

Cancer Control Research Advisory Council

2009 Annual Report

Submitted to the Governor, Legislature and Surgeon General

Pursuant to Section 1004.435, Florida Statute





MEMBERSHIP

Chairman

Thomas J. George, Jr., MD, FACP

Organization Represented

University of Florida College of Medicine

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Eric S. Sandler, MD

Susan Fleming, BSN, MPA

Lance F. Grenevicki, DDS, MD, FACS

Michael E. Kasper, MD, FACRO

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Florida Society of Clinical Oncology

Association of Pediatric Tumor Programs

Florida Department of Health

Florida Dental Association

American Cancer Society

University of Miami Sylvester

Comprehensive Cancer Center

State of Florida House of Representatives

Honorable Marti Coley

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Tonja Lemon Webb

John Mason, MD

Florida Obstetric and Gynecologic Society

Florida Society of Oncology Social Workers

Florida Nurses Association

Florida Osteopathic Association

General Public/Consumer Advocate

Florida Pediatric Society

University of Miami Miller School of Medicine

Florida Tumor Registrars

Florida Senate

Nova Southeastern College of Osteopathic Medicine

General Public Consumer Advocate

University of South Florida College of Public Health

Florida Department of Education

Florida Medical Association

General Public/Consumer Advocate

Department of Veterans' Affairs

Administrative

Merritt Martin, MPA

H. Lee Moffitt Cancer Center and Research Institute

MESSAGE FROM THE CANCER CONTROL RESEARCH ADVISORY COUNCIL

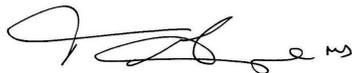
The Florida Cancer Control and Research Advisory Council, also known as CCRAb, is the state council responsible for advising the Legislature, Governor and Surgeon General on how to reduce the cancer burden in Florida. We monitor cancer trends and disparities, evaluate and promote effective interventions to help in cancer prevention, screening and treatment. We also develop position papers on cancer-related legislation and state policy issues.

CCRAb was established in state statute in 1979, and is currently governed by Florida Statute 1004.435. The Council is housed at, and funded by the H. Lee Moffitt Cancer Center and Research Institute, but operates as an independent group. Our membership includes leaders in health care, education, cancer research and treatment, and Florida government, many of whom are themselves cancer survivors. The Council meets at least twice a year, has membership that is appointed by the Governor, President of the Senate, and Speaker of the House (for the legislative members) and is overseen by a Chair and an Executive Committee.

We greatly appreciate Moffitt Cancer Center's continuing support for the Council's operations and for allowing the Council to function as an independent advisory board.

Updated information can be obtained online at our website www.ccrab.org. For additional copies of this report, or any additional information about CCRAb and its activities, please contact the Council office.

Respectfully submitted,



Thomas J. George, Jr., MD, FACP
Chair



Eric S. Sandler, MD
Past-Chair

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SUMMARY OF 2009 ACCOMPLISHMENTS

- ◆ CCRAB members authored sections and aided in the development of the *Florida Cancer Plan, 2009-2012*, working in conjunction with the Florida Department of Health Comprehensive Cancer Program and the Florida Cancer Data System.
- ◆ Advised individual legislators, House and Senate health-care committee members and staff, and the Surgeon General with regard to Florida's cancer burden and opportunities for improvements in prevention, screening, research, and survivorship within the state, ultimately to the benefit of the Florida citizens.
- ◆ Supported the continuation of the Bankhead-Coley Research Initiative, which provides peer-reviewed research dollars to Florida cancer researchers.
- ◆ Developed recommendations on tobacco control, including support for a \$1/pack increase in the state's tobacco tax.
- ◆ Worked closely with the Department of Health and the Centers for Disease Control to successfully develop and obtain grant funding for a colorectal cancer screening program.
- ◆ Continued ongoing communication with members of the Florida House and Senate in an effort to increase Council visibility while increasing the legislators' exposure to cancer control issues in Florida.
- ◆ Supported continued public and health care provider education on the benefits of human papilloma virus (HPV) vaccination for middle school-aged females as it relates to a reduction in cervical cancer. Supported and advocated for continued legislative efforts regarding mandatory parental education in this regard to reduce misinformation, in partnership with various health care organizations and the Junior Leagues of Florida.
- ◆ Supported the inclusion of Veterans' Affairs Cancer Registry data into the Florida Cancer Data System.
- ◆ Supported legislation to increase coverage within the Florida Breast and Cervical Cancer Early Detection Program to those under age 65, while recommending a limit to the number of years a woman can remain in the program to less than five.
- ◆ Supported legislation to increase the screening, detection and treatment of breast cancer in Florida.
- ◆ Supported legislation to prohibit the use of tanning beds by youths under the age of 16 and to require parental consent for those ages 16 and 17. The bills were sponsored by Senator Eleanor Sobel (D-District 31) and Representative Rick Roberson (D-District 104).
- ◆ Convened General Council and Executive Committee meetings in 2009.

SUMMARY OF ACTIVITIES AND OPPORTUNITES

Legislative Initiatives 2009

The CCRAB membership supported the following legislative initiatives in the area of cancer control during the 2009 legislative session.

Funding Allocations for Cancer Control

Total Florida legislative funding allocations for cancer control, research and treatment programs reached a record level of \$128 million in the 2009 legislative session. As part of this grand total, the James and Esther King Biomedical Research Program received \$27 million, the Mary Brogan Breast and Cervical Cancer Early Detection and Treatment Program received \$6.7 million, and the Closing the Gap - Reducing Racial and Ethnic Health Disparities Grant Program received \$3.3 million. The Bankhead-Coley Cancer Research Program received \$25 million. The tobacco prevention and education program received \$61.5 million. Other legislative allocations included funds for Moffitt Cancer Center, University of Miami Sylvester Comprehensive Cancer Center, and funds for graduate medical education in the field of oncology.

- *CCRAB Position: CCRAB commends the Florida Legislature for its fiscal commitment to cancer control, research, and prevention via tobacco control.*

James and Ester King and Bankhead-Coley Research Funds

The Council actively supported the continued funding of the Bankhead-Coley Cancer Research Program and the James and Esther King Research Program managed by the Department of Health. In 2009, the Florida Legislature eliminated the general revenue appropriation for both programs and provided that 2.5 percent of the revenue generated from the additional cigarette surcharge enacted in 2009, not to exceed \$50 million (\$25 million each), was to be transferred into the Biomedical Research Trust Funds for the King and Bankhead-Coley Programs.

- *CCRAB Position: The Council commends the Florida Legislature for supporting cancer research funding in both the James and Esther King and the Bankhead Coley research programs and strongly recommends a permanent source of funding be placed in statute for these programs.*

Training Florida's Health Care Providers

CCRAB identified a need for up-to-date information on prevention, screening, treatment and survivorship to health care providers.

- *CCRAB Position: CCRAB recommends that health care organizations and cancer control stakeholders develop and disburse Continuing Medical Education (CME) material on cancer prevention, screening, treatment and survivorship to be used as optional CME training courses for MD's, DO's, DDM's and other health care providers.*

Vaccination to Prevent HPV Infection and Cervical Cancer

In 2006, a major cancer prevention breakthrough occurred in the form of a vaccine to prevent Human Papilloma Virus (HPV) Infection, which is linked to most cases of cervical cancer. This was a major advance in cancer prevention and the first approved vaccination to prevent cancer since the hepatitis B vaccination, which decreases the occurrence of cirrhosis and liver cancer. The HPV vaccine is approved for females 9-26 but recommended at the earliest ages due to better immune responses generated at earlier ages and in order to reach girls prior to their becoming sexually active. It is clear now that HPV also causes a significant percentage of head and neck cancers, and may play a role in other cancers. Florida's rate of cervical cancer incidence of 9.2 per 100,000 is the 4th highest in the nation. The HPV vaccination is an opportunity for Florida to reduce health disparities and to decrease our state's cancer burden.

- ***CCRAB Position: The Florida Department of Health and the Florida Department of Education should work together to provide educational material developed by the federal Centers for Disease Control and Prevention (CDC) to parents of middle school-aged girls throughout Florida. We continue to strongly recommend that the Department of Education provide CDC educational material to parents of all middle school girls to allow parents to make an informed choice for their children. We believe this should occur without legislation.***

Florida Cancer Data System

Florida researchers, government agencies, program planners and policy makers are very fortunate to have access to the Florida Cancer Data System (FCDS), which is the single largest population-based cancer incidence registry in the nation. The Florida Cancer Data System represents an ongoing success for our state. It has been collecting data on new cancer cases since 1981. Over 160,000 cases are collected from patient medical records annually. Information about newly diagnosed cancer cases is submitted by hospitals, freestanding ambulatory surgical facilities, radiation therapy facilities, private physicians and pathology laboratories. The FCDS database contains approximately 3.8 million cancer records, 6 million discharge records from the Florida Agency for Health Care Administration and 3.5 million mortality records from Florida's Office of Vital Statistics.

The FCDS is part of the CDC's National Program of Cancer Registries and is nationally certified by the North American Association of Central Cancer Registries at its highest level, Gold certification. Gold certification is conferred on central cancer registries that exceed all standards for quality, completeness and timeliness. FCDS is funded by CDC and the State of Florida, and operated by the University of Miami Sylvester Comprehensive Cancer Center under contract from the Florida Department of Health.

The American Cancer Society estimates that there are up to 5,000 cases of cancer diagnosed in Florida Veterans hospitals each year that are not reported to our state cancer registry, FCDS. As a result, the National Cancer Institute (NCI) and other national surveillance organizations report that total US rates for prostate, lung, bronchus, colorectal and other cancers may be significantly underestimated both locally and nationally. Surveillance, geographic or cluster information, and

other research, are all affected.¹ Such discrepancies can have resource utilization and health care disparities impact on the state's cancer health care system as many veterans move between the Department of Veterans Affairs and civilian health care systems. CCRAB previously supported the integration of Veterans cancer data into the FCDS, which was accomplished this year.

- **CCRAB Position:** *CCRAB recommends continued support for and funding of the FCDS and exploration of the transition of the database from an incidence database to a functional outcomes database, which will track outcomes on some or all cancer patients in the state. Additional funding will be required for the latter. CCRAB commends the FCDS and Department of Veterans Affairs for improving the accuracy of the FCDS by integrating Veterans cancer data in the state.*

Breast and Cervical Cancer Program

Women between the ages of 50 and 65 who meet financial eligibility requirements can receive screening for cervical and breast cancer in Florida. Once a woman is accepted into the program, she is eligible for medical care coverage as long as she is being treated for cancer or is on preventative medications such as tamoxifen.

- *The state should extend Medicaid eligibility to all women diagnosed with breast or cervical cancer by any willing provider and add the wording limiting the number of years women may remain on the program to two years. This change would allow more women to be screened, diagnosed and treated but also limit the costs somewhat.*

Breast Cancer Detection and Treatment for Un-served and Under-served

Florida ranks second in the nation in new breast cancer cases and deaths per year.

Florida also ranks 48th in the nation, with 20.7 percent, of the population without health insurance, according to the United Health Foundation, America's Health Rankings 2008.

- **CCRAB Position:** *The Council commends the Florida Legislature for passing House Bill 1269 created, within the Florida Department of Health, a breast cancer early detection and treatment referral program for un-served and under-served Floridians aged 19 to 64.*

Colorectal Cancer Screening and Awareness for Un-served and Under-served

Colon cancer is the third leading cancer in incidence and death with Florida ranking 12th in the nation for incidence. Despite the evidence supporting the effectiveness of colorectal screening, half of the US population aged 50 and older has not been tested.² In response to a grant request from the CDC, CCRAB members worked with the Department of Health to submit and obtain \$850,000 in grant funding over 5 years to develop and implement a colorectal cancer screening and awareness program for adults aged 50-64 who lack the means of obtaining this cancer screening service otherwise.

¹ Furlow B. Accuracy of US cancer surveillance under threat. *Lancet Oncology* 2007;8(9):762-3.

² Shapiro JA, Seeff LC, Thompson TD, Nadel MR, Klabunde CN, Vernon SW. Colorectal cancer test use from the 2005 national health interview survey. *Cancer Epidemiol Biomarkers Prev* 2008;17(7):1623-30.

- **CCRAB Position:** *The Council commends the Florida Department of Health for successfully obtaining competitive CDC funds to develop this needed program in our state. CCRAB supports the program and urges the Florida Legislature to require insurers in the state to cover age-appropriate colorectal cancer screening as recommended by the CDC and other national cancer organizations.*

Disparities in Cancer Care and Outcomes

Certain population groups bear a disproportionate burden of cancer incidence and mortality. Notable examples of cancer health disparities include the fact that Hispanic women are twice as likely to contract cervical cancer as non-Hispanic White women; and African men are twice as likely to die of prostate cancer as White men. Disparities exist in incidence and outcomes for many other cancer disease site for specific population groups, which can be classified by gender, ethnicity, education, income, geographic location, or other factors.

Economic inequalities in access to medical care account for a big part of this problem, as do cultural barriers to seeking screening services and follow-up care. However, since disparities in survival rates have persisted in many cases where screening rates had measurably improved, it is clear that other factors need to be examined.

Increasing the participation of minority populations in clinical trials is critical to examining possible genetic links which may contribute to differences in cancer disease progression and development, as well as differences in response to treatment, among different populations.

A comprehensive approach to addressing cancer health disparities would first seek to define and describe issues related to cancer health disparities – inclusive of scientific as well as cultural, economic, and public-policy concerns. This will help to facilitate the adoption and implementation of cancer research, policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities.

- **CCRAB Position:** *The Florida Legislature should continue to support programs, research and access to care to reduce cancer care and outcomes disparities. Medical school education should include cultural courses to help future providers understand and combat cultural, institutional and individual barriers to cancer care prevention, screening, and treatment service.*

Access to Cancer Care

Those who are uninsured are less likely to get screened for cancer, more likely to be diagnosed with an advanced stage of the disease, and less likely to survive that diagnosis than their privately insured counterparts. Lack of coverage creates a dangerous cycle; approximately 54 percent of uninsured patients aged 18 to 64 do not have a usual source of health care, 26 percent delayed care due to cost, while nearly 23 percent did not get care because of cost. An estimated 23 percent did not get prescription drugs because of the expense.³ Health insurance coverage is tied closely to the strength of the economy, resulting in a challenging environment.

³ ["Association of Insurance with Cancer Care Utilization and Outcomes."](#) Published online Dec. 20, 2007, and in the Jan/Feb 2008 issue of *CA: A Cancer Journal for Clinicians* (Vol. 58, No.1). First author: Elizabeth Ward, PhD, American Cancer Society

- *CCRAB Position: Again, we commend the Florida Legislature and Department of Health for establishing programs such as Breast Cancer Detection and Treatment and the Colorectal Cancer Screening and Awareness Program for Un-served and Under-served which help to educate and save lives. We recommend eliminating out-of-pocket costs for prevention and screening and standardizing coverage for preventive and screening services to improve Florida cancer rates, reduce cancer disparities and reduce overall healthcare costs.*

Tobacco Use Prevention

Tobacco is the number one controllable risk factor in cancer deaths, and causes 30 percent of all cancer deaths in Florida. In 2009, a 62-cent federal cigarette tax increase and a \$1 per pack state tax went into effect. Statewide, cigarette sales that regularly topped 100 million packs per month dropped to 73 million packs the month the tax became law. Since then, sales have inched back to around 78 million packs but remain well below prior levels. It is projected that this will save 143,500 lives, induce 175,900 adult smokers to quit, and prevent 303,300 kids from ever taking up smoking.

- *CCRAB Position: We commend the Federal Government and the Florida Legislature for raising the tax on tobacco products. We look forward to reviewing the use of the tobacco surcharge monies to support tobacco-associated cancer programs, prevention, and education. We recommend evaluating implementation of a smoking ban in Florida's prison system consistent with the Clean Indoor Air Act.*

Sun Awareness Education for Florida's Youth

Skin cancer is the fastest growing cancer in the United States and in the State of Florida, and current statistics show Florida ranks second in the nation for melanoma occurrence. This disease is largely preventable by limiting direct ultraviolet and sun exposure during formative years of childhood and adolescence. CCRAB developed a partnership between the Donald A. Adam Comprehensive Melanoma Research Center at Moffitt Cancer Center and the Florida Keys Advanced Health Education Center (AHEC) to provide education to Florida's elementary school children on sun awareness. Moffitt-funded education will be provided by the Florida Keys AHEC for all third graders in Monroe County schools. The material used is free material from the US Environmental Protection Agency (EPA) called "SunWise," and is tied to the Florida Sunshine standards in grades K-8 for education. Our goal is to have all 67 Florida school districts adopt this free program to be used by the teachers in each school. Alternatively this could be a requirement of a wellness bill for Florida schools.

- *CCRAB Position: Our Council strongly recommends that sun awareness education be added to Florida's K-8 curriculum using the free EPA product SunWise. We additionally support changes in the current tanning bed law to allow only those over the age of 16 to use tanning beds and to require parental signature for 16 and 17 year olds using tanning beds.*

Clinical Trials

Clinical trials are the mechanism to find better ways to treat, prevent, diagnose and understand human disease. They can offer patients access to new and potentially lifesaving drugs and cures.

Unfortunately, insurance companies often deny coverage for routine care when a patient is enrolled in a clinical trial. There is no Federal or Florida law addressing this issue; but almost half of the states have passed legislation or instituted special agreements requiring health plans to pay the cost of routine medical care for beneficiaries enrolled in a clinical trial.⁴ Without routine cost being covered, patients are less likely to participate in a trial, potentially to their detriment and that of society. This is a correctable barrier to cancer care.

- *CCRAB Position: Our Council recommends insurance companies be mandated to cover a patient's routine care when enrolled in a clinical trial.*

FLORIDA CANCER PLAN ACTIVITIES

Florida Cancer Plan 2009-2012 Approval & Implementation

CCRAB is charged, by Statute, to approve the state cancer plan. This year, we continued to work with the Florida Department of Health and the Florida Cancer Plan Council on the development of an updated state cancer plan. Council members reviewed and commented on all sections of the new plan. The new state cancer plan, to be published in 2010 and distributed to the Governor, legislators, other key policy makers and cancer control stakeholders, will serve as a guide with recommended goals, policies, and priorities for cancer control across the state. The draft is currently in the approval process at the Department of Health.

ADMINISTRATIVE UPDATE

CCRAB STATUTE

No changes were made to the Council statute (Section 1004.435).

MEMBERSHIP

Mary Broccard, LCSW, was appointed to the Council and represents the Florida Society of Oncology Social Workers.

OFFICERS

Sue Middleton stepped down. Eric Sandler, MD, Association of Pediatric Tumor Programs, completed a year as Chairman in October 2009. Thomas J. George, Jr, MD, of the University of Florida College of Medicine succeeded Dr. Sandler as Chair. The appointed Executive Committee consists of Thomas J. George, Jr, MD; Eric Sandler, MD; Robert Cassell, MD, PhD; Dorothy Parker, MHS; Lance Grenvicki, DDS, MD; Anna Giuliano, PhD; Michael E. Kasper, MD; the Honorable Marti Coley, and Susan Fleming, BSN, MPA; The Executive Committee, led by the

⁴ National Conference of State Legislatures, Clinical Trials: What are States Doing? August, 2009.
<http://www.ncsl.org/default.aspx?tabid=14331>

Chairman, provides guidance, authors position statements and sets the overall agenda for the Council.

MEETINGS

The Council met on May 18, 2009, and November 17, 2009.

CANCER INCIDENCE & MORTALITY IN FLORIDA

According to the most recent Florida Cancer Data System report,⁵ which incorporates data from 2005, 99,745 Floridians were diagnosed with cancer in that year. The cancer rate for males and females combined is 380 per 100,000. These numbers do not show a significant change in cancer rates from the previous year. In our state, 65% of all cancers occur in people over age 65. The combination of tobacco-related cancers and those cancers detectable through screening represent nearly 60% of all cancers. This statistic demonstrates that we can significantly decrease cancer rates in Florida by taking action to decrease tobacco use and increase cancer screening rates.

Lung cancer was the most commonly diagnosed cancer in Florida, with 16,531 diagnosed cases in 2005. Prostate cancer was the second most frequently diagnosed, with 13,253 cases, followed by breast cancer with 12,428 cases and colon cancer with 10,336 cases diagnosed in 2005.

The percentage of cancers diagnosed at an early stage was 42% in 2004 while those cancers diagnosed at an advanced stage were 15%. The percentage of cancer diagnosed at a late stage varied greatly by cancer type. Over three-quarters of ovarian cancer and 65% of lung cancer cases are diagnosed at an advanced stage. Advanced cancers were found more often in the 40-64 age group than in those over age 65. Minorities are consistently more likely to have cancer diagnosed at an advanced stage.

⁵ Surendera Babu A, et al. Florida Annual Cancer Report: 2005 Incidence and Mortality. Tallahassee: Florida Department of Health, 2009

OTHER STATE CANCER CONTROL PROGRAMS

- **Florida Breast and Cervical Cancer Early Detection Program:** This 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, diagnostic and treatment referral services to uninsured women in Florida.
- **Florida Screen for Life; Colorectal Cancer Screening and Awareness Program:** This program is funded by the federal Centers for Disease Control and Prevention, and is administered by the Florida Department of Health. It is developing and implementing a colorectal cancer screening program for adults aged 50-64 who lack the means of obtaining this cancer screening service otherwise. It will also provide a state-wide awareness campaign to improve screening rates in all citizens.
- **American Cancer Society (ACS):** ACS is dedicated to eliminating cancer as a major health problem. ACS uses voter education and issue campaigns to influence legislation. CCRAB works closely with the American Cancer Society, Florida Division, to better understand cancer issues within Florida. Our Council has a representative from ACS and regularly communicates on legislative and cancer control issues.
- **Florida Center for Universal Research to Eradicate Disease (FL CURED):** FLCURED is a program within the Department of Health and was created specifically to focus on cures for diseases via FS 381.855. The center serves the research needs of the biomedical and biotechnical community and oversees the Bankhead-Coley and James and Esther King Fund allocations.
- **Florida Cancer Council (FCC):** This council coordinates with FL CURED and identifies ways to attract new research dollars into Florida, seeks to increase enrollment in clinical trials, and seeks to make the medical community more aware of clinical trials.
- **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 and the Department of Health for preparation of the State Cancer Plan. The University of Miami Miller School of Medicine, under contract with the Department of Health's Bureau of Epidemiology, runs FCDS. Data are available on the FCDS web site: www.fcds.med.miami.edu.
- **Comprehensive Cancer Control (CCC):** The Florida Department of Health's CCC Program is responsible for coordinating statewide cancer prevention and education activities with a focus on colorectal, lung, ovarian, prostate and skin cancers. The programmatic efforts are conducted through collaboration with public and private partners throughout Florida.
- **Florida Cancer Plan Council (FCPC):** The Florida Cancer Plan Council was established to help in implementing the State Cancer Plan. The Florida Cancer Plan provides strategies and action points to guide these cancer control activities throughout the state. The FCPC is comprised of statewide volunteer representatives from the Department of Health, CCRAB, the American Cancer Society, Cancer Information Services, Florida's universities and colleges, cancer hospitals, survivors and other cancer stakeholders.