



CANCER CONTROL RESEARCH ADVISORY COUNCIL (CCRAB) & FLORIDA CANCER PLAN COUNCIL (FCPC)

GENERAL MEMBERSHIP MEETING AGENDA

Monday, October 15, 2012 10:00 a.m. – 4:00 p.m.

Moffitt Cancer Center Stabile Research Building-Trustees Board Room

CCRAB Members in Attendance

- Thomas J. George, MD, FACP (*Chair*), *College of Medicine, University of Florida* (CCRAB/FCPC)
- Eric S. Sandler, MD, *Florida Association of Pediatric Tumor Programs* (CCRAB)
- Dorothy Parker, MHS, *Sylvester Comprehensive Cancer Center, University of Miami* (CCRAB/FCPC)
- Brian M. Rivers, PhD, *Moffitt Cancer Center* (CCRAB)
- Susan Fleming, RN, BSN, MPA, *Florida Department of Health* (CCRAB/FCPC)
- Lance Grenevicki, DDS, MD, FACS, *Florida Dental Association* (CCRAB)
- Gregory Hale, MD, *All Children's Hospital, Florida Pediatric Society* (CCRAB)
- Gerald Robbins, MD, *American Cancer Society* (CCRAB)
- Peter Delia (*by phone*) for Honorable Senator Eleanor Sobel, *Florida Senate* (CCRAB)
- Zenesha Barkley, DNP, MSN, RN, CNE, *Florida Nurses Association* (CCRAB)
- JoAnne Bujnoski, DO, *Florida Osteopathic Association* (CCRAB/FCPC-NORTHWEST COLLABORATIVE)
- Robert H. Cassell, MD, PhD, *Florida Society of Clinical Oncology* (CCRAB)
- Rose Marie Cossick, *Department of Children & Family Services* (CCRAB)
- Ellen Daley, PhD, BA, MPH, *College of Public Health, University of South Florida* (CCRAB)
- Sharmine Dipnarine, APRN, BC, LMHC, *Consumer Advocate* (CCRAB)

- Benjamin Djulbegovic, MD, PhD, *College of Medicine, University of South Florida* (CCRAB)
- Bonnie Donihi, *Florida Ovarian Cancer Alliance Speaks* (CCRAB)
- Robert Holloway, MD, *Florida Obstetrics & Gynecological Association* (CCRAB)
- Helen Lewis, BS, CTR, *Florida Cancer Registrars Association* (CCRAB)
- James G. Schwade, MD, *Florida Medical Association* (CCRAB)

FCPC Members in Attendance

- Marion Banzhaf (*By Phone*), *Florida Department of Health* (FCPC)
- Felisha Dickey (*By Phone*), *Florida Department of Health* (FCPC)
- Jeff Feller, *WellFlorida Council* (FCPC-NORTHEAST COLLABORATIVE)
- Sue Higgins, *Florida Department of Health* (FCPC)
- Paul Hull, *American Cancer Society* (FCPC)
- Heather Wildermuth, *American Cancer Society* (FCPC)
- Tara Hylton (*By Phone*), *Florida Department of Health* (FCPC)
- Camilla Reid, *Florida Department of Health* (FCPC-SOUTHWEST COLLABORATIVE)
- Vanessa Rivera-Colon, *Moffitt Cancer Center-Outreach Wellness Education & Resources* (FCPC)
- Recinda Sherman, *Florida Cancer Data System* (FCPC)
- Vanessa Vicente, *Leukemia & Lymphoma Society of Southern Florida* (FCPC)

- Megan Wessell, *American Cancer Society (FCPC)*

Guests in Attendance

- John Armstrong, MD, FACS (*Speaker*), Florida's Surgeon General
- Jill MacKinnon, PhD (*Speaker*), *Florida Cancer Data System*
- Margaret Byrne, PhD (*Speaker*), *University of Miami*
- Charlene Brady, MSN, CBHN, CBPN-C, *Comprehensive Cancer Center, Florida Hospital Memorial Medical Center*
- Kimberley Buccini, CCRAB Coordinator, *Moffitt Cancer Center*

- DelMarie Butler, RN, CBHN, BSHSA, *Florida Coalition of Oncology Nurse Navigators (FCONN)*
- Marite de Cespedes, *Southeast Florida Cancer Control Collaborative*
- Paul Jacobsen, PhD, *Moffitt Cancer Center*
- Nicole Joens, BRAC Coordinator, *Florida Department of Health*
- Laura Lenhart, CCRAB Liaison, *Moffitt Cancer Center*
- Chuck Miceli, LCSW, BCD, *Florida Society of Oncology Social Workers (FCONN)*
- Samantha Skubish (*By Phone*), *Mount Sinai Medical Center*

Introduction

The meeting began by Dr. George thanking all CCRAB and FCPC members, guests, and speakers for taking time to participate in the Council's fall meeting on behalf of their representative organizations and to the benefit of state citizens. Each participant took a moment to identify their name, title, and organization represented. Dr. George briefly reviewed the agenda and goals for the day's meeting and introduced Dr. John Armstrong, Florida's Surgeon General.

Remarks from Florida's Surgeon General: Dr. John Armstrong

Dr. Armstrong provided his vision for cancer control and public health in the State of Florida by outlining the top initiatives that the state's robust cancer care and public health infrastructure should address in order to maximize measurable outcomes, research, and education/training. The Surgeon General began by discussing the need for transparency in resources and treatment protocols enabling Floridians with cancer to identify the successful treatments. Dr. Armstrong went on to say that there needs to be a statewide research agenda in which CCRAB and BRAC work together to identify the biomedical infrastructure and resources to be aligned to achieve these overarching priorities throughout the state. Finally, Dr. Armstrong strongly encouraged the need for statewide education and training in order to nurture a research and clinical workforce for patients with cancer. Furthermore, the state has an opportunity to think about how to educate Floridians on behaviors that lead to cancer, and how to prevent these outcomes.

Dr. Armstrong reiterated his points by positing that we start with the treatment piece by energizing it with a coordinated systems approach and then move forward with strategies for prevention. The Surgeon General continued that they would like to see the State put dollars into a "Florida System of Cancer Care" and research that are achievable with measurable outcomes. He reviewed the summary of recommendations put forth by the three main cancer centers in the state: Moffitt Cancer Center, University of Miami Comprehensive Cancer Center, and University of Florida Shands Cancer Hospital: the identification of three key cancers in the State of Florida, and target them statewide in order to reduce mortality rates; increase the percentage of NCI funding received statewide; and develop and expand research workforce throughout the state. These three points are currently

being worked through in an initial response shared with all involved partners to align around common, measurable objectives. Dr. Armstrong believes that utilizing this framework will help to better educate legislators in Tallahassee, and ultimately help determine funding.

The Surgeon General opened up the discussion to question and answer, and proceeded to answer several questions from CCRAB and FCPC members. Dr. Armstrong was asked regarding plans for funding proposals. The Surgeon General responded by saying that the Council can acknowledge that we're in a world of scarce resources, but that the State of Florida should be better than fourteenth with regard to federal funding for biomedical research and cancer control and research. Moreover, the needed framework that was previously mentioned should be defined proactively to align with the research priorities of the state. However, when it comes to where we're applying state dollars, the Surgeon General added, the research community should establish a research agenda for cancer in the state that will answer questions for Floridians battling cancer.

With regards to infrastructure and establishing protocols, Dr. Armstrong added that building this framework would energize this infrastructure through measurable outcomes that lead to comparisons to allocate resources accordingly. He expanded upon this by adding that this is leverage for CCRAB/FCPC to look at and define best practices and evidence protocols toward the end of designating standardized measurable outcomes in the state, in order to move from efficacy to effectiveness. Comments were made that children with cancer fall into an entirely different box, than adults with cancer; they require an enormous amount of research dollars. The Surgeon General responded by saying that we're certainly not going to lose sight of demographics in this process, but that we have the infrastructure in the state to create a standardized protocol for all.

Dr. Armstrong would like CCRAB to look at the strategic plan from a systems perspective: metrics, research output related to NCI, measure and invigorate the research workforce, identify three specific cancers with high mortality rates in Florida. Focus around a systems approach. Dr. Armstrong ended by stating his value of the insights of these groups, these meetings will inform the decisions he makes for the State of Florida - alignment with all participating partners.

Legislative Update/Personalized Cancer Report for Legislators

The legislative update began by Peter Delia, Legislative Assistant to Senator Sobel, calling in on her behalf. Mr. Delia explained that Senator Sobel is planning on filing the tanning bed bill again, which would prohibit children sixteen years of age and under from tanning, and also require a signed permission slips from parents or guardians of sixteen and seventeen year olds seeking to use tanning facilities. Mr. Delia also noted that if any member of the Council should have any policy requests, to not hesitate reaching out to their office, as they are also taking new ideas for legislation.

Paul Hull, from the American Cancer Society, followed Mr. Delia. Mr. Hull began by thanking Florida's Surgeon General for being so engaged on the cancer issues facing the State. He also thanked Senator Sobel and Representative Coley, who are two the Council's strongest champions in the Legislature. The American Cancer Society's advocacy efforts have undergone a large merger as of September first of this year; all operations are now housed in ACS national headquarters in Atlanta, rather than individual state operations reporting up. Additionally, all advocacy efforts have been moved under the American Cancer Society's Cancer Action Network (ASCAN). Mr. Hull then took a moment to introduce Heather Wildermuth, ACSCAN's newest Director of Government Relations. Ms. Wildermuth comes from the Florida Association of Counties, and boasts many years of experience in Medicaid policy.

Mr. Hull shifted to speak in generalities about the legislative priorities for the upcoming legislative session. Funding Mary Brogan will continue to be a top priority this year. Moreover, funding tobacco prevention continues to be a top priority, as well as biomedical research for the King and Bankhead/Coley biomedical trust funds. Additionally, Mr. Hull reiterated the need for Council members to reach out during session.

Dr. George introduced the idea of creating a personalized cancer report for legislators for the 2013 Legislative Session. Each participant had a sample report created by FCDS. The Executive Committee reviewed this idea on an earlier call. Senator Sobel was on the call when this idea was initially discussed; she expressed that this would be valuable to her peers in the legislature, and that it may be best distributed by way of email, given the amount of information members receive on a daily basis. Each one-pager will continue district specific cancer information. The Council discussed the idea of simplifying the information, and also adding information about CCRAB and other resource contacts on the flyer as well.

FCDS: Ambulatory Cancer Reporting Update/Discussion

Dr. Jill MacKinnon, Florida Cancer Data Systems, provided an update on ambulatory cancer data reporting. The presentation reviewed varying ways in which FCDS has been working on beta tests to capture data from private physicians' offices, specifically from specialty physicians reporting from dermatology, urology, and oncology practices. Dr. MacKinnon also reviewed a private physicians reporting implementation plan and reporting options. Next, annual patient follow up reporting was discussed, as well as cancer surveillance enhancement with regards to capturing disparate data streams. Finally, Dr. MacKinnon reviewed data usage via web statistics. FCDS provides web access for public consumption, as well as password-protected access. Expansion of the ambulatory reporting project is planned for 2013 with webinars to instruct ambulatory clinics on how to comply with the state reporting requirements.

In the discussion that followed the update, Dr. MacKinnon reviewed the scope of reporting. FCDS sees 110,000 new cases reported per year. However, there is underrepresentation of reporting in some areas, due to changes in patient management and diagnosis, meaning that some cases are coming to FCDS mismatched or after the fact. A prevalent example of underreporting is prostate cancer in men who are treated at VA Clinics, as the case data that VA clinics collect is not shared with state registries, but in a national VA data bank. The Council began discussing ways in which this reporting practice by the VA could be changed. Dr. Armstrong vowed to work with Mike Prendergast, Executive Director of Florida's Department of Veterans' Affairs, to have this issue resolved or more clearly understood by the next CCRAB meeting. Dr. Armstrong asked the DOH team to provide him with a white paper on the issue.

[Florida's Cancer Data System Update](#)

CCRAB Website Update

Kimberley Buccini provided the Council with an overview of the updated CCRAB website. The new and improved site includes updated information on all subcommittees, list current members, meeting minutes and presentations from past meetings, and links relevant to the Council and FCPC. ccrab.org

Cancer Disparities in Florida Update

Dr. Margret Byrne, University of Miami's Sylvester Comprehensive Cancer Center, shared her findings from an ongoing research project identifying cancer disparities in Florida. The James and Esther King Biomedical Research Grant, which CCRAB champions funding for in the Florida Legislature yearly, has funded portions of Dr. Byrne's research. Dr. Byrne provided the Council with a brief introduction to health disparities, including what they are and how they arise, specifically looking at population-specific differences in the presence of outcome indicators, quality and access to health care, and prevalence of disease. Additionally including that the aforementioned span across racial and ethnic groups, socioeconomic groups, rural/urban areas, gender and sexual orientation, and what type of facility the patient was initially received care. Moreover, Dr. Byrne reviewed comprehensive web-based maps of cancer incidences, studies on disparities including methodologies and two additional studies with included data.

Post presentation when discussing Dr. Byrne's findings, the Council felt that her research confirms the need for continued community prevention and education efforts for Floridian's with low socioeconomic status and African Americans. Additionally, Dr. Byrne's findings facilitated a discussion on identification of race and nationalities, spurring the example of looking at culture, personal, and community identification within Hispanic groups. Additionally, outcomes for some specific cancers may be optimized through improved access to high volume centers.

[Cancer Disparities in Florida](#)

Update from DOH on CCC/CDC Funded Programs

Susan Fleming provided the Council with an update on Florida Department of Health (DOH) Comprehensive Cancer Control (CCC), and Center for Diseases Control Funded Programs in 2012. DOH has undergone realignment over this past year in some of its established programs. The Department has also gained a new Surgeon General, Dr. John Armstrong, and initiated the State Health Improvement Plan (SHIP) with its statewide partners. Ms. Fleming outlined funding and new initiatives for each of the Department's cancer's programs, walked the Council through a newly drawn map of the regional cancer collaborative networks and health councils, and also introduced a new member of the Department's team: Marion Banzhaf the new Policy, Environment, and Systems Change program director.

[Florida Department of Health Cancer Program](#)

Update on CDC Policy, Systems, and Environment Change Conference

Dr. Brian Rivers provided a brief Power Point presentation on key take away points from the Centers for Disease Control's Policy, Environmental, and Systems Change conference. PSE forum participants included: CDC, DOH, ACS Cancer Action Network, tribal communities, academia, and hospitals. Key summary points from the PSE Forum included: beginning with high-level overviews: PSE concepts and anti-lobbying restrictions, communications and media planning; focus on practice: key messages and researching target audiences, PSE policy action roles, and utilizing internal and external resources. Dr. Rivers expanded on these overarching goals, and explained that there will now be a monthly or quarterly conference call with all involved stakeholders to discuss lessons learned, share successes, and resources.

[Policy Systems and Environmental Education Forum](#)

Planning for CCRAB in Tallahassee Trip

The Council is planning on organizing a trip to Tallahassee during one of the Legislature's committee weeks in January or February 2013, in anticipation of the 2013 Legislative Session, with the intent of promoting cancer related policy and possibly a statute revision to the Council's statute. All interested members will convene via conference call at a later date to determine further details. Delivery of the personalized legislative district cancer profile will highlight the visits.

Subcommittee Updates and Priorities

Each committee chair reviewed identified action items from the spring CCRAB meeting and progress on those items in the months since.

Subcommittee Breakout Groups & Review Identified Spring Priorities

Each subcommittee separated into four breakout groups in order to determine new action items. The following will outline each subcommittee's identified action items.

Goal I – Infrastructure & System Capacity

- 2012-2013 Cancer Plan Priorities/Strategies Revision
 - Third Point – Goal I: "Educate and inform elected and appointed officials and the public on effective strategies to reduce the burden of cancer."
 - *2012-2013 Priorities/Strategies Updated*
- Statute Revision for improved inclusivity of cancer stakeholders from around the State
 - *Continue efforts to synergize CCRAB/FCPC missions with potential for statute revision or bylaw adjustments in future.*
- Update Bylaws to improve Council functions pending statute revision
 - *Bylaws revision tabled pending statute revision*
- Taking a proactive approach: "How Can CCRAB Help Your Organization?" Form & requests for assistance
 - *Vetting process and action plan determined for, "How Can CCRAB Help Your Organization?" form. Additionally, the form will be placed on the homepage of the updated CCRAB website.*
- One page, district specific, cancer report for member's of Florida's Legislature
 - *Generate template; modify and simplify information and data; submit to DOH/FCDS for final approval and format consistency.*
 - *Plan to deliver upon trip to Tallahassee during session*
- Support and distribute Information on FCDS Ambulatory Update and Webinars
 - *CCRAB website; FLASCO; FMA; FSGO; Cancer collaborative networks website; Florida Prostate Cancer Advisory Council; Urologists; Dermatologists*
- Reach out to the VA for non-voting representation on CCRAB
- Invite a member from each of the 6 collaborative networks to participate in CCRAB meetings. Have Sue Higgins provide updates on all collaborative activity on specified monthly calls.
- Invite member(s) from BRAC to participate on CCRAB and ensure linkage between separate council goals/priorities.

Goal II - Prevention

- Tobacco
 - *Tobacco – Letter to all colleges and universities commending tobacco free campus policies, cover letter to recipients, and press release disseminated in cooperation with the*

Tobacco Program to all tobacco grantees statewide. Grantees are working with their county Tobacco Free Partnerships to deliver letter to university leaders despite the Tobacco-Free College and University Initiative no longer serving as a work plan option for tobacco grantees,

- *Look closer at CT scanning and how to endorse option for high risk screening*
- *Consider Native American Populations – culturally sensitive education*
- **Human Papillomavirus (HPV)**
 - *Partnership with Merck, Florida Pediatric Society, and Bureau of Immunizations*
 - *Create educational posters on HPV specific to cancer prevention*
 - *HPV – New relationship with the Florida Pediatric Society and Merck – an opportunity to support and identify opportunities for five regional physician leaders to educate on vaccine to both lay people and healthcare providers. In addition, we were able to promote HPV vaccination along with the back-to-school vaccine campaign with the Bureau of Immunizations and Office of Communications.*
- **Skin/Sun Safety**
 - *Sun Safety – Identified volunteer healthcare providers to support Mole Patrol. Will monitor legislation restricting tanning bed use by minors in the 2013 Legislative Session including support for Sen. Sobel's proposed bill.*
- **Healthy Weight**
 - *Green ribbon schools*
 - *US Healthy School Challenge*
 - *CATCH/SPARK Training*
 - *Healthy Weight – Identifying opportunities to support green ribbon schools efforts and improving nutrition in schools.*
- **Committee Structure**
 - *Tobacco, HPV, Skin/Sun Safety, and Healthy Weight will convene monthly through conference calls and the full committee will meet via conference call quarterly.*

Goal III – Treatment & Access to Care

- **Summarize (definition/resources) the existing scientific evidence regarding patient navigation.**
 - *The committee continues to work on identifying a Florida specific definition.*
- **Map Resources for patient navigation in Florida.**
 - *Core elements of navigation; Training by Dr. Harold Freeman in State of Florida; Levels/tiers of navigation; Continued development of mapping resources for patient navigators in Florida.*
- **Identified models of certification/training for patient navigators nationally.**
 - *The committee is also working toward identifying models of certification/training for patient navigators.*
- **Consider development of legislation for Florida; identify examples from other states.**
 - *Identification of funding resources is ongoing, as well as continued coordination with the Florida Community Health Worker Coalition.*
- **Sustainability models/funding considerations for face-to-face meeting.**
 - *The committee is in the process of researching external funding resources for a face-to-face meeting*
- **Assist with the development of FCONN website**
- **Identify strategies for standard of navigation (in clinical settings)**
 - *3 disease sites/cancers; Best Practice strategies at patient level and system level factors*

Goal IV - Survivorship

- Distribution of Florida Survivorship Brochure ACoS, ACS, FLASCO, ONS, FSOSW, and Collaborative Networks
 - *The committee has approved a cover letter that will accompany the distribution of the “What Every Cancer Survivor Should Know” brochure to the ACoS cancer centers. The brochure has been distributed to the six regional cancer control collaboratives and members at the FSOSW conference.*
- National Cancer Survivorship Day – 6/5/12 Joint Resolution/Proclamation for 2013
 - *The committee is developing language to present to appropriate stakeholders to establish either a resolution by the Florida Legislature, or a Proclamation by the Governor, naming June 2013 as Florida Cancer Survivor month. This initiative would coordinate with the National Survivorship Day.*
- Speakers Bureau - Four in 2013: 3 professional, 1 community based settings or venues
 - *The committee continues to facilitate the organization of a speaker’s bureau. The committee agreed that they should identify appropriate venues to present at and then match a speaker to the venue; Speakers/Events/Funding*
- New Members ACCC
 - *The committee is vigilant in incorporating the most appropriate stakeholders to participate.*
- FCDS Project
 - *Continued development of Survivorship data set to patients/practices from FCDS data collection and additional quality improvement projects as a result of provider participation.*

Action Items

- **DOH to provide Dr. Armstrong with a white paper on VA cancer reporting issue**
- **One page, district specific, cancer report for member’s of Florida’s Legislature**
- **Distribute Information on FCDS Ambulatory Update**
- **Reach out to the VA for non-voting representation on CCRAB**
- **Invite a member from each of the 6 collaborative networks to participate in CCRAB meetings. Have Sue Higgins provide updates on all collaborative activity on specified monthly calls.**
- **Invite member(s) from BRAC to participate on CCRAB and ensure linkage between separate council goals/priorities; Align mission of two councils with generation of white paper to Dr. Armstrong in follow-up to his request for statewide cancer strategy/priorities/infrastructure/outcomes**
- **Continue efforts to synergize CCRAB/FCPC missions with potential for statute revision or bylaw adjustments in future**
- **Assist with the development of FCONN website**
- **Identify strategies for standard of navigation (in clinical settings)**
- **Continued distribution of, “What Every Cancer Survivor Should Know” brochure**
- **Recognition of Survivorship Day in Florida, through proclamation by governor or resolution by Legislature**
- **Continued development of Speaker’s Bureau**
- **Continued progress on FCDS Pilot Project**

Adjourn & Network

The meeting adjourned at 4:00 pm EST. The full Council will reconvene upon the call of the Chair.