July 20) involved a discussion of sections that needed changing and updating. TAG members submitted comments, and Dorothy worked on revising the text. In September, it was noted that a new NCI brochure was very similar to the CCRAB material being revised. Therefore, it was suggested, and approved by the Executive Committee, that CCRAB use the NCI brochure and develop a supplement that contains information specific to Florida and a more detailed resource list. In October, Sandy Blank offered a counter proposal with suggestions for wider distribution and a separate brochure for providers. A second conference call was held November 4. After the call, a poll of TAG members found that the majority favored using the NCI plus a Florida supplement. However, since there was a strong objection to this plan, it was decided that the issue would be brought to CCRAB for a final decision.

Discussion: The pros and cons of the NCI vs. the CCRAB brochures were discussed at length, including a discussion of cost, content, reading level, etc. Dr. Hopkins suggested offering a choice of either the NCI or the CCRAB brochure. A straw vote was taken: 8 members favored revising the CCRAB brochure, 10 voted for using the NCI brochure plus a supplement, and one favored offering a choice.

Dr. Goodwin asked about evaluation and if there was any negative feedback on the first CCRAB brochure. Although there was no formal evaluation, many positive comments were received from both providers and patients, including those who preferred it to others that are available. No negative comments were received. Dr. Goodwin suggested including an evaluation component this time. Ms. Allen suggested that the Florida Cancer Data System could be used to conduct a sample survey of breast cancer patients to see if they received information.

A motion was made that CCRAB distribute a folder that includes the NCI brochure and supplemental material that covers Florida insurance laws and resources for newly-diagnosed patients (Ms. Speyer commented that using a folder for educational material has been shown to be successful, as described in a recent article in *Cancer* -- copy attached).

Results: 8 in favor, 8 against, 1 abstention. As Chair, Dr. Goodwin, broke the tie with a vote against the motion -- favoring the revision of the CCRAB brochure.

ACS & TRI-AGENCY COALITION REPORT

Ralph DeVitto presented the 1999 legislative agenda of the American Cancer Society (ACS), Florida Division, and the Florida Tri-Agency Coalition for Smoking and Health. Their top priorities are: (1) dedicating a portion of Florida's tobacco settlement money for a comprehensive tobacco control program and for biomedical research (including psychosocial and prevention research), and (2) removing the preemption clause from the Florida Clean Indoor Air Act. Mr. DeVitto described the current use of the tobacco settlement funds, and discussed plans for continued funding for the next fiscal year. There was discussion about continuing to focus tobacco prevention programs on youth vs. adults. The need for more research into effective methods of smoking cessation for teens and young adults was mentioned, but it was agreed that it is important to focus on youth. Mr. DeVitto also reported that the ACS Florida Division will continue to fund cancer research programs.

A motion was made that CCRAB endorse the ACS/TriAgency legislative agenda. The motion was seconded and approved unanimously.

CCRAB PUBLIC FORUM

Following up on the discussion at the last CCRAB meeting on ways to increase the involvement of advocates in cancer control program planning, the Executive Committee met via conference call on August 26 to discuss the proposed idea of a summit, and to review the list of advocacy groups and the plan prepared by Sandy Blank. The committee agreed to plan for a *public forum* (not a summit) in conjunction with the spring CCRAB meeting. The purpose is to hear what the advocates and the general public have to say about what the State can do in the areas of cancer prevention and control.

This idea was discussed, and suggestions were made for ways to publicize the event, groups to invite, and how to involve state legislators. It was suggested that the forum be used to get input on the Florida Cancer Plan, and to help CCRAB and the Department of Health develop more specific objectives and strategies. It was noted that in order to have an impact on Legislative Budget Requests for the year 2000, we will need to forward any recommendations to state agencies by July 1999.

Since Florida is such a large state and it may be difficult to attract people from all areas, a series of regional town hall meetings was suggested. Dr. Hopkins mentioned that his office could provide data for each area of the state to help identify regional problems. However, it was agreed that we should start with one central forum in Tampa and then consider other venues. It was also agreed that the Executive Committee would help Dorothy Parker work on plans for the forum, to be held in mid or late May, or early June.

NEW ITEMS/ANNOUNCEMENTS

American College of Surgeons/Commission on Cancer: Dr. McSwain and guest Dr. Reichert presented information about a program being developed by the Florida Chapter of the American College of Surgeons (ACOS) and the Commission on Cancer -- the Triad Program, a collaborative effort with ACOS, the American Cancer Society, and the Florida Tumor Registrars Association. A copy of Dr. Reichert's ACOS newsletter article was distributed. Since they want to work with many of the organizations represented on CCRAB, and our goals overlap, ways in which CCRAB and the Triad could work together were discussed.

Dr. Reichert also brought up the issue of HMOs requiring outpatient pathology specimens to be sent to freestanding (non-hospital) pathology labs. A questionnaire on this issue was included in the ACOS newsletter. Many surgeons Dr. Reichert has spoken to are concerned for several reasons, e.g., timeliness of reporting, having the pathologist be part of the treatment team, and accuracy of pathology reports. He

raised the question of initiating legislation to address this problem, and asked what could be CCRAB's role. Several members suggested that Dr. Reichert contact the agencies represented on CCRAB that have lobbyists, e.g., Florida Medical Association and the Florida Osteopathic Medical Association, to discuss introducing legislation, which CCRAB could then endorse.

Skin Cancer Prevention in Schools: Dorothy Parker reported that a health educator in Tampa is asking if CCRAB would be interested in sending a letter to all school districts in the state emphasizing the importance of protecting children from exposure to the sun. The issue arose when the health educator's son was told he could not wear his hat on the school playground. The mother has written several letters to the school district to address this issue in Hillsborough County.

Ms. DeSonier mentioned that the University of Florida, in conjunction with ACS and the Skin Protection Federation, produced a program and material on this subject using the *Slip, Slop, Slap* message. It was also noted that this issue is compatible with the Florida Cancer Plan's goals and objectives for skin cancer prevention.

It was moved, seconded, and approved unanimously, that CCRAB write a letter to each school district in support of efforts to reduce sun exposure in schools.

Joint Cancer Conference: Dr. Goodwin announced that the three university-based cancer centers in Florida will sponsor the third annual Joint Cancer Conference in Orlando, January 28-30, 1999. A postcard on the conference was distributed (full agenda to be distributed with minutes). CCRAB is again being offered a complimentary exhibit table. It was agreed that CCRAB should take advantage of this opportunity to increase awareness of the Council and to promote the Florida Cancer Plan.

UPDATE FROM STATE PROGRAMS

Florida Tobacco Pilot Program: Dr. Trapido gave an update on the evaluation component of the Tobacco Pilot Program, which he is coordinating. The evaluation consists of surveys and analyses -- being conducted by several Florida universities. Quarterly evaluation reports are being produced. Dr. Trapido commented that changes have already been observed, e.g., a 10% decrease in the proportion of youth who say they smoke and in those who are considering smoking. Among teen smokers, a decrease in the percentage who report they smoke daily has been reported.

Prostate Cancer Task Force: Since all appointments have not yet been made, the task force has not met. Dorothy Parker reported that Dr. Clarence Brown was nominated, and appointed by the Governor, to represent CCRAB on the task force.

The task force is not part of CCRAB; it will be administered by the Moffitt Cancer Center. Of concern to C-CRAB, however, is the fact that the Council agreed to defer to the task force for recommendations on how best to address the need for prostate cancer educational material. The \$50,000 appropriated to CCRAB for these materials is being held in the Department of Health, along with the \$50,000 for the breast cancer material. Dorothy Parker stated that Moffitt will try to have the money extended into the next fiscal year since it will not likely be spent in this fiscal year.

Department of Health: Dr. Hopkins reported that, in conjunction with the upcoming change in administration, a transition team is visiting the Department of Health. It is not known, at this time, who Jeb Bush will appoint as Secretary of Health.

A new Division of Tobacco Control is being created, which will include the currently independent

Tobacco Pilot Program. The Bureau of Epidemiology has been working with the evaluation component of the tobacco program, and has helped produce five reports using data from the Youth Tobacco Survey conducted earlier this year. A second survey will be conducted in February/March 1999 that will allow for comparisons of pre- and post program attitudes, knowledge and behaviors relating to smoking. Dr. Hopkins mentioned that his Bureau is also participating with the CDC in conducting the Youth Risk Behavior Survey that covers many topics related to health risk, including tobacco use.

Legislative Proposals: Dr. Howell is reviewing The Department's Legislative Budget Requests (LBRs). At this time, the cancer control program is not among the top priorities. A copy of a proposal to use state funds to expand the breast and cervical cancer early detection program to more counties was reviewed, along with a proposal to expand the program to include screening for skin and colorectal cancer, and prostate cancer education.

It was suggested that CCRAB send letters to Dr. Howell and to Governor-elect Bush to ask that higher priority be given to the request to expand the breast and cervical cancer program. Ms. Blank indicated that she could not support expanding the program at this time.

A motion was made to write letters to Dr. Howell and to Jeb Bush regarding the importance of the breast and cervical cancer program in saving women's lives, and to ask that the program be given higher priority for state funding (not to expand to screening for other cancer sites). The motion passed. It was suggested that as the CCRAB Chair, Dr. Goodwin call Dr. Howell to convey this message. Dr. Smith said he would also call, and encouraged others to do so as well.

Comprehensive Cancer Control Grant: Dr. Hopkins mentioned that the Comprehensive Cancer Control Grant Application submitted to CDC last summer was recommended for approval but not funded (only six states received funding). The reviewers commented that the Florida Cancer Plan does not contain measurable and time-phased objectives, even though the proposal addressed this issue, and included a plan to do just that. The Department will consider reapplying when the next funding opportunity arises, and CCRAB offered to work more closely with the Department so that the comments could be addressed.

The Department of Health recently completed a new strategic plan that contains objectives related to cancer. In addition, the national *Healthy People* objectives for 2010 have just been released. These can help CCRAB and the Department of Health develop measurable objectives to add to the Florida Cancer Plan.

Cancer Information Service: Ms. Speyer reported the region served by her CIS office now includes the U.S. Virgin Islands, in addition to Florida and Puerto Rico. Her office is preparing a proposal for continued funding that will be submitted early next year. She also announced that they have received new computers and a new phone system that will help handle the increased volume of calls, which averages 2,000 per month. Florida was selected as one of the three Spanish-language call centers in the U.S., and they currently receive the highest volume of calls in Spanish.

There was no further new business, and meeting was adjourned at 4:40 p.m.

Minutes submitted by Dorothy Parker, 11/25/98

C-CRAB Executive Committee Conference Call
April 29, 1998
8:30 – 9:00 a.m.

Participants:

Drs. Brown, Goodwin (Chair), Krischer, McGuire, Ruckdeschel, and Trapido;
Dan Thompson, Margo Blake and JoAnn Green (Dept. of Health), Dorothy Parker

Topic: Planning for the June 11 C-CRAB meeting

Dr. Goodwin asked for input from the Executive Committee in planning for the June 11 CCRAB meeting. There were four areas he wants to cover:

1. Since Florida has not been successful at getting the Legislature to fund cancer control programs and research, Dr. Goodwin and others thought that it might be helpful to learn about other states' efforts. To learn about the California program, Charles (Larry) Gruder, Ph.D., Executive Director of the Special Research Programs office at the University of California, has been invited to speak at the June 11 C-CRAB meeting.
2. Following up on the March 6 meeting with Dr. Howell, Dr. Goodwin would like the June 11 C-CRAB meeting to include a workshop-type discussion on ways in which C-CRAB and the Department of Health can work together in the future to expand and enhance cancer control programs in Florida. A summary of that meeting was mailed to Executive Committee members prior to the conference call.
3. Dr. Goodwin also mentioned that cancer survivors can be effective allies and advocates, and suggested C-CRAB think about how to work with them in advancing Florida's cancer control efforts.
4. Preparation for the upcoming "sunsetting" review also needs to be discussed.

The sequence and format of the meeting was discussed. It was suggested that Drs. Goodwin, Ruckdeschel, Dr. Hopkins' representative(s), and Dorothy meet with Dr. Gruder before the CCRAB meeting to brief him on what we want to know, etc. (Dr. Hopkins will be at a conference out of town, and has asked Dan Thompson to attend in his place. Margo Blake has also asked that JoAnn Green, from the Breast and Cervical Cancer Program, attend since she will also be out of town).

Dr. Goodwin asked Dorothy to prepare material before the meeting on the following: (1) how is California working with cancer survivors to establish research funding; (2) more information about cancer control funding in California; (3) meeting with Dr. Howell, and (4) sunsetting process and requirements.

C-CRAB Executive Committee Conference Call**August 26, 1998****9:00 – 9:45 a.m.**

Participants: Drs. Goodwin (Chair), Hopkins , Krischer, McGuire, and Dorothy Parker

Topic: Planning Advocacy Activities

Dr. Goodwin reiterated his enthusiasm for CCRAB's goals to work better with the Department of Health and to involve survivors and the advocacy community. The purpose of this call is to develop plans to keep these initiatives on track: specifically, to discuss plans for what has been referred to as an "advocacy summit." Dorothy mentioned that, during the 1999 legislative session, the Triagency Coalition will be seeking a portion of the state's tobacco settlement money for tobacco-related research. Ralph DeVitto (ACS) has asked if CCRAB wants to work with them in this effort.

There was discussion about Sandy Blank's memo regarding the Breast and Cervical Cancer Early Detection Program. It was suggested that CCRAB expand its network of survivor/ advocates to achieve broader representation, and that the proposed activities could be the mechanism for getting their input rather than expanding CCRAB membership to include more advocacy representatives. We could also work with the American Cancer Society (ACS) and their existing network of advocacy organizations. It was also suggested that future concerns or controversies, such as the one raised by Ms. Blank, be directed to, and addressed by, the individuals or agencies involved before sharing the information with the Executive Committee.

Dr. Goodwin asked if sponsorship of the "summit" should be CCRAB or a joint effort of CCRAB, the Department of Health and the ACS. It was agreed that it should be CCRAB since the Department of Health and ACS are represented on the Council.

Regarding the list of advocacy organizations compiled by Ms. Blank, it was agreed that we should expand the list. Dr. Krischer suggested that instead of inviting groups on the list, we could provide public notice of the event and ask groups who are interested to request time to present their concerns. We could look at how the President's Cancer Council operates, and learn from their experience. The committee supported this suggestion.

The objective is to get input not only on state funding for cancer control programs and research, but on policy issues. We would also like for the advocacy groups to endorse CCRAB's efforts to get funding rather than for each group to propose funding for their own organization.

Dr. Hopkins suggested the list of advocacy groups include youth tobacco groups, such as the SWAT teams and others involved in the State Tobacco Pilot Program, since they are advocates for preventive strategies to reduce cancer. He also suggested choosing a terms other than

"summit" to describe this event, e.g., public forum. The committee agreed with these suggestions.

Effective ways to provide public notice were discussed briefly. The Florida Administrative Weekly is the official mechanism but it is not widely read. Newspaper ads statewide would be expensive. The CCRAB newsletter is one mechanism, but we need to explore others. We also need to determine resources and administrative support needed. If costs do not exceed those for a regular CCRAB meeting, external funding will not likely be needed.

Action Plan:

1. Expand the list of advocacy groups
 - a. Follow up on Dr. Goodwin's letter to Gail Broader to see if she knows of other groups.
 - b. Send list to Bob Samuels.
 - c. Check with ACS
2. Plan the next CCRAB meeting for early December (half-day). Include a discussion of how CCRAB can support the Triagency Coalition's efforts to get money from the tobacco settlement money for cancer-related tobacco research.
3. Plan to have the public forum in conjunction with the spring CCRAB meeting. CCRAB will hold a business meeting in the morning, and the public forum will be in the afternoon. The meeting will be planned for May, after the legislative session.
4. Explore ways to provide public notice. Look into how this is done for other groups, such as the President's Cancer Council.

Proclamation

State of Florida
Executive Department
Tallahassee

WHEREAS, across the nation, prostate cancer is the most common form of cancer affecting men; and

WHEREAS, according to the American Cancer Society, more than 184,500 American men will be diagnosed with prostate cancer and 39,200 will die of the disease this year alone; and

WHEREAS, in 1998 an estimated 14,100 men in Florida will be diagnosed with prostate cancer, and an estimated 3,000 men in Florida will die from prostate cancer; and

WHEREAS, the risk of getting prostate cancer increases with age, and in Florida 88 percent of prostate cancers are found in men 60 years and older, and there are 1.5 million men in Florida in this age group; and

WHEREAS, in 1998 the Florida Legislature recognized the importance of education and informed decision-making about prostate cancer screening and created The Florida Prostate Cancer Task Force to identify where public awareness, public education, research, and coordination about prostate cancer are lacking, and to prepare recommendations to increase research on prostate cancer and the public's awareness of the importance of early detection and treatment of prostate cancer; and

WHEREAS, the legislature also charged the Cancer Control and Research Advisory Council with the development of educational material for prostate cancer patients and for men who are considering prostate cancer screening;

NOW, THEREFORE, I, Lawton Chiles, by virtue of the authority vested in me as Governor of the state of Florida, do hereby proclaim September 1998 as

Prostate Cancer Awareness Month

in Florida and urge all Florida men to become aware of their own risk and learn about screening options and all residents to become involved in the fight against prostate cancer through education and advocacy.



IN WITNESS WHEREOF, I
have hereunto set my hand and
caused the Great Seal of the
state of Florida to be affixed
at Tallahassee, the Capital, this
8th day of September in the year
of our Lord nineteen hundred
and ninety-eight.

Lawton Chiles
GOVERNOR

ATTEST:

Sandra Northam
SECRETARY OF STATE

**Cancer Control and Research Advisory Council
Breast Cancer Treatment Options Technical Advisory Group**

Miriam Bell, MPH, CHES
Health Educator
H. Lee Moffitt Cancer Center, Tampa

Miki Billian
Breast cancer survivor
Ft. Lauderdale

Sandra Blank *
Breast cancer survivor
Florida Breast Cancer Resource Network
Deerfield Beach

Linda Casey, ARNP *
Nurse Practitioner/Radiation Oncology
Tampa VA Hospital

Bobbi de Cordova-Hanks
Bosom Buddies, FCCJ Women's Center,
Jacksonville

Marcia DeSonier, RN, MSW *
Nurse/Social Worker
Baptist Hospital, Kugelman Cancer
Center, Pensacola

Beth Emsley, ARNP, AOCN
Nurse Practitioner
M.D Anderson Cancer Center Orlando

James Fiorica, MD *
Gynecologic Oncologist
H. Lee Moffitt Cancer Center, Tampa

JoAnn Green
Nurse
Breast & Cervical Cancer Program
Department of Health, Tallahassee

John Horton, MB, ChB, FACP
Medical Oncologist
H. Lee Moffitt Cancer Center, Tampa

Rita Mahaffey
Nurse
MD Anderson Cancer Center Orlando

George R. McSwain, MD *
Surgeon, Bradenton

Cathy Meade, RN, PhD
Nurse/Health Educator
H. Lee Moffitt Cancer Center, Tampa

Susan Minton, DO
Medical Oncologist
H. Lee Moffitt Cancer Center, Tampa

Jo Beth Speyer *
Director, Cancer Information Service
Sylvester Comprehensive Cancer Center
Miami

Alayne Unterberger, MA
Medical Anthropologist
University of Florida, Gainesville &
Tampa

Ann Von Spiegelfeld, MS, ARNP
Nurse Practitioner
H. Lee Moffitt Cancer Center, Tampa

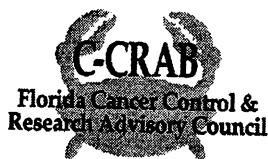
Sharlene Weiss, RN, PhD
Nurse/Psychosocial
Sylvester Comprehensive Cancer Center
Miami

* C-CRAB Members

ANNOUNCING . . .

Public Forum on Cancer

What is needed to improve cancer control and prevention efforts in Florida?



The Florida Cancer Control and Research Advisory Council (C-CRAB) is planning a public forum to solicit input from cancer advocacy groups, health care providers, and other concerned individuals on how to improve cancer control efforts in Florida.

DATE: June 17, 1999
TIME: 1:30 p.m. - 4:30 p.m.
LOCATION: Tampa Airport Marriott Hotel

Goals:

- To solicit public input for cancer control planning at the state level, and to get ideas for expanding the objectives and strategies in the *1998-1999 Florida Cancer Plan*.
- To translate ideas and suggestions into legislative or program initiatives.
- To form a group of health care professionals and other concerned individuals to plan and organize future advocacy efforts.

For more information, please return the bottom section to:

C-CRAB, Dept. of Cancer Control
H. Lee Moffitt Cancer Center & Research Institute
12902 Magnolia Dr., Tampa, FL 33612
Fax: (813) 632-1334 E-mail: parkerdf@moffitt.usf.edu

Please send me information on the June 17 C-CRAB Public Forum:

Name: _____
Organization: _____
Address: _____
City: _____ State: _____ Zipcode: _____
Phone: _____ Fax: _____
E-mail: _____



What does C-CRAB do?

What is C-CRAB and What Does it Do? The Cancer Control and Research Advisory Council (known as C-CRAB) was created by the Florida Legislature in 1979. The current mandate for the Council can be found in Chapter 240.5121, Florida Statutes. The Council's role is to:

Structure & Composition

Florida Cancer Plan

Breast Cancer Pamphlet

Prostate Cancer

Newsletters

How to Contact

- Advise the Governor, state legislature, and state agencies on cancer control issues.

- Prepare position statements on cancer-related legislation.

- Develop and approve the Florida Cancer Plan.

- Prepare and distribute a pamphlet on breast cancer treatment options and on prostate cancer screening and treatment.

- Pending the availability of resources, allocate funds for research and demonstration projects that address the priorities of the Florida Cancer Plan.

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Structure & Composition: There are 35 members on C-CRAB: 33 are appointed by the Governor, one by the President of the Senate, and one by the Speaker of the House. They represent public and private agencies, professional associations, cancer centers, universities, and consumers [[Click here for a list of organizations](#)]. Members are appointed for four-year terms.

The Governor also appoints a Chairperson who serves for two years. The Chairperson for 1997-1998 is **W. Jarrard Goodwin, M.D.**, Director of the Sylvester Comprehensive Cancer Center. The Executive Committee includes C-CRAB members from the four university-based cancer centers, the Florida Department of Health, the American Cancer Society, and others appointed by the Chair.

Newsletters: The C-CRAB newsletter includes updates on C-CRAB activities, plus state and national cancer news items. Click below to view the newsletters. (Note: The newsletters are in PDF format, and Acrobat Reader is needed to read them. If you do not have Acrobat Reader, you can download it for free.



- [January 1999](#)
- [Fall 1998](#)
- [Spring 1998](#)
- [Winter 1998](#)
- [Fall 1997](#)
- [Spring 1997](#)

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How to Contact

Dorothy Parker, Executive Director
Cancer Control & Research Advisory Council (C-CRAB)
H. Lee Moffitt Cancer Center & Research Institute
12902 Magnolia Dr.
Tampa, FL 33612

Phone: (813) 632-1339
Fax: (813) 632-1334
E-Mail: parkerdf@moffitt.usf.edu

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[Updated 1/25/99]

Administrative support is provided by the H. Lee Moffitt Cancer Center & Research Institute. The C-CRAB office is part of the Department of Cancer Control.

Technical Advisory Groups (TAGs) are created to address specific issues. The TAGs include C-CRAB members as well as others in Florida with expertise on the issue being addressed. In recent years, TAGs have been created on the following issues: state health care reform, cancer-related basic insurance benefits, Florida's cancer registry, breast cancer treatment options, and prostate cancer screening.

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Florida Cancer Plan: C-CRAB is required to approve a state cancer plan, and has done so since 1980. The most recent version was approved in December 1997. [CLICK HERE](#) to view the **1998-1999 Florida Cancer Plan** (in PDF), or [click here](#) to request a copy be mailed to you.

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Breast Cancer Pamphlet: Florida law requires physicians to inform patients diagnosed with breast cancer about the treatment options (Sections 458.324 and 459.0125, Florida Statutes). It also requires C-CRAB to prepare and distribute a patient education pamphlet that describes breast cancer treatment options (Section 240.5121 (4)(m)).

In 1996, C-CRAB developed a pamphlet with funding from the Florida Legislature. The pamphlet includes a description of breast cancer, and the types of treatment. It also explains clinical trials, bone marrow transplantation, and other related issues such as nutrition, rehabilitation, support groups, and follow-up care. A comprehensive list of resources is also included. The Legislature appropriated funds for FY 98-99 to revise the pamphlet, and to print a Spanish version. When the new edition is ready (by June 1999), it will be posted on this web site. To see the text of the pamphlet, *If You Have Breast Cancer: Information About Breast Cancer Treatment Options*, [CLICK HERE](#).

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Prostate Cancer: In 1998, the Florida Legislature gave C-CRAB a mandate to develop educational material on prostate cancer screening and treatment. Recommendations from the soon-to-be-created **Prostate Cancer Task Force** will be used to identify educational needs before new material is developed.

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