

Florida Cancer Control & Research Advisory Council

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

GENERAL MEMBERSHIP AGENDA

Monday, May 13, 2013 8:00 a.m. – 3:30 p.m. Moffitt Cancer Center Stabile Research Building-Trustees Board Room

MEMBERS IN ATTENDANCE

- Thomas J. George, MD (Chair), College of Medicine of the University of Florida (CCRAB/FCPC)
- Richard Bookman, PhD, University of Miami Miller School of Medicine (Chair, BRAC)
- John H. Armstrong, MD (Speaker), Surgeon General, State of Florida
- David Woodmansee, (Speaker), National Lead for Access Issues Regarding PPACA
- Robert Morris, MS, MPH, Senior Director, Southern Region, ACS CAN
- Karen M. Peterson, Esq, Advocacy Leader, Florida Division, ACS CAN
- Honorable Eleanor Sobel (By Phone), Member of the Senate (CCRAB)
- Megan Wessell, American Cancer Society (FCPC)
- Brian M. Rivers, PhD, Moffitt Cancer Center (CCRAB)
- Eric S. Sandler, MD, Florida Association of Pediatric Tumor Programs (CCRAB)
- Susan Fleming, Florida Department of Health (CCRAB/FCPC)
- Zenesha Barkley, PhD, Florida Nurses Association (CCRAB)
- Michael Bolin, Agency for Health Care Administration (CCRAB)
- JoAnne Bujnoski, DO, Florida Osteopathic Association (CCRAB/FCPC-NORTHWEST COLLABORATIVE)
- Rose Marie Cossick, Consumer Advocate (CCRAB)
- Ellen Daley, PhD, College of Public Health, University of South Florida (CCRAB)
- Benjamin Djulbegovic, MD, College of Medicine, University of South Florida (CCRAB)
- Bonnie Donihi, Florida Ovarian Cancer Alliance Speaks (CCRAB)
- Jeff Feller (Lauren Pollock Representing), WellFlorida Council (FCPC-NORTHEAST COLLABORATIVE)
- Sue Higgins, Florida Department of Health (FCPC)
- Robert Holloway, MD, Florida Obstetric & Gynecological Association (CCRAB)

- Jill MacKinnon, PhD (Speaker), Florida Cancer Data System
- Robert L. Hood, PhD (Speaker), Florida Department of Health
- Helen Lewis, Florida Cancer Registrars Association (CCRAB)
- Dorothy Parker, Sylvester Comprehensive Cancer Center of the University of Miami (CCRAB/FCPC)
- Ryan Reid (Speaker), American Cancer Society
- Vanessa Rivera-Colon, Moffitt Cancer Center-Outreach Wellness Education & Resources (FCPC)
- James G. Schwade, MD, Florida Medical Association (CCRAB)
- Gerald J. Robbins, MD, American Cancer Society (CCRAB)
- Vanessa Vicente, Leukemia & Lymphoma Society of Southern Florida, Co-Chair Southeast Collaborative (FCPC)
- Julio Poswang, MD, Moffitt Cancer Center
- Luke Ihnen, Moffitt Cancer Center
- Merritt Martin Lindstrom, Moffitt Cancer Center
- Jamie Wilson, Moffitt Cancer Center
- Sandra Stonecypher, Moffitt Cancer Center
- Tiffani Mulder, Program Consultant (Speaker), Centers for Disease Control
- Barbara Roberts, MS, RD, LD, Florida Department of Health, Hillsborough County
- Tiffini Joseph, CCRAB Survivorship Committee
- Mark Whalen, Pfizer Corp
- Ellen Feiler, MS, MCHES, Co-Chair, South Florida Cancer Control Collaborative
- Teresa Kelly, Coordinator, SW Florida Cancer Control Collaborative
- Lourdes Arvelo, Chair, SW Florida Cancer Control Collaborative

NON-ATTENDEES

- JoAnne Carrin, Consumer Advocate (CCRAB)
- Sharmine Dipnarine, Consumer Advocate (CCRAB)
- Robert H. Cassell, MD, PhD, Florida Society of Clinical Oncology (CCRAB)
- Honorable Marti Coley, House of Representatives (CCRAB)

- Brian Calkins, Florida Association of Pediatric Tumor Programs, Inc. (FCPC)
- Dewey Painter, MD, Southeast Native American Indian Council (FCPC)
- Elizabeth Shenkman, University of Florida Shands Cancer Center (CCRAB)
- Phil Fusca, Co-Chair Southeast Collaborative (FCPC-SOUTHEAST COLLABORATIVE)
- Gregory Hale, MD, All Children's Hospital, Florida Pediatric Society (CCRAB)
- Pascal Jean-Pierre, PhD, University of Miami, School of Medicine (CCRAB)
- Gerry Lange, Southeast Native American Indian Council (FCPC)
- Maureen Mann, Association Comprehensive Community Hospital-Holy Cross Hospital (FCPC)

- Camilla Reid, Florida Department of Health (FCPC-SOUTHWEST COLLABORATIVE)
- Recinda Sherman, Florida Cancer Data System (FCPC)
- Rosemary Irene Sullivan, Florida Society of Oncology Workers (CCRAB)
- Lance Grenevicki, DDS, MD, FACS, Florida Dental Association (CCRAB)
- Cynthia Harris, PhD, FAMU Institute of Public Health (CCRAB)
- Elizabeth Shenkman, PhD, University of Florida Shands Cancer Center (CCRAB)
- Jeffrey A. Bubis, MD, Association of Community Cancer Centers (CCRAB)
- Naushira Pandya, MD, Nova Southeastern College of Osteopathic Medicine (CCRAB)

Introduction

The meeting began with CCRAB Chair, Dr. Thom George, welcoming the group and thanking everyone for their participation. Dr. George then reviewed the agenda for the day, and asked that everyone in attendance take a moment to introduce him or herself, and briefly identifying what organization they're with.

Florida System of Cancer Research & Care

Dr. Robert Hood of the Florida Department of Health provided the council with an update on the Florida System of Cancer Research & Care (FSCRC) that Surgeon General Armstrong spoke about at the Fall Meeting. The CCRAB Executive Committee and General Membership submitted a position statement to the Surgeon General's office in January. Dr. Hood explained that the goals of the FSCRC were to be a premier cancer research destination, to have a premier cancer research network with transparent metrics, and to offer premium care.

Dr. Hood explained that the passage of SB1660 by the Florida Legislature during the 2013 Legislative Session has shifted the focus of the FSCRC to the cancer "Centers of Excellence" award placed into statute by the legislation. The bill empowers CCRAB and BRAC to jointly develop metrics and a rating system for cancer providers statewide to apply to become centers of excellence. The Department of Health (DOH) is tasked with the administration of the program.

Dr. George opened the floor to a discussion of what standards should be put in place for the award and what standards are already in place that could be copied. The discussion focused on the 20+ standards put in place by the American College of Surgeons. Concerns were raised that many independent centers that deal with cancer (radiology, pediatrics, etc) are not ACOS certified due to deference to other certifying institutions, and thus not eligible for the centers of excellence award as written into statute. CCRAB members will look further into the legislation and propose possible changes for the next legislation session.

Update from BRAC

Dr. Richard Bookman, BRAC Chair was introduced to give an update on what that council is working towards. Because of SB1660, BRAC and CCRAB will be working closer together in the future to jointly develop standards and a rating system. Dr. Bookman mentioned the strong working

relationship he has developed with Dr. George over the past year – they have each attended each other's meetings.

Dr. Bookman outlined the King and Bankhead-Coley program goals and statutory mandates for BRAC. He also discussed BRAC's grant process and the types of awards and to whom: all grants are peer reviewed outside of the state – BRAC members never know who they are, which encourages innovation within the process. BRAC's responsibilities regarding grants are portfolio balancing decisions.

Dr. Bookman discussed the program's highlights and challenges, the FSCRC, and the three components of BRAC's research agenda: infrastructure, talent, and specific problems. Dr. Bookman ended his presentation by presenting BRAC's "Big Goal:" "By 2025, if you're diagnosed with cancer in Florida, you will have the option of having your genome sequenced." This opened the floor to discussion and specifically, metrics needed to meet these types of goals.

2012-2013 Legislative Session Summary

Senator Eleanor Sobel provided an update and her perspective on the legislative session. She talked at length about the process and eventual victory of the "Cancer Treatment Fairness Act" which mandates insurance companies to provide oral chemotherapy treatments if they are available. CCRAB had signed on as an organizational sponsor for the legislation and tracked its progress closely through the session. Senator Sobel discussed some of the other pertinent cancer legislation including the appropriations for the King and Bankhead-Coley research programs, her filed legislation for tanning bed legislation, and SB1660.

Ryan Reid provided the Council with a broader update from the 2013 Legislative Session. During the 2013 Legislative Session the Legislature allocated \$135,924,813 to cancer control and research efforts. The following allocations were supported by the American Cancer Society and CCRAB, and are listed individually:

King Biomedical Research Program	\$10,000,000
Bankhead-Coley Biomedical Research	\$10,000,000
Program	
UF Shands Cancer Hospital	\$7,050,000
UM Sylvester Cancer Center	\$7,050,000
Moffitt Cancer Center	\$7,050,000
Sanford-Burnham	\$5,600,000
Torrey Pines	\$3,000,000
Endowed Research Chairs	
Moffitt Cancer Center	\$3,330,000
UF Shands Cancer Hospital	\$3,330,000
UM Sylvester Cancer Center	\$3,330,000
Comprehensive Statewide Tobacco	\$65,640,769
Prevention and Education	
Mary Brogan Breast and Cervical Cancer	\$1,500,000
Program	
Minority Health	\$3,134,044
Rural Primary Care Residency Expansion	\$5,200,000
La Liga (League Against Cancer)	\$210,000
UF McKnight Brain Institute	\$500,000
TOTAL CANCER-RELATED ISSUES AND	\$135,924,813
ACS PRIORITIES FUNDED	

In addition to reviewing these budget allocations, Mr. Reid reiterated the process for the oral parity and cancer centers of excellence legislation. He thanked the efforts of CCRAB members, Senator Sobel and Representative Coley for their work and dedication to the cancer community. He had special praise to Senator Lizbeth Benacquisto and Representative Debbie Mayfield for their fight in the oral parity legislation.

Reid labeled the session a success for the cancer community, with the one negative being the inaction on Medicaid expansion. Senator Sobel urged CCRAB members to encourage and educate their representatives to move them closer to the Senate's plan.

Finally, the Council supported the following bills through its subcommittee structure during the 2012 Legislative session:

Bill	Outcome
Relating to Community Health Workers	- Passed House - Passed 2 Senate committees
Relating to Cigarette Products of Non-settling manufacturers	- Never heard in committee
Relating to the Florida Clean Indoor Air Act	Never heard in House Passed 2 Senate committees
Relating to Cancer Treatment	- Passed House and Senate with effective date of 07/2014
Relating to Pharmacy	- Passed House and Senate
Relating to Surcharge on Cigarettes	- Never Heard in Committee
Relating to Quality Cancer Care and Research	- Passed House and Senate
Relating to Prevention of Cancer in Youth	- Never heard in committee

<u>Update on DOH CDC Funded Cancer Control Programs</u>

Susan Fleming introduced Tiffani Mulder, Program Consultant with the Centers for Disease Control and Prevention, to give an update on the Department of Health CDC Funded Cancer Control Programs. Tiffani discussed the grant process and requirements, and the steps that the Florida Department of Health Program staff had taken to move the state forward.

Susan Fleming introduced Darcy Abbott, Chief of the Bureau of Chronic Disease Prevention to discuss the "State Health Improvement Plan" (SHIP) and the role the cancer program plays in the plan. She discussed that bureau staff and partners participate on "action teams" including: worksite, school, community, and clinical teams. She also discussed a new program the bureau is rolling out entitled the "4 Life Plan" and the plan's media campaign. Finally, she mentioned a new CDC grant opportunity regarding actions to prevent and control diabetes, heart disease, obesity and associated risk factors.

Susan Fleming discussed the programs she supervises: Breast & Cervical Cancer Early Detection Program, Colorectal Cancer Control Program, and the Comprehensive Cancer Control Program. She provided updates on the section of the SHIP relating to cancer and gave some progress reports regarding SHIP Indicators for colorectal and breast and cervical cancer. She introduced council members to the Department's partnership with the American Cancer Society for workshops on colorectal, and breast and cervical cancers and the targeted media campaigns for both. She discussed the "Community Health Workers" program and the regional cancer control collaboratives, and the CCRAB goal areas the Department works to facilitate. She ended her presentation with a chart showing "CCRAB In-Kind Hours" by members of CCRAB, FCPC, DOH, and other participants totaling 870 hours.

Florida Cancer Data System, Cancer Registry Update

Dr. Jill MacKinnon provided some background information and an update of current activities regarding Florida Cancer Data Systems (FCDS). The presentation briefly covered the creation of the registry, location, how data is collected and from whom, ways in which the data can be accessed and utilized, and the need/ways in which the registry could be improved.

When asked how CCRAB could help the registry, Dr. MacKinnon responded by saying that the Council would help the registry design a task force to create more uses of the metrics provided by the registry.

Lunch Break

Patient Protection and Affordable Care Act

Dave Woodmansee gave the council an update on the Patient Protection and Affordable Care Act (PPACA) implementation and how Florida will be affected, particularly as it relates to the Medicaid expansion and exchanges. Mr. Woodmansee stated that 7 states are running a partnership exchange with the government, 17 states and the District of Columbia are running their own exchange, and 26 states where the government is running the exchange.

Mr. Woodmansee discussed some of the challenges on the federal level including funding, which could adversely affect the 26 states where the government is running the exchange due to the sequester, and concerns with conforming language in states where the insurance commissioner doesn't have authority to enforce laws of the bill.

He mentioned a small concern over the tobacco rating/surcharge portion of the bill that will affect disparate tobacco using populations. As a result, smokers will not have to abide by the individual mandate which will put us in the same state we were in before. He also mentioned that ACS is working to make sure that rating doesn't apply to states where the federal government is running the exchange.

Another concern mentioned regarding cancer medications, was that the Department of Health and Human Services gives insurers wiggle room to move drugs around between classes, which is part of the ten basic categories of basic health benefits covered in the bill. ACS will monitor this development closely.

He brought up a concern with the preexisting condition program that was put in place to bridge the passage of PPACA to its implementation is almost out of money, which is causing the government to

put a ceiling on benefit disbursements. However, Mr. Woodmansee brought up that this will only take place in states where the federal government subsidizes a state's preexisting program. Regardless, he mentions that from a perspective of cancer,, the elimination of preexisting conditions clause in insurance plans will be a huge benefit to the state.

<u>Discussion on Florida System of Cancer Research & Care</u>

Dr. George opened the discussion on the FSCRC with the question: "How does CCRAB tackle the issue of establishing standards when there are currently no clear standards?" After brief discussion, Dr. Robert Hood offered that he hoped CCRAB would take the position of weighing in on different approached and recommending to the state what the standards should be. After a discussion on clinical trials, Dr. Hood offered that CCRAB needs to engage the question of whether the state needs to engage in clinical trials. Throughout the discussion, the focus was on developing metrics that can be measurable and achievable for the largest group possible.

Dr. John H. Armstrong, Florida Surgeon General, joined the meeting and discussed the implications of SB1660, the "Centers of Excellence" legislation. Dr. Armstrong expressed that the legislation was important and renewed legislative interest in cancer care and research and that he, personally, was heartened by increases in the budget for cancer research. He discussed the importance of forging better ties between cancer institutions in the state and is excited for the opportunities Florida cancer providers have. He believes the state is in a better place than when he accepted the position.

Dr. Armstrong asked that CCRAB and the Florida Cancer Plan Council revisit the plan with an eye towards measurable outcomes. He believes the plan is too general right now which makes it hard to show the governor and legislature the improvements. Dr. Armstrong wants the state to be able to track progress in research, outcomes, etc... He brought up the proposals from BRAC and CCRAB, as well as other groups, around 3 cancers that will form the basis for pilots as targets for clinical trials, research, and education. He mentioned that proposal will be put out in the next few months.

Dr. Armstrong reiterated the Governor's desire for the state to be an end destination for cancer care and research dollars. To illustrate the point of better collaboration, he mentions that the state ranks 14th in NCI dollars but is soon to be the 3rd largest state. He believes CCRAB can use the tool of SB1660 to define existing and premature centers of excellence. Must look at where the gaps exists and work towards bridging them before making statutory adjustments to the bill language. This will help to "raise all boats."

The question is raised on how to pursue the kind of resources needed to achieve the goals of SB1660 and the FSCRC. Dr. Armstrong discusses the importance of a system of linkages with research and measurable outcomes and mentions that this will provide the kind of proof cancer interests need to present a proposal for a larger investment in the future. Dr. Armstrong closes by expressing a desire to compete against other states and countries as opposed to each other.

Subcommittee Updates & Priorities & Working Groups

The members broke into their subcommittee and working groups to discuss and update goals and actionable items for the next year.

Review Identified Priorities

It was asked that Sue Higgins send out the survey again for comments, and the groups are tasked with having a meeting within one month of the Spring Meeting. Dr. Sandler reminds guests of the Survivorship Meeting the following day.

The meeting is adjourned at 3:32 P.M.

BRAC Agenda to CCRAB

CCRAB May 2013 FCDS Update