

Florida Cancer Control and Research Advisory Council



2005 ANNUAL REPORT

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

February 15, 2006

Michael E. Kasper, M.D., F.A.C.R.O., Chairman
Sue C. Middleton, M.H.A., Executive Director

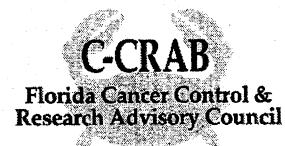
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Cancer Control and Research Advisory Council 2005 Annual Report

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HIGHLIGHTS

- ◆ The Council elected a new chair, Michael E. Kasper, M.D., F.A.C.R.O., following the retirement of the previous chair, JoBeth Speyer, M.S.W. Dr. Kasper is a Radiation Oncologist at Boca Raton Community Hospital and also serves as the President of the Florida Division of the American Cancer Society.
- ◆ CCRAB recommended to the Governor and the Florida State Legislature the passage of the Bankhead-Coley Research Initiative, which provides \$9 million in peer-reviewed research dollars to Florida cancer researchers.
- ◆ In order to discourage use of tobacco products by young people, CCRAB recommended to the Governor and the Florida State Legislature the passage of any statutes that would increase tobacco product price. It has been documented that increases in tobacco product prices can be directly correlated with decreases in tobacco use by minors.
- ◆ The Council partnered with the Departments of Health and Education, the U.S. Environmental Protection Agency and national philanthropic foundations to evaluate measures that can be taken to decrease Florida's melanoma and non-melanoma skin cancer rates.
- ◆ CCRAB membership voted to initiate a melanoma risk reduction Technical Advisory Group (TAG) entitled the Sun Awareness Education TAG. The Group is focusing on increasing sun awareness education in Florida's K-8 schools.
- ◆ CCRAB membership voted to initiate a Cancer Data Technical Advisory Group, which will evaluate the issues and data needs related to creation of a new statewide Cancer Plan.
- ◆ The Council Chairman, Dr. Michael Kasper and Executive Director, Sue Middleton met with the Secretary of Health, Dr. M. Rony François. The meeting focused on common goals and partnership opportunities.
- ◆ CCRAB increased communication with other leading Cancer Control groups in Florida, and initiated collaborations with the American Cancer Society and the Florida Dialogue on Cancer.
- ◆ The Council continued its work with the Florida Cancer Plan Council and the regional collaboratives to address implementation of the Florida Cancer Plan. The groups focused on four goals from the 2003-2006 Cancer Plan.
- ◆ The Council continued to distribute the Breast Cancer educational booklet "If you Have Breast Cancer." Approximately 5,000 copies were distributed in CY 2005 with both Spanish and English versions being requested. The response to the information continues to be positive and appreciated.

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SECTION 1: ADMINISTRATIVE UPDATE

1. CCRAB STATUTE

No changes were made to the Council statute (Section 240.5121, Appendix 1).

2. Membership

A list of members can be found in Appendix 2. The only new appointments during 2005, were Lance F. Grenevicki, D.D.S., M.D., F.A.C.S., who represents the Florida Dental Association, and Cynthia Brown, R.N., who represents the Florida Nurses Association. Cynthia Brown replaced outgoing member Linda C. Casey, A.R.N.P., M.S.C.

Other members leaving CCRAB in 2005 include JoBeth Speyer, M.S.W., who was Chairperson for nine months and represented Cancer Information Service. Donna Malvey, Ph.D., from the University of South Florida School of Public Health, moved to the University of Central Florida. Dr. Sean Tedjarati, who represented the Florida Society of Clinical Oncology, left his position in the State of Florida. These three positions have yet to be replaced. The terms of 10 other members ended prior to or during 2005, but the Governor has not yet made reappointments or new appointments.

3. Officers and Bylaws

JoBeth Speyer, M.S.W., acted as Chairperson for nine months of 2005, prior to her retirement. The Council voted to replace her with Michael E. Kasper, M.D., F.A.C.R.O. Dr. Kasper is a Fellow of the American College of Radiation Oncology and is a specialist in radiation oncology at Boca Raton Community Hospital. Dr. Kasper also serves as the current President of the Florida Division of the American Cancer Society and is a member of the Executive Committee of the Florida Dialogue on Cancer. Members of the Council and the Executive Committee are indicated in Appendix 2.

4. Meetings

The Council met on May 20, 2005 and September 30, 2005. The Sun Awareness workgroup met on December 13, 2005. Minutes of these meetings can be found in Appendix 3.

SECTION 2: SUMMARY OF ACTIVITIES

1. Legislative Initiatives

The CCRAB membership voted to support specific legislative efforts in the area of Cancer Control for the 2006-2007 legislative session. First, the Council recommended support of a \$9 million budget request for the proposed Bankhead-Coley Cancer Research Program under the Department of Health. Bankhead-Coley legislation would create and fund a competitive, peer-reviewed cancer research grant program. This legislation was offered by Representative Adam Hasner and by Senators Burt Saunders and Mike Fasano. Of particular interest to CCRAB is the support this bill offers for research into the prevention, diagnosis and treatment of Florida's second-leading cause of death and disability, cancer. The Council felt strongly that the program helps create a nationally prominent biomedical and research community in Florida that will be competitive in attracting research dollars to Florida.

CCRAB supports a second general category of legislative activity in the area of tobacco product price. The Council asked the Governor and legislative body to support legislation in general that would result in an increase in the price of cigarettes and other tobacco products, including special levees and other cost-increasing measures. It is clear that tobacco is the number one controllable risk factor in cancer deaths, creating an estimated 30% of all such deaths. Research has shown that as the price of tobacco products increases, the use among our youth in Florida decreases. A 10% increase in tobacco product cost results in an estimated 7% reduction in youth tobacco use. CCRAB membership supported this legislative action because a decrease in youth use of tobacco products is clearly an investment in the citizens of Florida, but is also a cost control effort to ultimately prevent numerous hospitalizations and resulting loss of life. Reducing tobacco use will reduce cancer and cancer related expenditures in the State of Florida.

Letters of support on these legislative efforts were sent from the Council to the Governor and to each member of the Florida House of Representatives and the Florida Senate.

2. Sun Awareness Education Exploratory Workgroup

Skin cancer is the fastest growing cancer in both the United States and the State of Florida, and current statistics show Florida ranks #2 in the nation for melanoma occurrence. People raised in Florida are at a greater risk of getting melanoma compared to those raised in other states with a lower UV index. The risk you assume as a child, based on your UV exposure and the UV index of your childhood home, is the risk you carry with you for life. In addition, all races and ethnic groups in Florida have a greater risk of getting melanoma when compared to states with a lower UV index. In 2005, the American Cancer Society estimates that 4,600 Floridians will get melanoma, and 600 or more will die from melanoma. These rates are expected to increase, particularly in younger age individuals. Based on the clear rise in the rates of skin cancer in Florida, CCRAB developed an exploratory workgroup to evaluate options for reducing melanoma

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and non-melanoma skin cancers in the State of Florida. The workgroup represented a partnership with the Departments of Health and Education, the U.S. Environmental Protection Agency and two national philanthropic foundations; the Curt and Shonda Schilling SHADE Foundation and the Richard David Kann Melanoma Foundation. The group met in December and reviewed the current activities of each key stakeholder and outlined how the groups could collaborate to bring about positive change.

As a result of the work group's efforts, CCRAB membership voted to create an official Skin Cancer Awareness Technical Advisory Group.

3. Development of Technical Advisory Groups

- A. CCRAB membership voted to create three technical advisory groups (TAGs), which shall be formed in 2006. The first Technical Advisory Group is the Skin Cancer Awareness TAG, which will be chaired by Robert Kirsner, M.D., Ph.D., of Sylvester Cancer Center and the Department of Dermatology at the University of Miami. Dr. Kirsner has significant research and clinical expertise in the area of melanoma and other forms of skin cancer. In addition, he has studied the Florida-specific issues related to occurrence, education and prevention.
- B. The Council also voted to develop a Florida Cancer Plan Data TAG. This group will look at cancer occurrence data and issues related to creating a 2007 State of Florida Cancer Plan.
- C. Finally, the Council membership voted to create a Cervical Cancer TAG to examine current rates, issues and new treatments related to cervical cancer.

4. Breast Cancer Booklet

In 1998, the Legislature appropriated \$50,000 to CCRAB to revise and distribute a breast cancer treatment options booklet. The Department of Health contracted with the H. Lee Moffitt Cancer Center, the fiscal agent for CCRAB, to disperse funds for this project. The booklet was revised with the assistance of CCRAB's Breast Cancer Technical Advisory Group, and reviewed by a group of breast cancer patients. A translator was hired to translate the booklet into Spanish.

English and Spanish versions of the second edition of *If You Have Breast Cancer... Information About Treatment Options* were printed in June. Sample copies and order forms were mailed to primary care and oncology physicians and to all accredited mammography facilities in the state. A total of 62,500 copies were printed (49,000 in English and 13,500 in Spanish).

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The second edition included a tear-out reply card for feedback on the usefulness and comprehensibility of the booklet. We continue to receive compliments from health care providers and patients who have received copies.

In 2005, approximately 5,000 copies of the booklets were distributed. Another 5,000 remain available for distribution in 2006. The Council will need to evaluate in 2006 whether or not this publication should be updated in either the Web or paper version, or both. Funds will need to be identified if the Council determines that the booklet should be updated and reproduced for distribution.

The booklet is available on the Internet in PDF format, and can be accessed from the CCRAb web page (www.moffitt.usf.edu/ccrab).

5. Cancer Plan 2003-2006 Implementation

The Council has worked with the Florida Cancer Plan Council on the implementation of four goals from the 2003-2006 Cancer Plan. The intent is to involve the key cancer stakeholders in each of four geographical regions of Florida through the already established cancer collaboratives. The Southeast Region collaborative, based at the Sylvester Cancer Center, is a true model for the other regional collaboratives and for others across the nation attempting to take a comprehensive approach to cancer control. Much progress has also been made through the efforts of the Florida Cancer Plan Council in engaging cancer stakeholders across the State of Florida.

The four Focus goals selected from 12 current goals in the State Cancer Plan addressed this year by the collaboratives and the Florida Cancer Plan Council are outlined in the table below:

	Goal and Strategy	Proposed Lead	Proposed Partner	Current Members
Goal 4	<p>Increase healthy behaviors associated with primary prevention of cancer among Floridians of all ages.</p> <p>Strategy 4b - Develop, implement and evaluate comprehensive school health education programs that address priority areas.</p> <p>Lead - Eric Sandler, MD</p>	DOE	Local School Boards, Florida Regional Cancer Collaboratives	<p>Brian Calkins</p> <p>Bobbi deCordova Hanks</p> <p>Pedro Diaz Pow-Sang, MD, CTR</p> <p>Eric Sandler, MD</p> <p>Patricia Spencer, MD</p> <p>Deborah Glotzbach</p> <p>Sue Higgins</p> <p>Laurie Osgood</p>
Goal 5	<p>Increase communication and collaboration among public and private cancer stakeholders statewide.</p> <p>Strategy 5c - Develop synergy among the state-wide initiative, Regional Cancer Control Collaboratives, and other stakeholders.</p> <p>Lead - Jan Domlesky</p>	DOH	CCRAB, Florida Regional Cancer Collaboratives, Universities, FDOC, Other Cancer Stakeholders	<p>Angela Adams, PhD</p> <p>Jan Domlesky, MPA</p> <p>Pedro Diaz Pow-Sang, MD, CTR</p> <p>Patricia Spencer, MD</p> <p>Deborah Glotzbach</p> <p>Sue Higgins</p> <p>Laurie Osgood</p>
Goal 7	Reduce disparities in Florida's cancer	AHEC	FMA, FHA	Angela Adams, PhD

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	burden. Strategy 7d - Build on existing efforts to educate healthcare providers to improve cultural competencies. Lead - Folake Odedina, PhD			Folake Odedina, PhD Pedro Diaz Pow-Sang, MD, CTR Deborah Glotzbach Sue Higgins Laurie Osgood
Goal 8	Enhance quality of life for Floridians with cancer and their families and friends. Strategy 8c - Provide training with continuing medical education credits for physicians, nurses, and medical and nursing students regarding quality of life issues affecting persons with cancer. Lead - Hope Wood	Florida Medical Schools	State and county medical societies' continuing medical education programs.	Brian Calkins Pedro Diaz Pow-Sang, MD, CTR Eric Sandler, MD Jill Tager Deborah Glotzbach Sue Higgins Laurie Osgood

CDC's Division of Cancer Prevention and Control defines *comprehensive cancer control* as "an integrated and coordinated approach to reduce cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation."

More information is available on the CDC web site:

www.cdc.gov/cancer/ncccp/index.htm.

6. Other State Cancer Control Programs

- A. **Florida Breast and Cervical Cancer Early Detection Program:** CCRAB continues to follow the progress of the Florida Breast and Cervical Cancer Early Detection Program. The program is funded by the federal Centers for Disease Control and Prevention, and is administered by the Florida Department of Health. It provides education, outreach, screening and diagnostic services to uninsured women in Florida.
- B. **The Florida Dialogue on Cancer (FDOC):** The Council Chairman and Executive Director continue to be active members of the Florida Dialogue on Cancer. The two groups are currently looking into ways they can partner to address cancer prevention in 2006 and beyond.
- C. **American Cancer Society (ACS):** CCRAB is working with the American Cancer Society in the area of cancer prevention. The Council is working to foster a collaborative approach for data-driven cancer control initiatives through the support and participation of the ACS. The process of revising the Florida Cancer Plan next year will offer opportunities for collaborative efforts.
- D. **Florida Cancer Data System (FCDS):** Florida's statewide cancer registry continues to be a valuable source of information about cancer incidence and mortality in Florida. The data have been used by CCRAB for the Florida Cancer Plan. The University of Miami School of Medicine, under contract with the Department of Health's Bureau of Epidemiology, runs FCDS. Data are available on the FCDS web site fcds.med.Miami.edu.

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- E. **Comprehensive Cancer Control (CCC):** The Division of Comprehensive Cancer Control in the Department of Health is an integral participant in the initiatives and activities of the Council. CCC is an important link between ideas, initiatives and implementation via the Department of Health.
- F. **Florida Cancer Plan Council (FCPC):** Florida Cancer Plan Council was established to help in implementing the State Cancer plan. CCRAB members are active members of the FCPC and the implementation teams.

7. Communications and Promotion

- A. **Meeting with the Secretary of Health:** The Council Chairman, Dr. Michael E. Kasper, and Executive Director, Sue Middleton, met with Dr. M. Rony François, Secretary of Health, in December to review the CCRAB agenda and identify areas of commonality in our respective missions. Dr. François was extremely supportive of the efforts of the CCRAB membership. He brings to his position experience in the area of cancer control and prevention. The Council membership feels strongly that a partnership with the Secretary of Health and Divisions within the Department of Health will be most effective in enacting positive change in cancer control in the state of Florida.
- B. **CCRAB Web Page:** The CCRAB web page (www.moffitt.usf.edu/ccrab) continues to provide general information about the Council, its activities, and its publications, such as the Florida Cancer Plan and the breast cancer booklet.

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SECTION 3: PLANS FOR 2006

During calendar year 2006, the Cancer Control and Research Advisory Council plans the following initiatives:

1. Monitor and issue position statements, as appropriate, on bills to be introduced during the 2007-2008 legislative session.
2. Assess the feasibility of updating and continuing to publish and print the Breast Cancer Treatment Options pamphlet.
3. Continue active dialogue with the Secretary of Health to implement comprehensive cancer control programs in the state of Florida.
4. Determine the needs related to the creation of a 2007 State of Florida Cancer Plan.
5. Develop a draft of the 2007 Cancer Plan.
6. Complete a pilot project in the area of Sun Awareness education partnering with the Departments of Health and Education and major skin cancer prevention stakeholders.
7. Develop a Technical Advisory Group and potential position statement related to Cervical Cancer in the State of Florida.
8. Continue to support and collaborate with other statewide cancer control agencies, e.g., the Comprehensive Cancer Control Program, the American Cancer Society, Florida Dialogue on Cancer and the Florida Cancer Plan Council.
9. Work with media outlets to inform the public about cancer control programs in Florida and about individual behaviors that aid in cancer prevention.

List of Appendices

1. Council Statute (Section 240.5121, Florida Statutes)
2. Council Membership List
3. Meeting Minutes
 - 3A Council Meeting Minutes, May 20, 2005 and September 30, 2005
 - 3B Sun Awareness Work Group Meeting Minutes, December 13, 2005
4. Legislative correspondence
 - 4A Letter to Governor Jeb Bush
 - 4B Sample letter to House and Senate Membership

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it is the only thing that ever has.”

Dr. Margaret Mead

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APPENDIX 1

Florida Cancer Control and Research Advisory Council Statute Section 240.5121, Florida Statutes (Amended 1998)

240.5121 Cancer control and research.--

(1) **SHORT TITLE.**--This section shall be known and may be cited as the "Cancer Control and Research Act."

(2) **LEGISLATIVE INTENT.**--It is the finding of the Legislature that:

(a) Advances in scientific knowledge have led to the development of preventive and therapeutic capabilities in the control of cancer. Such knowledge and therapy must be made available to all citizens of this state through educational and therapeutic programs.

(b) The present state of our knowledge concerning the prevalence, cause or associated factors, and treatment of cancer have resulted primarily from a vast federal investment into basic and clinical research, some of which is expended in this state. These research activities must continue, but programs must be established to extend this knowledge in preventive measures and patient treatment throughout the state.

(c) Research in cancer has implicated the environment as a causal factor for many types of cancer, i.e., sunshine, X rays, diet, smoking, etc., and programs are needed to further document such cause and effect relationships. Proven causes of cancer should be publicized and be the subject of educational programs for the prevention of cancer.

(d) An effective cancer control program would mobilize the scientific, educational, and medical resources that presently exist into an intense attack against this dread disease.

(3) **DEFINITIONS.**--The following words and phrases when used in this section have, unless the context clearly indicates otherwise, the meanings given to them in this subsection:

(a) "Cancer" means all malignant neoplasms, regardless of the tissue of origin, including lymphoma and leukemia.

(b) "Council" means the Florida Cancer Control and Research Advisory Council, which is an advisory body appointed to function on a continuing basis for the study of cancer and which recommends solutions and policy alternatives to the Board of Regents and the secretary and which is established by this section.

(c) "Department" means the Department of Health.

(d) "Fund" means the Florida Cancer Control and Research Fund established by this section.

(e) "Qualified nonprofit association" means any association, incorporated or unincorporated, that has received tax-exempt status from the Internal Revenue Service.

(f) "Secretary" means the Secretary of Health.

(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 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; 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 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

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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; 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).

(b) The terms of the members shall be 4 years from their respective dates of appointment.

(c) A chairperson shall be appointed by the Governor for a term of 2 years. The chairperson shall appoint an executive committee of no fewer than three persons to serve at the pleasure of the chairperson. This committee will prepare material for the council but make no final decisions.

(d) The council shall meet no less than semiannually at the call of the chairperson or, in his or her absence or incapacity, at the call of the secretary. Sixteen members constitute a quorum for the purpose of exercising all of the powers of the council. A vote of the majority of the members present is sufficient for all actions of the council.

(e) The council members shall serve without pay. Pursuant to the provisions of s. 112.061, the council members may be entitled to be reimbursed for per diem and travel expenses.

(f) No member of the council shall participate in any discussion or decision to recommend grants or contracts to any qualified nonprofit association or to any agency of this state or its political subdivisions with which the member is associated as a member of the governing body or as an employee or with which the member has entered into a contractual arrangement.

(g) The council may prescribe, amend, and repeal bylaws governing the manner in which the business of the council is conducted.

(h) The council shall advise the Board of Regents, the secretary, and the Legislature with respect to cancer control and research in this state.

(i) The council shall approve each year a program for cancer control and research to be known as the "Florida Cancer Plan" which shall be consistent with the State Health Plan and integrated and coordinated with existing programs in this state.

(j) The council shall formulate and recommend to the secretary a plan for the care and treatment of persons suffering from cancer and recommend the establishment of standard requirements for the organization, equipment, and conduct of cancer units or departments in hospitals and clinics in this state. The council may recommend to the secretary the designation of cancer units following a survey of the needs and facilities for treatment of cancer in the various localities throughout the state. The secretary shall consider the plan in developing departmental priorities and funding priorities and standards under chapter 395.

(k) The council is responsible for including in the Florida Cancer Plan recommendations for the coordination and integration of medical, nursing, paramedical, lay, and other plans concerned with cancer control and research. Committees shall be formed by the council so that the following areas will be established as entities for actions:

1. Cancer plan evaluation: tumor registry, data retrieval systems, and epidemiology of cancer in the state and its relation to other areas.
2. Cancer prevention.
3. Cancer detection.
4. Cancer patient management: treatment, rehabilitation, terminal care, and other patient-oriented activities.
5. Cancer education: lay and professional.
6. Unproven methods of cancer therapy: quackery and unorthodox therapies.
7. Investigator-initiated project research.

(l) In order to implement in whole or in part the Florida Cancer Plan, the council shall recommend to the Board of Regents or the secretary the awarding of grants and contracts to qualified profit or nonprofit associations or governmental agencies in order to plan, establish, or conduct programs in cancer control or prevention, cancer education and training, and cancer research.

(m) If funds are specifically appropriated by the Legislature, the council shall develop or purchase standardized written summaries, 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

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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 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 to reflect current standards of medical practice in the treatment of breast cancer and prostate cancer. The council shall develop and implement educational programs, including distribution of the summaries 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.

(n) The council shall have the responsibility to advise the Board of Regents and the secretary on methods of enforcing and implementing laws already enacted and concerned with cancer control, research, and education.

(o) The council may recommend to the Board of Regents or the secretary rules not inconsistent with law as it may deem necessary for the performance of its duties and the proper administration of this section.

(p) The council shall formulate and put into effect a continuing educational program for the prevention of cancer and its early diagnosis and disseminate to hospitals, cancer patients, and the public information concerning the proper treatment of cancer.

(q) The council shall be physically located at the H. Lee Moffitt Cancer Center and Research Institute, Inc., at the University of South Florida.

(r) On February 15 of each year, the council shall report to the Governor and to the Legislature.

(5) RESPONSIBILITIES OF THE BOARD OF REGENTS, THE H. LEE MOFFITT CANCER CENTER AND RESEARCH INSTITUTE, INC., AND THE SECRETARY.--

(a) The Board of Regents or the secretary, after consultation with the council, shall award grants and contracts to qualified nonprofit associations and governmental agencies in order to plan, establish, or conduct programs in cancer control and prevention, cancer education and training, and cancer research.

(b) The H. Lee Moffitt Cancer Center and Research Institute, Inc., shall provide such staff, information, and other assistance as reasonably necessary for the completion of the responsibilities of the council.

(c) The Board of Regents or the secretary, after consultation with the council, may adopt rules necessary for the implementation of this section.

(d) The secretary, after consultation with the council, shall make rules specifying to what extent and on what terms and conditions cancer patients of the state may receive financial aid for the diagnosis and treatment of cancer in any hospital or clinic selected. The department may furnish to citizens of this state who are afflicted with cancer financial aid to the extent of the appropriation provided for that purpose in a manner which in its opinion will afford the greatest benefit to those afflicted and may make arrangements with hospitals, laboratories, or clinics to afford proper care and treatment for cancer patients in this state.

(6) FLORIDA CANCER CONTROL AND RESEARCH FUND.--

(a) There is created the Florida Cancer Control and Research Fund consisting of funds appropriated therefor from the General Revenue Fund and any gifts, grants, or funds received from other sources.

(b) The fund shall be used exclusively for grants and contracts to qualified nonprofit associations or governmental agencies for the purpose of cancer control and prevention, cancer education and training, cancer research, and all expenses incurred in connection with the administration of this section and the programs funded through the grants and contracts authorized by the Board of Regents or the secretary.

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APPENDIX 2

Cancer Control and Research Advisory Council Membership List

* = Executive Committee Members

** = Terms ended in 2005; reappointments not yet made

Name & Address	Dates of Term	Organization Represented
Michael Alberts, M.D.**,* H. Lee Moffitt Cancer Center & Research Institute 12902 Magnolia Drive/MCC-VP Tampa, FL 33612	9/12/2002-12/1/2005	H. Lee Moffitt Cancer Center & Research Institute
Joyce A. Allan, M.P.H., C.T.R.** Registry Solutions Inc. 8431 Orient Way, NE St. Petersburg, FL 33702	9/12/2002-12/1/2005	Florida Tumor Registrars
Guy I. Benrubi, M.D. 653-1 West 8 th Street Jacksonville, FL 32209	7/31/05-12/01/07	Florida Obstetric and Gynecologic Society
Cynthia J. Brown, R.N. 14248 Eleventh Street Dade City, FL 33523	7/13/2005-12/1/2008	Florida Nurses Association
Joanne L. Bujnoski, D.O. Center for Cancer Care 5151 North 9 th Avenue Pensacola, FL 32504	5/21/2003-12/1/2006	Florida Osteopathic Medical Association
Linda C. Casey, A.R.N.P., M.S.N., O.C.N Radiation Oncology (124) James A. Haley VA Hospital 1300 Bruce B. Downs Blvd. Tampa, FL 33612	4/17/2002-12/1/2004 Ended appointment and replaced in 2005	Florida Nurses Association
Rose Marie Cossick 3905 Lombardy Street Hollywood, FL 33021	5/21/03-12/1/2006	General Public as a Consumer Advocate
Michele Delafranchi, L.C.S.W. Department of Clinical Social Work 1400 S. Orange Avenue, MP770 Orlando, FL 32806	5/21/2003- 12/22/2006	Florida Society of Oncology Social Workers
Marcia W. DeSonier, R.N., L.C.S.W. * Cancer Support Services Baptist Hospital P.O. Box 17500 Pensacola, FL 32522-7500	9/12/2002-9/12/2006	Florida Hospital Association
The Honorable Carl J. Domino State of Florida House of Representatives 3300 PGA Blvd., Suite 520 Palm Beach Gardens, FL 33410 Or 580 Village Blvd., Suite 225 West Palm Beach, FL 33409	6/4/2002-6/4/2006	State of Florida House of Representatives
Deborah W. Glotzbach* Program Administrator Bureau of Chronic Disease Prevention 4025 Bald Cypress Way, Bin A-18 Tallahassee, FL 32399-1744	4/23/2004- 12/31/2007	Florida Department of Health
Lance F. Grenevicki, D.D.S., M.D., F.A.C.S. Institute of Facial Surgery 1093 S. Wickham Road West Melbourne, FL 32904	7/13/2005-12/1/2007	Florida Dental Association

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Name & Address	Dates of Term	Organization Represented
Cynthia M. Harris, Ph.D.* 2989 N. Umberland Drive Tallahassee, FL 32309	5/21/03-12/22/06	Florida Agricultural & Mechanical University, Institute of Public Health
William H. Hartmann, M.D.** 5220 E. Longboat Blvd. Tampa, FL 33615-4232	4/17/2000-12/1/2004	University of South Florida College of Medicine
Stephen P. Hunger, M.D.** University of Florida 1600 SW Archer Road, Rm M401 Gainesville, FL 32610-0296	9/12/2002-12/1/2005	Florida Pediatric Society
D. Wayne Jenkins, M.D.**,* Medical Director M.D. Anderson Cancer Center Orlando 1400 S. Orange Avenue, Mail point 760 Orlando, FL 32806	5/21/2003-9/19/2005	Statutory Teaching Hospital Affiliated with a Community-Based Cancer Center
Marcos G. Joppert, M.D.** Oncology Physicians, P.A. 3253 McMullen Booth Road Clearwater, FL 33761	4/23/2004-9/19/2005	Florida Agency for Health Care Administration
Michael E. Kasper, M.D., F.A.C.R.O.* Boca Raton Community Hospital Dept. of Radiation Oncology 800 Meadows Road Boca Raton, FL 33486	5/21/2004-12/31/2007	American Cancer Society
John W. Kilkeny, III, M.D., F.A.C.S.** University of Florida HSC-Jacksonville, Dept. of Surgery 653-2 W. 8 th Street Jacksonville, FL 32209	9/12/2002-12/1/2005	University of Florida College of Medicine
Robert S. Kirsner, M.D. University of Miami Dept. of Dermatology 1201 NW 16 th Street Miami, FL 33125	5/21/2003-12/31/2008	University of Miami School of Medicine
James W. Lynch, Jr., M.D.*,** University of Florida Health Sciences Center Box J100277 JHMCH Gainesville, FL 32610	9/12/2002-9/19/2005	University of Florida Shands Cancer Center
Donna M. Malvey, Ph.D.** University of South Florida, College of Public Health MDC-56 13201 Bruce B. Downs Blvd Tampa, FL 33612	9/12/2002-9/19/2005	University of South Florida College of Public Health
Thomas A. Marsland, M.D. 2161 Kingley Avenue Orange Park, FL 32073	9/12/2002-9/12/2006	Association of Community Cancer Centers
Ronnie B. Martin, D.O. Associate Dean of Academic Affairs Nova Southeastern University College of Osteopathic Medicine 3100 North Ocean Blvd. #2608 Ft. Lauderdale, FL 33308	5/23/2004-7/1/2007	Nova Southeastern University College of Osteopathic Medicine
John W. Mason, M.D.** One Beach Drive Southeast St. Petersburg, FL 33744	9/12/2002-12/1/2005	Florida Society of Pathologists
Dorothy Parker, M.H.S. UM/Sylvester Comprehensive Cancer Center P.O. Box 016960 (D4-11) Miami, FL 33101	5/21/2003-12/22/2006	University of Miami Sylvester Comprehensive Cancer Center

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Name & Address	Dates of Term	Organization Represented
Todd Parrish 302 S. Highland Avenue Winter Garden, FL 34787	7/13/2005-12/1/2008	General Public Acting as a Consumer Advocate
Shyam B. Paryani, M.D.** Florida & Georgia Radiation Oncology Group 3599 University Blvd. South #1000 Jacksonville, FL 32216	4/17/2001-12/1/2005	Florida Radiological Society
Cathy J. Reed, M.S., R.D., L.D./N. Program Director Florida Dept. of Education Food & Nutrition Management 325 W. Gaines Street #1032 Tallahassee, FL 32399-0400	5/21/2004- 12/31/2007	Florida Department of Education
Eric Sandler, M.D. Nemours Children's Clinic-Jacksonville Div. of Hematology/Oncology 807 Nira Street P.O. Box 5720 Jacksonville, FL 32247-9946	4/3/2004-12/1/2007	Florida Association of Pediatric Tumor Programs
James G. Schwade, M.D. 9130 S. Dadeland Blvd. Suite 1528 Miami, FL 33156	7/13/2005- 12/31/2007	Florida Medical Association
The Honorable Jim Sebesta State of Florida Oaks at Gandy 9887 4 th St. North, #319 St. Petersburg, FL 33702	7/3/2002-7/3/2006	Member of the Florida Senate Appointed by the President of the Senate
JoBeth Speyer, M.S.W.* (Chair), ** Cancer Information Service Miami	12/22/98-9/1/05	Cancer Information Service
Sean S. Tedjarati, M.D., F.R.C.S** Assistant Professor/International Cancer Liaison University of South Florida/H. Lee Moffitt Cancer Center & Research Institute MCC-GYNPROG 12902 Magnolia Drive Tampa, FL 33612	4/23/2004-12/1/2005	Florida Society of Clinical Oncology
Tonja Lemon Webb Senior Analyst Governor's Office of Policy & Budget 2324 Hartsfield Way Tallahassee, FL 32303	4/23/2004- 12/31/2007	General Public Acting as Consumer Advocate

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**APPENDIX 3A
MEETING MINUTES**

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

Friday, May 20, 2005

Tampa Airport Marriott Hotel ~ 1:00 pm - 4:30 pm

MEMBERS PRESENT:

Ms. Marcia DeSonier, LCSW
Florida Hospital Association
Also representing: Michele Delafronconi, LCSW

Ms. Deborah Glotzbach
Department of Health

William Hartmann, MD
University of South Florida
Also representing: Dr. John Mason

Michael Kasper, MD, FACRO
American Cancer Society

Dorothy Parker, MHS
UM/Sylvester Comprehensive Cancer Center

Cathy J. Reed
Florida Department of Education

JoBeth Speyer, MSW
Cancer Information Service
CCRAB Chairperson

Sean J. Tedjarati, MD, FRCS
Florida Society of Clinical Oncology

GUESTS PRESENT:

Ms. Jan Domlesky
Coastal Partnership Program Manager
Cancer Information Service

Jamie Suarez, RHIT, CTR
Manatee Memorial Hospital Bradenton
for Joyce Allan, MPH, CTR

Ms. Sue Higgins
Department of Health

Ms. Kara O'Neil
*H. Lee Moffitt Cancer Center
& Research Institute*

Ms. Megan Wessel
American Cancer Society

Carol N. Weys, MA
American Cancer Society

MEMBERS EXCUSED:

Joyce A. Allan, MPH, CTR
Florida Tumor Registrars

JoAnne L. Bujnoski, MD
Florida Osteopathic Association

Ms. Rose Marie A. Cossick
General Public acting as a Consumer Advocate

Ms. Michele M. Delafronconi, LCSW
Florida Society of Oncology Social Workers
Institute of Public Health

Marcos G. Joppert, MD
Agency for Health Care Administration

Stephen P. Hunger, MD
Florida Pediatric Society

John Kilkenny, MD
University of Florida, College of Medicine

John Mason, MD
Florida Society of Pathologists

Eric Sandler, MD
Florida Association of
Pediatric Tumor Programs, Inc

Tonja Lemon Webb
General Public as Consumer Advocate

CCRAB STAFF PRESENT:

Mr. Brian J. Calkins
Program Director, CCRAB

Ms. Myrna G. Hastings
CCRAB Administrative Assistant

Welcome and Introductions

JoBeth Speyer, MSW, CCRAB Chairperson

Ms. Speyer opened the meeting by introducing herself and had each member, staff, and guest introduce themselves and the agency they represent. She also stated that this would be her last meeting as Chair and member of the C-CRAB. She thanked everyone for their support and said that it had been a wonderful experience for her and an honor for having served on this board.

Approval of Meeting Minutes October 22, 2004

JoBeth Speyer, MSW, CCRAB Chairperson

Marcia DeSonier requested that the October 22, 2004 minutes be amended to reflect that she was excused from the meeting because of a scheduling conflict. Dr. Kasper motioned for the amendment, Deborah Glotzbach seconded. The minutes were approved by all.

Election Results and Vote on New Chairperson

JoBeth Speyer, MSW, C-CRAB Chair

The election ballots resulted in two prime candidates. It was decided at the Executive committee meeting that follow up would be done with the two candidates to ascertain which candidate's schedule would best allow them to accept the Chair position at this time. Once a candidate was decided upon a new ballot would be sent to members for a vote.

We will have someone established before the next meeting.

Update on the 2005 Legislative Session

Michael Kasper, MD, American Cancer Society

Each year the American Cancer Society works with the Florida Legislature to pass laws and policies that can fund cancer research, ensure access to care, offer prevention, early detection, and quality cancer care to the medically underserved, and reduce suffering from tobacco-related illnesses. The following is a report of these issues during the 2005 Florida Legislative Session.

Cancer Research and Treatment

Florida Cancer Research and Treatment Act – The session ended with \$9 million for cancer research grants on the table unapproved. CS/SB's 1872 and 2378, which would have appropriated the funds and directed the Legislature to follow suit in ensuing years, passed the Senate, but was not acted upon in the House, as many potential deals fell apart in the last week of session.

Strong bipartisan support, including 81 members, over two-thirds of the House, as well as 9 of 40 senators eventually signed on to legislation that would provide a new source of funding to Florida cancer institutions and research through a competitive, peer-reviewed process. If eventually passed grants could be authorized to recruit new cancer research talent, fund operational start-up, and provide financial assistance for the construction of additional laboratory space to expand research capacity.

The Florida Cancer Research and Treatment Act, HB 1233, was sponsored by Reps. Adam Hasner, Ann Gannon (D-Delray Beach), Holly Benson (R-Pensacola), and others. Similar bills

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on the Senate side, SB 1872 by Sen. Burt Saunders (R-Naples) and SB 2378 by Sens. Mike Fasano (R-New Port Richey), Rod Smith (D-Gainesville), Jim King (R-Jacksonville), and others, were combined into a broader biomedical research package. The Senate legislation passed the upper chamber. The House legislation cleared one hurdle, the House Health Care General Committee. The lack of ultimate passage by both chambers notwithstanding, the cancer research issue garnered significant attention and is teed up well for the 2006 session and beyond.

James and Esther King Biomedical Research Program – The James and Esther King Biomedical Research Program supports Florida-based science involving basic and clinical research. Its goals are to research better prevention, diagnosis, and treatments of diseases related to tobacco use, advance biomedical research and healthcare work, and stimulate new initiatives in biomedical research that will attract additional funding and stimulate economic activity.

Session Result – The research program received a record appropriation of \$10.1 million for a second year, far above expectations from when the program was created.

Tobacco Control

Youth Tobacco Prevention – For the third consecutive year, the Legislature failed to address youth tobacco prevention education in any substantive way by appropriating only \$1 million this session.

Nonsettling Cigarette Manufacturers – A bid to require tobacco companies not a party to Florida's original tobacco settlement to pay a new fee to the State was put forth by Sen. Paula Dockery (R-Lakeland). Senate Bill 2012 would have provided \$16 million annually for youth tobacco prevention and was later amended to allocate up to \$25 million annually for the Florida Cancer Council by the Senate Commerce Committee. The bill did not advance any further, however, and the House version of the measure did not receive a hearing.

Clean Indoor Air – An effort to weaken the current Clean Indoor Air Act was successful with passage of a bill to benefit Sloppy Joe's in Key West. The legislation raises the stand-alone bar exception food threshold from ten percent to twenty percent for any establishment located within a building listed on the National Register of Historic Places. An aggressive effort to convince the Governor to veto this bill is underway.

Access

Closing the Gap Minority Health Initiative – Is a grant program designed to address the serious health disparities in access to care and health outcomes experienced by racial and ethnic minority groups. The funded communities implement projects related to at least one of six priority areas: maternal and infant mortality, **cancer**, HIV/AIDS, cardiovascular disease, diabetes and adult and child immunization. **Session Result** – This program will receive level funding for FY 2005-06 at \$5.7 million.

Mary Brogan Breast and Cervical Cancer Early Detection and Treatment Program – A program that allows women diagnosed with breast and cervical cancer through Florida's Breast and Cervical Cancer Early Detection and Treatment Program to qualify for a Medicaid waiver. Once enrolled in the Medicaid treatment program, a woman is assured complete health care

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access for the duration of her cancer treatment. **Session Result** – The program was appropriated \$6.3 million for FY 2005-06, sufficient funding to meet the current program needs.

Cancer Awareness Resolutions

Colorectal Cancer Awareness (March 05)	Sen. Dave Aronberg	Rep. Rich Glorioso
Cancer Control Awareness (April 05)	Sen. Dennis Jones	
Prostate Cancer Awareness (September 05)	Sen. Tony Hill	Rep. Frank Peterman
Breast Cancer Awareness (October 05)	Sen. Nancy Argenziano	Rep. Matt Meadows
Lung Cancer Awareness (November 05)	Sen. Paula Dockery	Rep. Air Porth
Cervical Cancer Awareness (January 06)	Rep. Anitere Flores	
20th Anniversary Relay for Life	Sen. Nan Rich	Rep. Julio Robaina
Minority Cancer Awareness (April 05)	Sen. Frederica Wilson	Rep. Arthenia Joyner

Appropriation Issues

ACS Appropriations Issues Summary - \$28.13 Million	
James and Esther King Biomedical Research Program	\$10.1 million
Youth Tobacco Control Program	\$1 million (with prohibitions on advertising)
Mary Brogan Breast and Cervical Cancer Early Detection and Treatment Program	\$6.3 million
Closing the Gap Minority Health Initiative	\$5.7 million
Cervical Cancer Elimination Task Force	\$30,000
Breast Cancer Research at University of Miami	\$5 million

I have to be frank that this was a very disappointing session for us overall. While there were several allocations made some probably more than we expected but the big issue that keeps coming back is youth tobacco control. This year we had a huge push for the Florida Cancer Research and Treatment Act. We felt this could gather quite a bit of steam and we thought we were doing very well as this was backed by the Florida Dialogue on Cancer Council. We felt that since they did create the organizational infrastructure for this that they would fund it at least in some way. And we started off in a big way and proposed a couple of funding mechanisms that we thought would be something to leap frog us into the area relative to other states and relative to the NCI currently. We were way down on the list as far as how much money we would receive. With all of the talk about Scripps we thought that this was an opportune time and a great idea to really improve cancer control. So the Florida Cancer Research and Treatment Act was proposed. We actually got 81 House members to co-sign the bill. That's two-thirds of the House, we also had a significant number of Senators as well so we were very encouraged by that and we did get quite a bit of publicity. There were some competing bills that we felt that together would move them in the right direction to get at least some funding. There was a proposal in the Senate which did pass which was significantly less, \$9 million a year, but it never passed in the House, which was hard to believe. Despite two-thirds of the House members and the people of Florida wanting this, it was not passed. It was very disappointing. I think what was even worse is that this was a year where we had an incredible surplus; we had a 2.2 billion increase in our budget revenues from the hurricanes above and beyond what we had before, so it wasn't a lack of money. It wasn't a lack of funding; it was clearly a lack of will. I think I have to tell you, we have a board meeting coming up and in light of all of this we're going to have a long look at

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what we need to do next to move our cancer agenda forward in the State. I think we can reach no other conclusion than that there is a lack of will, when the Florida Youth Tobacco only gets \$1 million. It's a disgrace.

We're taking a long hard look at again coming up with several constitutional amendments. CDC is spending 72 million to completely fund a good comprehensive tobacco youth campaign and we think that this should be funded as it's a small portion of the tobacco settlement monies. We're trying to find ways to fund research and treatment, perhaps coming up with a "user's fee" to increase the tobacco tax, since we're one of the lowest in the country on tobacco tax and we know how greatly that influences teen smoking. So I have to tell you that we are going to be looking at those items at our board meeting coming up next month.

Parker: I have a question; we had two-thirds of the House that signed on, but it never got to the House floor so they didn't get to vote?

Kasper: The original bill actually requested \$250 million and \$25 million up front; it was a total of \$500 million over a 5-year period. And when it came back from the Senate, a separate bill came back that was for a much smaller amount.

Higgins: Deb and I, because we're funded through the CDC are required to go to their annual meeting and so we attended the Colorado session this year. Colorado just got an excise tax done and it was a comprehensive cancer control program that did it. They were able to get \$28 million for their breast and cervical program alone. They did it and they were very effective and it was important for us to see because as you know we work with the Florida Cancer Plan Council (FCPC). We're a convener for that group. I think through the FCPC we can actually help you. We have four collaboratives throughout the State, so we could work with our Chairs that oversee these groups and ask them to put these important issues on their email distribution list, and ask them to put them on their agendas. If you give people a project they're willing to do it. People will come together better if there's a project. They won't come to a meeting, but if they know that they are actually working towards something they're willing to do it. So Colorado is a good example and I'm getting information from our counterpart on how they went about accomplishing their goals.

Parker: Actually we just had a meeting of the SE regional collaborative yesterday and they wanted to know who was the person for them to contact regarding advocacy issues.

Weys: Paul Hull

Glotzbach: At the same meeting in Colorado I met with the cancer coordinator for Delaware. Delaware is a state of 600,000 people. They get \$10 million for their comprehensive cancer control program in the matched settlement agreement, through their legislative process. It just shows the difference of what one state gives in comparison to another state. I know it's all political, but for 600,000 people they get \$10 million to do comprehensive cancer and Florida gets nothing. Their state legislators felt that it was important and they are actually increasing it this session to \$15 million. So it's a commitment from their Governor and their state representatives.

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Kasper: There have been an incredible number of states who have increased their tax recently and many of them have a republican house, a republican senate and a republican governor. We however in Florida have just completely come up against a wall.

Hartmann: This is a good report, but it's an incremental report. Maybe I'm supposed to know this. It seems to me that one of the things that we have to have is some idea of what the baseline funding for cancer control is in the state of Florida. I think that it would be better for us to know what the baseline allocation of monies is, assuming there is one.

Higgins: From the Florida Dept. of Health, what I can tell you is that from the master settlement of nearly \$440 million Florida is supposed to get, the tobacco program gets \$1 million. We also receive funding through the "Closing the Gap" initiative, which is one of the disparities programs. This is an initiative that started in 2000, in which they identified 6 areas of health disparities for minorities and ethnicities, and there is some money available for cancer but its only \$280,000. Those are the only dollars I'm aware of.

Hartmann: I respect your memory and it helps me very much. But I think we need something a little more formal. So that we know, what is the entire amount of money that is allocated on a yearly basis?

Weys: We have a historical allotment on the record for the Closing the Gap program as well as for the tobacco control program. We can print out the information for you.

Glotzbach: For comprehensive cancer for the DOH, we get no money from the State; we only get \$300,000 from the CDC.

Weys: We can break down which monies are coming from the State and which ones are Federal dollars.

Calkins: My question is how this would benefit our goal of additional legislative funding for cancer programs? These funding short comings are well known and documented. We all know where we rank in incidence, where we rank in funding and the legislative body is certainly aware of these issues, however, we don't seem to be getting any closer to obtaining the additional dollars necessary to achieve our goals.

Hartmann: It certainly can't hurt to have it documented, I'm assuming this will fit on an 8x11 1/2 sheet of paper. This would be a very powerful tool to give to your legislature on a weekly basis.

Glotzbach: I think it's fabulous, and I'm so glad that we have the American Cancer Society that can do this for us. But I also think that it's very important for individuals when you're down in your region of your county to hit up your legislators and let them know about these issues, that are very important to you and that they need to work on passing this legislation.

We all have CDHPE-Chronic Disease Health Promotion & Education specialists in other counties, there are 35 of them that cover the State. They're funded out of our heart disease and stroke prevention program, they're working on risk factors: Obesity, 5-a-day, tobacco, diabetes, heart disease and stroke. All the risk factors are cancer-related, so they are also like little soldiers out there in the State that can give information out on the local level and we have a direct tie to

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them. Dorothy has the distribution list of all the collaboratives so we have a large audience that we can get information out to and drum up business as well.

The Comprehensive Cancer Program does not provide the funding for their position, but we provide them with stuff, if you will. We provide fact sheets, packets of sunscreen and lip balm, we have even tried to push our skin cancer program. We also provide them information on colorectal cancer. We're building up our relationship with them, so even though we don't fund their position, we provide support.

This paper that Carol is going to put together is something that we can provide to all of these people, so they can get the word out to the people of Florida, to say, "look we're not getting our fare cut of things".

Higgins: I think it would be great for someone who is unaware of Florida's cancer burden and lack of funding. If we could compare the Florida cancer incidence data and funding with other states then they can see that we're not very successful.

Glotzbach: I think it is important for C-CRAB, not only to write to the Governor and the Secretary, because those letters will only wind up on my desk, but to write to the members of the Senate and House and specifically write to those members that sit on the Healthcare Committee. I think that it's very important to continually educate them on these issues.

DeSonier: If you start looking at the data, smoking is one behavior, but there are behavioral things that supposedly are responsible for the majority of cancers. If you look at goal #4 which is the 1st goal under the cancer plan, it's to increase healthy behavior associated with primary prevention of cancer among Floridian, and it talks about school programs, school educational programs.

That to me seems like a concrete piece of legislature that you might want to put together. Put something in the school programs that would change behaviors and ultimately reduce the risk and incidence of cancer. Research is wonderful, but we need to focus, and prevention and behaviors is the way to do it. So it seems to me that it's important for everyone to know what's not being said and yet if we're going to focus on something as a body, perhaps it needs to be something that's a part of this cancer plan that we are supporting. I think globally we're supposed to advice the legislature and we've not been able to do it very well, there are some mechanisms in place, but maybe we need to get something more focused and create a piece of legislation and try to get that supported.

Higgins: Actually, that's exactly what the goal 4 group headed by Dr. Sandler is working on. They are trying to get the tobacco dollars back to Florida, back to the appropriate programs. Sorry, I know I'm not a member, but maybe I could help clarify. Maybe the best way is we could make a motion to ask "how can the C-CRAB members help you achieve this goal?" This group obviously is committed to your initiative, what would you need them to do? Then you guys can make a motion whether or not you can do that action.

Kasper: If I were King or if I were Governor, I would be right with you and agree and say that's what we need to do. But back to reality, I think what you're saying is about getting money for the tobacco. I mean that's a simple thing. The first thing everyone thinks about is Scripps.

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Tedjarati: I am very concerned about health disparities in the State. We're looking at an initiative at Moffitt. Talking about creating a center for health disparities and it's going to focus not just on clinical trials but health services that affect a very diverse community of Hispanics and African Americans. Very simply, we just do not see the patients that don't have enough affiliation or partnership in the county or are not part of the county. We will address the specific issue of services for the underserved but more importantly understanding the biology of cancer in this population. If we're going to take on a cause, this is one that is going to happen. Not only because this is what Dr. Dalton, the CEO of Moffitt wants to do, but ultimately it is something mandated by the National Cancer Institute. About 2 weeks ago there was a meeting, an Association of Cancer Research, where the NCI Director and all the Cancer Center Directors were there and the main focus of it was on cancer health disparities in the United States. The problem is that they mandated a certain amount of patients be enrolled in clinical trials and other services, yet the money has actually gone down from the Federal level. Still, I think it would really be critical and politically very smart to go to the legislators with one mandate from this committee to be focused on really addressing and reducing the issues of cancer health disparities in this State. This is a very diverse State. We have in some areas of this county 22% Hispanics and we see less than 3% of them. There are biological issues in addressing cancer and there are services that need to be addressed. I would recommend that this be our focus, and pardon my ignorance if I'm just repeating something that has already been discussed. I think this would be a very strong way of combining both prevention and care in cancer health disparities as we can present smoking issues as a part of it. Look at an area that has a high incidence, for example cervix cancer, that is related to smoking or other cancers that have a relationship as part of your education and prevention package. The issue of clinical trials and the lack of trust in the research community is another issue. This is something that Moffitt is going to do. I know that Dr. Dalton has asked me to put in up to 50% of my time into focusing on this. There is no question that this is going to happen. This is just a suggestion that would be something that we could think about as our focus. It needs to be directed to the legislature that they have to put money aside as this is a critical issue in the nation. If you look at our cancer incidence data and the fact that the death rate has gone up as well it become very important. It is not just the intervention, it is not just that people don't have health insurance; there are so many issues to address.

I have been working on a model in Costa Rica that looks at indigenous populations in the mountains that are very similar to some populations here. Epidemiology studies on cervical and breast cancer have provided certain models for populations that are essentially isolated. Their isolation is not that different from our patients here and Costa Rica is a country that has a decent health screening program. There are populations here that don't have access to proper screening and healthcare, but there is still the question of how to get funding. C-CRAB Meeting

Weys: We have a meeting next month with our volunteers and we will be discussing what our priorities will be for 2006. What we can do then is publish what our priorities will be and present them to the C-CRAB. Something that states "this is how we will be proceeding in 2006, etc.," which gives you then the chance to look and say our priority and initiatives should maybe be, such and such.

I will be sharing a history of breast and cervical, early detection programs, screening and treatment dollars and history of the youth tobacco prevention funding, history of closing the gap funding, history of comprehensive cancer control funding, history of cancer registry's funding,

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history of Moffitt's funding as well as the history of the funding and the history of where the Florida funding sources are from. I also have a request that will include a comparative study of how our State compares to comparable states. I will admit that the 2nd piece will require a 2nd sheet. You will have 1 to 2 pages.

Glotzbach: I have a comment and a question. After the ACS board meets to make the decision of where their focus is going to be for 2006, is that something that you could share with us so that I can send that out to my distribution list of over 400 people. I think it's something that's going to be important for those people out there in the counties to see, particularly the comparison data of the comparable states. I think that's going to light a fire.

Weys: As soon as the 2006 agenda is approved, I'll make that available as well.

Florida Cancer Plan Council Formation/Activities

Jan Domlesky, MPA, CIS

Many of you were involved in the formation of the Plan, I think it was two years ago. We put stickers up on the wall and talked about goals and what your priorities were. From that we got the Florida Cancer Plan. All of you wrote it, contributed to it and approved it. There was a period of maybe about a year that there was not a lot done with it. We were thinking of how to implement it. We had a great Plan, we didn't want it to meet the fate of a lot of other cancer plans which was the lack of implementation. So we had an opportunity for a number of people from Florida to go to a Leadership Institute that the National partners from CDC, ACS and NCI put on.

A leadership institute group from each state was invited and a number of us went to it last July. We decided then that we would form what is now know as the Florida Cancer Plan Council with the idea that this would be the implementation arm of the Plan. There is C-CRAB and a number of other cancer organizations like the Florida Dialogue on Cancer so why do we need another organization? This is the only organization, The Florida Cancer Plan Council; that is actually charged with rounding up people to implement the Florida Cancer Plan. We are not the only people that are presumed to do this, but we're the people that we hope will give a little bit of push and impetus to the organizational structure around the implementation of the Florida Cancer Plan. So after the leadership institute of last July, we have met several other times and we now have bylaws and have four work groups formed. The Florida Cancer Plan has 12 goals and a number of strategies so when we, the Florida Plan Council, looked at it we thought it's really difficult to work with 12 goals and numerous strategies at one time. So we thought we would take four focus goals to get started and direct our attention on them this year.

The Council has decided to turn their energies into the following four goals and strategies as their focus:

	Goal and Strategy	Proposed Lead	Proposed Partner	Current Members
Goal 4	Increase healthy behaviors associated with primary prevention of cancer among Floridians of all ages Strategy 4b- Develop, implement and evaluate comprehensive school health education programs that address priority	DOE	Local School Boards, Florida Regional Cancer Collaboratives	Brian Calkins Bobbi deCordova Hanks Pedro Diaz Pow-Sang, MD, CTR Eric Sandler, MD Patricia Spencer, MD Deborah Glotzbach Sue Higgins

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	areas. Lead - Eric Sandler, MD			Laurie Osgood
Goal 5	Increase communication and collaboration among public and private cancer stakeholders statewide. Strategy 5c- Develop synergy among the state-wide initiative, Regional Cancer Control Collaboratives, and other stakeholders. Lead - Jan Domlesky	DOH	C-CRAB, Florida Regional Cancer Collaboratives, Universities, FDOC, Other Cancer Stakeholders	Angela Adams, PhD Jan Domlesky, MPA Pedro Diaz Pow-Sang, MD, CTR Patricia Spencer, MD Deborah Glotzbach Sue Higgins Laurie Osgood
Goal 7	Reduce disparities in Florida's cancer burden Strategy 7d- Build on existing efforts to educate healthcare providers to improve cultural competencies. Lead - Folake Odedina, PhD	AHEC	FMA, FHA	Angela Adams, PhD Folake Odedina, PhD Pedro Diaz Pow-Sang, MD, CTR Deborah Glotzbach Sue Higgins Laurie Osgood
Goal 8	Enhance quality of life for Floridians with cancer and their families and friends. Strategy 8c - Provide training with continuing medical education credits for physicians, nurses, and medical and nursing students regarding quality of life issues affecting persons with cancer. Lead - Hope Wood	Florida Medical Schools	State and county medical societies' continuing medical education programs.	Brian Calkins Pedro Diaz Pow-Sang, MD, CTR Eric Sandler, MD Jill Tager Deborah Glotzbach Sue Higgins Laurie Osgood

Domlesky: What we hope to do today is to generate a little bit of enthusiasm toward working on these goals. Maybe you or someone from your organization will say, "yeah this is what we're thinking about working on in our organization and we would like to work on it with you". So we're going to have a little bit of presentation about each of these goals so that you can sort of know what these goals are and what the different groups are doing. So the first goal being goal 4, I'm going to hand it over to Brian who is on that workgroup.

Calkins: What we are focusing on is how to get anti-smoking education back into the school system without reinventing the wheel. As of our last meeting we are researching what types of educational videos already exist for elementary and middle schools. Videos that we can reproduce if necessary at a minimal cost and then begin working with the Department of Education, after going through the proper state channels, to get out into the school systems and see if we can get them to commit throughout the different counties to showing these videos, possibly at the beginning of the school year. Someway to get youth tobacco education back into the school system without having to spend a great deal of money. There are a lot of materials available out there that were successful before the funding was cut, materials that have already been produced and paid for so why not utilize what's available and see what we can accomplish with limited resource. We have the mechanisms in place; however we will need to get the Department of Education to buy into the plan.

Domlesky: Through the Child Reauthorization Act we are required to form a wellness committee and we're working on that with the DOH and SHAC (School Health Advisory Council). So this is a vehicle that we can just piggyback because we're already working on it. It is all part of the big picture and once the SHAC's are established then that's a vehicle that can be used to get that information into the schools.

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Calkins: That is the type of vehicle and commitment we have been looking for. It demonstrates how each of us as a member and individual can participate in actually accomplishing some of these goals. If we can get the youth tobacco information back out there into the schools we will have taking a large step in the right direction.

Domlesky: We have a lot of information and videos already going out to the schools. What we're hoping to do is go back to the schools and determine what's good what's not good, what things should we not invest our time and money into. Sort of do a resource of what's out there and see what's being used, what's not being used, and what is successful. That way we can provide, whether we have to write a grant for this or however we get the money, for those videos or teaching material, for example: "this is working great in Escambia county can we get that down in Hillsborough county too?" That way we are not just buying stuff that isn't being used. I know that everything that the Tobacco program bought was evaluated. There are a lot of teaching modules out there and we just want to see what the teachers are using, what the districts are using, what's good, what's not good. There are a few things that we're addressing and one is how to evaluate what synergy is. How do we evaluate what collaboration is, how do we evaluate communication. Deborah why don't you tell the group about the evaluator.

Glotzbach: As part of our grant last year, CDC requested that we do some kind of evaluation, as the comprehensive cancer control program at the CDC is relatively new and only been in place for the past 4-5 years. They don't have any standard evaluation of what the programs do, it's a sort of you make it up as you go kind of thing. Some of the programs, the state of Washington, Michigan, and Iowa have been around a little bit longer than we have, so they have come up with a survey instrument. Sue and I attended the last meeting in Atlanta and when we were there a couple of weeks ago we met with the evaluation folks. We contacted an evaluator who is now working with us and who is developing an instrument to measure synergy, collaboration, with questions like: how do you feel about the cancer council? How do you think the collaboratives are working? How do you think the groups are working?

The person from Washington's name is Melody. She is working on the evaluation instrument, and her counterparts will be interviewing everybody that is on the Florida Cancer Plan Council, not only as a council member, but also if you are a goal leader. She will also have separate questions for Jan as the Chair to get a baseline of what's happening. We are working with her to do that. This should all be completed by June 30th, 2005.

We should get our new grant from the CDC July 1, and we'll have another little pot of money to be able to do more evaluations for next year. We're building an evaluation module because that's what the CDC wants.

Higgins: Goal 7-Reducing disparities in Florida's cancer burden. I would encourage anyone who is interested to participate in this group. Folake is leading it; she is actually a professor at FAMU in the college of pharmacy. She has been very successful obtaining funding. She is in the 2nd year of a grant she has from the DOD for a \$1 million, to increase minority participation in clinical trials. Dr. Tedjarati, I think you would be very interested in talking to her. She is actually working with Moffitt right now. Our local hospital is tied to Memorial Hospital-TMH activities. She is a very effective motivator and speaker. We are currently looking at cultural competencies throughout the State, what training is being conducted with medical personnel. They're going to bring it together and share the best practices for those who don't have any. So that's currently

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the task that they're working on right now, gathering that information. They are also looking at developing a survey instrument to find out what's happening as far as cultural competency. They are going to develop the questions, short, one page, no more than 10 questions on the survey through email. We're going to work with our epidemiologist in the office of survey solutions. We are going to distribute it out to our 400+ distribution list to get this information out. Her dollars that she's getting are specifically for prostate cancer and she wants to focus not just looking at African-Americans, but also looking at Nigerian populations. She definitely has a passion and she has a lot of great contacts. I'm sure she would more than want to work with you. Because she's with the college of pharmacy, she has access to every single pharmacist and pharmaceutical company, her contacts are amazing.

Glotzbach: Goal 8-is the quality of life concept goal. Hope Wood who is a nurse with the breast and cervical cancer program, is the lead and this is her passion. She has taken it on. She has been working very closely with the cancer-care person at CDC gathering information that she's been distributing out to her goal members. She is also attending a conference in June in Virginia relating to this issue. It is put on by the American Society of Clinical Oncology, and encompasses education, palliative care and an end-of-life care project through the NCI. It's a workshop, a sort of train the trainer session. The Comprehensive Cancer Control Program is paying for this training, and as soon as she comes back, we will get her out into the communities to train the trainers on end of life care. If you have anyone interested, please contact Deb and we can get you in touch with Hope to have her come to your area. It is specifically geared for palliative care.

DeSonier: I have a concern. How, as someone who works with cancer patients who don't necessarily have end of life issues, did you get from quality of life to end of care and palliative care so quickly? Because it would seem to me that pain management and other quality of life issues are also an important aspect of this. Palliative care, end of life issues to me are really different from quality of life issues with cancer patients. I realize I missed the meeting and I do apologize because I couldn't be there. I would hate for the world to think that quality of life for cancer patients is only palliative care.

Glotzbach: Right, this is goal 8 and it's only one of the strategies.

DeSonier: Right, but when you look at the other, it's kind of fuzzy. I was just at a meeting this morning with the Florida Pain Initiative who has partnered with ACS in that group. We're looking at how to inform people of their right for pain management and how to access resources. To me that fits in really well with Goal 8. There is a lot being done with palliative care and part of the problem with palliative care is that the general population I don't think understands that truly palliative care begins with the day that you're diagnosed. There are more people living with cancer who have quality of life issues than people dying who have palliative care end of life issues. That's my concern.

Glotzbach: I do know that she is getting information on pain management also. I think she's doing the whole gamut.

Higgins: I would love for you to help with Goal 8. Please come on board and ensure that when we do this with Hope that we are addressing all aspects of this. I don't want to overlook anything because this is one of our priority goals and we would love your input on this project.

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DeSonier: I would be happy to do that, I feel very strongly about this and I struggle daily because people do not understand palliative care but they tend to associate it with end of life which is not necessarily the case and there are lots and lots of people living with cancer that have quality of life issues that need to be addressed.

Higgins: I can tell you that I do know what I learned from Hope is that she's working with Eric and they're trying to do training with pediatricians and for those dealing with adult cancer. I know that Eric has developed a power-point presentation for pediatricians and I know he wants to use it as a tool to use with other pediatric oncologists and I know he is currently working on the adult cancer program as well.

Domlesky: For anyone that is interested we would encourage you to let us know what goal you and your organization would like to be involved in so we can include you in the conference calls.

Glotzbach: We at the DOH act as a convener, we try to set the conference calls up for everybody; we send the information out, we work with the goal leaders on the agenda. The SE collaborative has really wrapped their arms around the goals and the groups, so they are doing their own little thing in the SE collaborative and what we want to do is work with the other regional collaboratives to get them to do the same thing. When someone comes up and asks, "what have you done?" we can show them we are moving ahead. Even though we don't have funds, we are moving ahead and doing things. I can only imagine what we could get accomplished if we had funds.

Domlesky: We're working on two levels, we're working on statewide workgroup-affinity groups and also the collaboratives have taken the four focus goals and are working on a regional level on these goals. The SE collaborative has taken on a life of its own.

Parker: Actually yesterday we had a meeting with the SE collaborative, and it's really amazing how the group is changing with new people coming on.

Domlesky: The Affinity workgroups came up with specific action steps.

Regional Workgroups	Youth Tobacco Prevention Workgroup	Synergy Workshop	Disparities Workgroup	Palliative Care Workgroup
Corresponding state goals, strategies and affinity groups	State Goal 4-Prevent cancer State Strategy 4B- Enhance school health education State Affinity Group 4B-fund the State youth prevention tobacco program at 1999 levels.	State Goal 5-Better communication and collaboration between stakeholders State Strategy 5C- Synergy Affinity Group 5C- Develop Resource Directories throughout Florida	State Goal 7- Reduce disparities State Strategy 7A- Better data collection, analysis and dissemination on race, ethnicity and SES Affinity Group 7A- reduce cancer disparity burden for minorities	State Goal 8-Increase quality of life for patients and families State Strategy 8C-to provide CMEs to physicians, nurses and students on palliative care and quality of life issues Affinity Group 8C- implement EPEC programs throughout Florida.
State and SE Regional Leaders (and contacts)	SE Leader: Pedro Diaz Pow-Sang SE Co-Leader: Debra Eddington State Leader: Eric	SE Leader: Carthy Thomas SE Co-Leader: Barbara Hartstein State Leader:	SE Leader: Martha Oliveros SE Co-Leader: Angel Loor State Leader:	SE Leader: Phil Fusca SE Co-Leader: Joanne Leahy State Leader: Hope Woods, RN

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	Sandler, MD DOH Contact: Greg Smith	Jan Domlesky DOH Contact: Deborah Glotzbach	Folaki Odedina, PhD DOH Contact: Betty Smith	DOH Contact: Hope Woods, RN
SE Collaborative Members	Latasha Moore FCCCI Staff: Rita Soza	Amparo Alvarez Helga Snure Arleen Uria-Speed Rose Marie Cossick Nicole Kellier FCCCI Staff: Islara Souto	Debra Eddington Pascale Auguste Linda Lott Nicole Kellier Marta Oliva Natasha Moore Carole Todini FCCCI Staff: Dorothy Parker	Phyllis Sullivan Debra Eddington Linda Lott FCCCI Staff: All

Domlesky: Four years ago there was very little going on except for C-CRAB. And now there has been an incredible amount of talk between organizations, not only at the statewide level but at the local level. When we started the collaboratives with the comprehensive cancer control initiative, people were not talking to each other. Now people are really talking to each other, getting to know each other's programs, working together on certain projects. It's really amazing to see how things have progressed in four years. We have to keep that going.

Calkins: I would like to reiterate that our goal is not to have another cancer plan that just sits on the shelf and collects dust. The idea is to at least take something from the plan, even without funding, possibly as a grass roots initiative and truly try to accomplish something. Then we can at least turn around and say to the legislators, "This is what we are accomplishing without your assistance, what are you doing to help?" We keep sending letters and putting our support behind general statements, when they are well aware of the cancer burden in the State, yet nothing is being done on their part.

Tedjarati: If we could pick an area that could be our success story anywhere in the State, if there's an area that really doesn't have a valid focus as a major issue that's cancer related it would be either intervention or screening. I think that would be really helpful. Take that as a success story to the legislators. It sort of feels like everything is all over the place and there's not really an area that we can focus on. I think that would give a lot of credibility.

Calkins: Your disparities project sounds like a viable project with actual backing from Moffitt, perhaps we could use that as a stepping stone. When will you begin to roll out the program?

Tedjarati: July 1st we will begin to roll it out in Hillsborough county.

Next Steps for C-CRAB/Open Discussion

Higgins: We at the DOH are already discussing how to proceed with the next Cancer Plan. As you know the current Plan was for 2003-2006. We would like to start gearing up for updating the Plan. We worked so well with C-CRAB that we would like to come back to you and say we need your input on updating the report? What should the next Plan look like, etc.? I don't necessarily want to create a whole new plan but perhaps an updated version for 2006-2007 with a report showing what we have accomplished.

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DeSonier: I think we could use the Cancer Control Planet information that documents where the problems exist; which is something we did not do when we started this Plan the last time. We took a global approach as to what the needs were and we did not have hard data as I remember. It would seem that by maybe going to the Cancer Control Planet and updating where real problems exist and figuring out how they fit into the current Plan's goals that are either being worked on or goals that we would need to then create.

Higgins: I would like to encourage that we use the FCDS data which would give a clear picture of Florida. We want and need your input. We would like to come up with some kind of mechanism that would give the DOH some input from C-CRAB to find out how the next plan should look. Some means, I don't know if you want to get on a conference call, or if you would prefer to fill out a form. I am not certain yet what it would take logistically but we want your input in the next Plan. You all were pivotal in the first one. We want to have something in place by January 1, 2007. The current Plan goes through 2006. We want to have something in place by 2007 for distribution.

Speyer: It would be good to have that on the next meeting's agenda.

Brian Calkins presented JoBeth Speyer with a plaque thanking her for her years of service on the Council and as the Chairperson.

JoBeth Speyer thanked everyone again and said it was an honor to have served on the council.

Adjourn

JoBeth Speyer, MSW, C-CRAB Chairperson

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MEETING MINUTES

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

Friday, September 30, 2005

Tampa Airport Marriott Hotel 1:00 pm – 4:30 pm

MEMBERS PRESENT:

Joyce A. Allan, MPH, CTR
Florida Tumor Registrars

Cynthia J. Brown, RN
Florida Nurses Association

JoAnne L. Bujnoski, DO
Florida Osteopathic Association

Ms. Rose Marie A. Cossick
Consumer Advocate General Public

Ms. Michele Delafronconi, LCSW
Florida Society of Oncology Social Workers

Ms. Marcia DeSonier, LCSW
Florida Hospital Association

Ms. Deborah Glotzbach
Department of Health

Lance F. Grenevicki, DDS, MD, FACS
Florida Dental Association

Stephen P. Hunger, MD
Florida Pediatric Society

Marcos G. Joppert, MD
Florida Agency for Health Care Administration

Michael Kasper, MD, FACRO
American Cancer Society

Ronnie B. Martin, DO
NOVA Southeastern Univ., College of Osteopathic Medicine

John Mason, MD
Florida Society of Pathologists

Dorothy Parker, MHS
UM/Sylvester Comprehensive Cancer Center

Todd Parrish
Consumer Advocate General Public

Cathy J. Reed
Florida Department of Education

Eric S. Sandler, MD

MEMBERS ABSENT:

Guy I. Benrubi, M.D.
Florida Obstetric and Gynecologic Society

Honorable Carl J. Domino
Florida House of Representatives

Cynthia M. Harris, Ph.D.
Florida Agriculture & Mechanical Univ., Institute of Public Health

Robert S. Kirsner, MD
University of Miami, School of Medicine

Thomas A. Marsland, MD
Association of Community Cancer Centers

Honorable Jim Sebesta
Florida Senate

GUESTS PRESENT:

Sue Higgins
Comprehensive Cancer Control Program, DOH

Carol N. Weys, MA
American Cancer Society

Cynthia Seaborn
National Cancer Institute, Cancer Information Services

Pedro Diaz Pow-Sang, MD, CTR
Broward General Comprehensive Cancer Center

Laurie Osgood
Comprehensive Cancer Control Program, DOH

CCRAB STAFF PRESENT:

Brian J. Calkins
Program Director, CCRAB

Myrna G. Hastings
CCRAB Administrative Assistant

Sue Middleton, M.H.A.
Executive Director, CCRAB

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Florida Association of Pediatric Tumor Programs

James G. Schwade, MD
Florida Medical Association

Tonja Lemon Webb
Consumer Advocate General Public

William Hartmann, MD
University of South Florida School of Medicine

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Welcome and Introductions

Approval of Meeting Minutes May 20, 2005

The inclusion of 'Cancer Control PLANET' in the minutes was discussed. The term PLANET is an acronym for Plan, Link, Act, Network with Evidence-based Tools. Cancer Control PLANET is a collaborative effort between the National Cancer Institute, Centers for Disease Control and Prevention (CDC), American Cancer Society and other national partners, which provides access to Web-based resources. The minutes were approved.

New Chairperson and Executive Director

Brian Calkins, outgoing Executive Director of CCRAB, introduced Sue Middleton as the new Executive Director of CCRAB. Mr. Calkins then introduced Dr. Michael Kasper as the newly elected Chairperson of CCRAB, since the previous Chairperson, JoBeth Speyer retired. Dr. Kasper expressed his desire for a new beginning for CCRAB. He stated that he was very interested in working closely with the membership and receiving input for the future and ensuring that efforts will be targeted to most effectively fight cancer in the state of Florida.

Update on the 2005 Legislative Session

Dr. Kasper, the current President of the Florida Chapter of the American Cancer Society (ACS), outlined the ACS' 2005 legislative agenda which was described as "very ambitious" focusing on three main initiatives: 1) cancer research & treatment; 2) tobacco product price increase; and a new item which has not been seen in previous agendas, 3) the new Citizens Initiative process to promote youth tobacco education.

Dr. Kasper detailed the history of the first initiative, cancer research and treatment, as an initiative started by the Florida Dialogue on Cancer (FDOC) and Florida Cancer Council (FCC). In the 2005 legislative session, a proposal was submitted requesting \$500 million over 5 years, for cancer research and treatment. This was an ambitious plan with clear benefits in cancer research and treatment, but also economically a win for the state. This bill had incredible support in both the House and Senate, but was not endorsed at the highest level. The current legislative proposal is still in the process of negotiation and you will be hearing more about this bill as it is finalized. Carol Weys, from American Cancer Society explained that the overall goal of this ACS program is to fund and maintain more cancer researchers and keep researchers in the State of Florida. As state funding increases more cancer research programs are established, and more federal and private funds follow. The current thought is the funds would be allocated through an ACS peer review competitive grant award process.

The second ACS initiative is in the area of a **tobacco price increase**. Based on studies, as the price of tobacco goes up, the usage goes down. A decrease in tobacco use is seen as a top priority for Cancer Control in ACS. The state of Florida had a large budgetary surplus last year, which made raising taxes a very difficult sell, and a price increase was not passed last year. The goal is to direct any incremental funds from increased tobacco taxes toward cancer research. This proposal will be on the table again this year.

The third ACS initiative is the **Citizens Initiative Process to Promote Youth Tobacco Education**. This initiative is a collaborative effort between the American Heart Association,

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American Lung Association and the American Cancer Society brought about due to the dramatic decrease in funding for the Florida DOH youth tobacco education program. This initiative is similar in scope and design to what happened several years ago with Amendment 6, the tobacco program to limit smoking in workplaces. Amendment 6 passed was very successful, and was supported by 71% of the people in the state. Amendment 6 was a true testament to what can happen when all the health organizations speak with one voice. Dr. Kasper explained that the total funds obtained under the **Citizens Initiative** tobacco plan which mandates that 15% of the tobacco settlement funds be directly allocated to tobacco education, would have resulted in \$54 million in funding for the state last year. The CDC calls for \$72 million in funding for a comprehensive adult and youth campaign in a state the size of Florida.

The Florida DOH Tobacco Program started in 1997, when the state and then elected Governor Chiles allocated \$23 million to establish a tobacco youth education pilot. The following year, the program was allocated \$70 million, and we saw a dramatic decrease in the number and percentage of youth who were using tobacco products. The program included an evaluation component. Each year since, the amount of funding decreased. Some decreases in funding made sense after the program was fully established. At \$44 million, the program was still a well-run effective program. In the last three years, SWAT support, the advertising budget and basically every component of the youth tobacco education program was cut, with funding of only \$1 million per year for the past three years. This level of funding goes up against the advertisement budgets of the tobacco companies, who spend over \$1 billion to advertise tobacco in Florida, which is more advertising than in any other state.

Currently over 10% of the required signed petitions, to get the amendment on the ballot, have been submitted to the State Attorney General.

Carol Weys, explained that any tobacco settlement funds obtained through the **Citizen's Initiative** would be used to put in place a program primarily for youth tobacco education, with some adult education, that follows the CDC guidelines.

Dr. Martin suggested looking into the option of taxing tobacco advertisement in the state of Florida.

Motion: CCRAB membership passed a motion to support ACS' Citizen's Initiative Process to Promote Youth Tobacco Education, Amendment 104.185.

The membership expressed concern in supporting the entire ACS legislative agenda because it is a fluid document and not all of the agenda items relate to cancer control efforts.

Motion: The membership passed a motion to vote on each of the three ACS initiatives individually rather than as a group.

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Motion: The first initiative, Cancer Research and Treatment, is supported by the membership of CCRAB. Motion Passed.

Motion: The second initiative, any measure that would increase the price of cigarettes and other tobacco products including special levees and other cost increasing measures, is supported by the CCRAB membership. Motion Passed.

Motion: CCRAB membership voted against the concept of supporting non-specific Citizen's Initiatives.

Dr. Kasper and Sue Middleton agreed to draft a letter in support of the motions to be sent to the Governor and legislative members.

Florida Department of Health, Comprehensive Cancer Control Program Update
Deborah Glotzbach, Comprehensive Cancer Control (CCC) Program, **announced two new staff members.** Laurie Osgood, who will be working with the collaboratives and Lynell Joiner who is the program's staff support. The Comprehensive Cancer Control Program, in collaboration with the department's Epidemic Intelligence Service, conducted a **skin cancer pilot project** in which they surveyed people age's 13-21 on Florida's upper eastern beaches on their sun practices. Florida currently lacks a comprehensive approach to sun prevention.

The CCC Program also continues to work on Reducing Racial and Ethnic Health Disparities also called 'Closing the Gap' contracts in which they manage three projects. All three projects focus in the area of prostate cancer, with some lung and colorectal cancer education. This is the final year of a three-year program. The department will be requesting proposals for the new three-year cycle in January for projects to begin in July 2006.

Ms. Glotzbach also reminded CCRAB members to visit the CCC Program's Web site, which has recently been updated and contains helpful links.

As part of the department's agreement with the CDC, the CCC Program has created one-page fact sheets on the program's 5 focus cancers and one on cancer screening. These are posted on the Web site for use. The program distributed these materials to the 35 local chronic disease health promotion and educational specialists who oversee the 67 counties chronic disease program activities.

Ms. Glotzbach told the group membership that the Florida Cancer Plan Council (FCPC) met September 29th. The FCPC agreed to take the current Florida Cancer Plan 2003-2006 and write a progress report, which will outline the accomplishments related to the cancer plan's goals and objectives. This will include the results of a short survey to gain information on what hospitals

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are doing to support the Cancer Plan. The FCPC also voted yesterday to increase the membership of FCPC to include representation from H. Lee Moffitt Cancer Center, M.D. Anderson in Orlando, Shands, Mayo Clinic in Jacksonville, UM Sylvester Comprehensive Cancer Center and the Florida Cancer Data Systems.

At the FCPC meeting, Hope Wood, a nurse with the DOH Breast and Cervical Cancer Program, presented the American College of Surgeon's materials regarding end of life palliative care. The presentation is available for CME/CMU credit. Interested parties may contact the department for more information. Ms. Wood is working on getting the training into the curriculum in medical schools throughout the state. Dr. Sandler pointed out that palliative care is not the same as end of life care; palliative care is symptomatic care. This training is for care delivered at any time during the cancer treatment process.

Ms. Parker informed the membership and CCC that Dr. Kirsner has completed numerous studies on sun safety, effective curricula and on attitudes to sun exposure. She suggested that the CCC should collaborate with others interested in melanoma prevention.

Dr. Hartmann expressed concern about potential duplication with all the cancer related groups and asked for an explanation of the role of the Florida Cancer Council. Ms. Glotzbach explained that their role is to make Florida a center of excellence for cancer research. Dr. Kasper expressed the desire for CCRAB to increase communication with all the other cancer related groups and to coordinate efforts rather than duplicate.

Sue Higgins stated that the department would offer support to CCRAB in creating a new Cancer Plan if that is the agreed-upon agenda or decision. The 2003-2006 plan was a joint effort with CCRAB and CCC in order to ensure that we had an active plan for implementation. CDC required an updated plan in order to provide funding to CCC. The CCC Program, after consulting with their CDC project officer, will be submitting a progress report to include the activities and strategies that occurred in trying to meet the Plan's goals and objectives.

Sue Middleton expressed that CCRAB has the responsibility to understand the cancer situation in Florida and approve a new Cancer Plan, not just let an expired plan continue. At the spring meeting, we will present data to help the group understand the cancer situation in Florida and next steps related to approval of a new Cancer Plan.

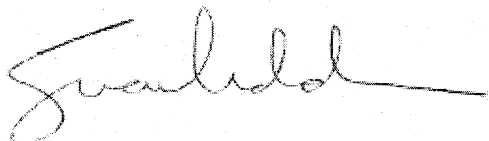
Dr. Kasper indicated that we want a Cancer Plan and/or implementation strategies that have measurable goals, which would help us to be more effective as a group. Specific short- and long-range goals will help us to meet and measure our progress. The current plan is a nice framework and first step to an improved plan.

Ms. Middleton expressed her vision to increase the role of CCRAB to be a key advisory body in the state. CCRAB needs to understand cancer incidence, research, access and cancer control and be a liaison between the various cancer control stakeholders in the state.

Dr. Kasper thanked the group and told them that he looked forward to gaining their input and expertise. The meeting was adjourned at 3:00.

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Respectfully submitted,

A handwritten signature in black ink, appearing to read "Sue Middleton", written in a cursive style.

Sue C. Middleton
Executive Director, CCRAB

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APPENDIX 3B

Sun Awareness Task Force Meeting Summary

December 13, 2005

10:30-3:30 pm

Members Present

Sue Middleton
CCRAB

Robert Kirsner, MD PhD
CCRAB

Sue Gorham
SHADE Foundation

Linda Rutsch
U.S. EPA SunWise Program

Jer Zenieris, PhD
Richard David Kann Melanoma Foundation

Tamika Paey
Richard David Kann Melanoma Foundation

Carol Vickers
Department of Health

Seft Hunter
University of South Florida

Members Absent

Cathy Reed, MS, RD, LD
Department of Education

Richard Roetzheim, MD
University of South Florida

Paul Jacobsen, PhD
Moffitt Cancer Center

Guests Present

Rania Abdulla
University of South Florida

Sue Middleton called the meeting to order at 10:30 am, and task force members introduced themselves to the group.

Dr. Kirsner explained the general goals of the meeting. These goals included providing the participants the opportunity to share their current sun awareness education activities and to learn from others around the table. He explained that the group was to examine options for implementation of programs to decrease the occurrence of melanoma in the state of Florida. The group had narrowed its focus to increasing sun awareness education to Florida's nearly 3,800 public, private and charter schools.

Dr. Kirsner reviewed current rates of melanoma ranking Florida as the #2 state for melanoma occurrence. People raised in Florida are at a greater risk of getting melanoma compared to other states with a lower UV index. The risk you assume as a child, based on your UV exposure and the UV index of your childhood home, is the risk you carry with you for life. In addition, all races and ethnic groups in Florida have a greater risk of getting melanoma when compared to states with a lower UV index. In 2005, the American Cancer Society estimates the 4,600 Floridians will get melanoma, and 600 will die from melanoma. These rates are expected to increase and the rates are increasing in younger age individuals.

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Linda Rutsch then reviewed the U.S. EPA SunWise program. SunWise is an environmental and health educational program for K-8 and has been requested by over 12,000 schools nationwide. The program's goal is to educate children and their caregivers on how to protect themselves from overexposure to the sun. Through the use of classroom-based and community-based components, SunWise seeks to develop sustained sun safe behaviors in schoolchildren. In addition, SunWise is a mandatory program in all Arizona K-8 schools. The program is free to all interested schools. Ms. Rutsch explained that the program's effectiveness has been evaluated by researchers at Boston University (see attached). Significant improvements were seen in SunWise schools in the area of intention to play in the shade. Improvements were also seen in the areas of intention to wear sunscreen and in attitudes toward looking tan. Ms. Rutsch estimated that of the 747 schools in Florida who requested SunWise materials approximately 70% of those use SunWise in the classroom.

Sue Gorham introduced the group to the Curt and Shonda Schilling SHADE Foundation. The SHADE Foundation was started by Shonda Schilling after she was diagnosed with melanoma. The SHADE Foundation, which started approximately three years ago, has provided 50 shade coverings to playground areas. The Foundation has raised more than \$2,000,000, with 88% going directly to support programs. Their annual poster program has resulted in over 30,000 posters submitted by elementary children across the country.

It is estimated that 75 million people nationwide have seen the SHADE Foundation's overall marketing campaign. The SHADE Foundation programs include SunWise education in schools, SHADE grants, poster contests, screening, behavioral research and community outreach. Ms. Gorham stated that the SHADE Foundation is very interested in working with Florida's health care providers, foundations, cancer control programs, and educational leaders to increase sun awareness in Florida's schools.

Jer Zenieris, Director of the Richard David Kann Melanoma Foundation, presented the Foundation's educational programs. The Foundation is dedicated to the prevention and early detection of skin cancer. The Foundation was established in 1995, by family members who lost Richard Kann to late-detected melanoma. The Foundation purchased the rights to the successful SunSmart Australia curricula and modified it to meet the needs of Florida schools. The program is for grades K-12 and is available in several languages. Currently the program effectiveness is being evaluated through a collaborative grant with the University of Miami.

Tamika Paey, Education Director with the Richard David Kann Melanoma Foundation, outlined the educational program and the process for interacting with the schools. The Foundation meets with the school districts prior to classes starting in the fall and basically 'trains the trainers'. The Foundation provides health educator trainers free of charge to schools in addition to the free educational materials.

Seft Hunter, from the University of South Florida, provided an overview of the USF NIH grant designed to influence sun awareness and behavior for 4th graders in the Hillsboro county area. He is Project Director for this grant. USF has partnered with More Health, to provide an intervention of hat wearing at the 4th grade level. Pre-grant

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surveys found that 57% of parents on Florida's beaches did not apply or provide any sun protection for their children. Of those parents that did provide sun protection, only 34% provided or promoted hats. In that many people apply sunscreen incorrectly or not frequently enough, the use of hats appeared to be an intervention worth evaluating. Other factors contributing to the hat use intervention were that the head and neck are common sites of cancer and hats are not frequently used in schools currently. Hat use both in and out of school was evaluated. Post study results show that 60% of kids are still using their hats 9 months after the study.

Carol Vickers, from the Department of Health explained how school health policies are established and potentially changed. School health advisory councils were established for each district in 1973. These councils develop school health plans and the plans' content. The county health department, the local school board, and the school health advisory council develop the plans jointly. The general purpose of the advisory councils is to identify health problems and concerns, set priorities and design solutions. The councils are comprised of 9 to 11 members who are health and community leaders. The majority of health policy in school is set at the local level. Ms. Vickers explained that change can happen through education of health departments, school nurses, principals, health and physical educators and the members of the health advisory councils. Ms. Vickers has found one way to bring about change is to provide an example of existing policies from other states and school districts that address the issue, rather than providing more vague explanations.

Discussion

Dr. Kirsner asked each member of the group to comment on what they would like to see happen. Mr. Hunter expressed an interest in collaboration and hoped the members at the table could work together rather than duplicate efforts. The group discussed what its goal should be. Ms. Middleton wanted a long-range goal of 100% of elementary schools providing some sort of acceptable sun awareness education. Some member of the group felt that a goal of 100% was unrealistic. The group will look at the issue of targets and goals again when the Florida school survey is completed. The group agreed to focus its efforts on K-8 school age children with a specific focus on elementary schools in Florida. The interventions will include:

1. Poster contest sponsored by the SHADE Foundation
2. Partnering with the DOH/DOE to provide information and education to schools, health departments, and school health advisory councils
3. Survey to all school principals and potentially to school nurses to assess current level of sun awareness education.
4. Increased media coverage
5. Increased web site information and marketing
6. Present a unified front

The survey will be administered again in 2008 to assess the impact of our interventions.

Next steps include

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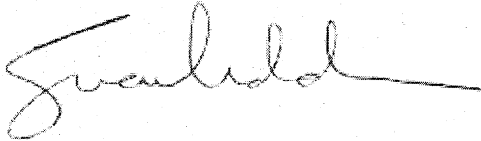
1. Meeting with the Secretary of Health, Dr. Francois to review the project and define a DOH home for the project.
2. Organize poster contest and awards
3. Complete the survey and administer through the Department of Health

Other potential partners and contacts

Bill Dance, American Academy of Dermatology, Florida Foundation for School Health-Sandra Gallagher, Red Cross, Safe and Drug Free Schools, Comprehensive Cancer Control and the PTA

The meeting was adjourned at 3:00 pm.

Respectfully submitted,

A handwritten signature in cursive script, appearing to read "Sue Middleton", written in dark ink.

Sue Middleton

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APPENDIX 4A

December 28, 2005

The Honorable Jeb Bush
Governor of Florida
PL 05 The Capitol
400 S. Monroe St.
Tallahassee, FL 32399-0001

Dear Governor Bush:

We are writing on behalf of the State of Florida Cancer Control and Research Advisory Council (CCRAB) to ask that you support the following cancer control related initiatives for the 2006 budget year.

The first is the William G. "Bill" Bankhead Jr. and David Coley Cancer Research Program under the Department of Health. Bankhead-Coley is an important piece of legislation that benefits Floridians of all ages. Of particular interest to CCRAB is the support for research into the prevention, diagnosis and treatment of Florida's second-leading cause of death and disability, cancer. The program will help create a nationally prominent biomedical and research community in Florida that will be competitive in attracting research dollars to Florida. Florida is soon to be the third largest state in the country, but currently ranks only 17th in grant funding from the National Institutes of Health (NIH). Bankhead-Coley will ultimately result in increased funds flowing into Florida.

Second, CCRAB asks you to support legislation in general that would result in an increase in the price of cigarettes and other tobacco products, including special levees and other cost-increasing measures. Tobacco is the number one controllable risk factor in cancer deaths, creating an estimated 30% of all such deaths. As the price of tobacco products increase, the use among our youth in Florida decreases. A 10% increase in tobacco product cost results in an estimated 7% reduction in youth tobacco use. A decrease in youth use of tobacco products is clearly an investment in the citizens of Florida, but is also a cost control effort to ultimately prevent numerous hospitalizations and resulting loss of life. Reducing tobacco use will reduce cancer and cancer related expenditures in the State of Florida.

The Cancer Control and Research Advisory Council (CCRAB) is an advisory council created by the Florida Legislature, with members appointed by the Governor, to provide advice to state government on cancer-related issues. Our Council advises your consideration and approval of these critical legislative efforts.

Thank you.

Sincerely,



Michael E. Kasper, MD, FACRO
Chairman
Cancer Control and
Research Advisory Council



Sue C. Middleton, MHA
Administrative Director
Cancer Control and
Research Advisory Council

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APPENDIX 4B

Sample Letter to House and Senate members

January 5, 2006

Dear:

We are writing on behalf of the State of Florida Cancer Control and Research Advisory Council (CCRAB) to ask that you, as a member of our Florida Legislature, support the following cancer control related initiatives for the 2006 budget year.

The first is the William G. "Bill" Bankhead Jr. and David Coley Cancer Research Program under the Department of Health. Bankhead-Coley is an important piece of legislation that benefits Floridians of all ages. Of particular interest to CCRAB is the support for research into the prevention, diagnosis and treatment of Florida's second-leading cause of death and disability, cancer. The program will help create a nationally prominent biomedical and research community in Florida that will be competitive in attracting research dollars to Florida. Florida is soon to be the third largest state in the country, but currently ranks only 17th in grant funding from the National Institutes of Health (NIH). Bankhead-Coley will ultimately result in increased funds flowing into Florida.

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The Cancer Control and Research Advisory Council (CCRAB) is an advisory council created by the Florida Legislature, with members appointed by the Governor, to provide advice to state government on cancer-related issues. Our Council advises your consideration and approval of these critical legislative efforts.

Thank you.

Sincerely,



Michael E. Kasper, MD, FACRO
Chairman
Cancer Control and
Research Advisory Council



Sue C. Middleton, MHA
Administrative Director
Cancer Control and
Research Advisory Council