



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

GENERAL MEMBERSHIP MEETING MINUTES SUMMARY

Monday, May 14, 2012, 10:00am-4:00pm
Moffitt Cancer Center - Stabile Research Building

MEMBERS IN ATTENDANCE

- Thomas J. George, MD (*Chair*), College of Medicine of the University of Florida (CCRAB/FCPC)
- Robert H. Cassell, MD, PhD, Florida Society of Clinical Oncology (CCRAB)
- Honorable Marti Coley (*By Phone*), House of Representatives (CCRAB)
- 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)
- Brian Calkins, Florida Association of Pediatric Tumor Programs, Inc. (FCPC)
- JoAnne Carrin, Consumer Advocate (CCRAB)
- 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, WellFlorida Council (FCPC-NORTHEAST COLLABORATIVE)
- Phil Fusca, Co-Chair Southeast Collaborative (FCPC-SOUTHEAST COLLABORATIVE)
- Gregory Hale, MD, All Children's Hospital, Florida Pediatric Society (CCRAB)
- Sue Higgins, Florida Department of Health (FCPC)
- Robert Holloway, MD, Florida Obstetric & Gynecological Association (CCRAB)
- Pascal Jean-Pierre, PhD, University of Miami, School of Medicine (CCRAB)
- Gerry Lange, Southeast Native American Indian Council (FCPC)
- Jill MacKinnon, PhD (*Speaker*), Florida Cancer Data System
- Kelly Markey (*Speaker*), Moffitt Cancer Center
- Maureen Mann, Association Comprehensive Community Hospital-Holy Cross Hospital (FCPC)
- Dinah Merrill (Filling in for Helen Lewis), Florida Cancer Registrars Association (CCRAB)
- Dorothy Parker, Sylvester Comprehensive Cancer Center of the University of Miami (CCRAB/FCPC)
- Camilla Reid, Florida Department of Health (FCPC-SOUTHWEST COLLABORATIVE)
- Ryan Reid (Filling in for Paul Hull), American Cancer Society (CCRAB)
- Vanessa Rivera-Colon, Moffitt Cancer Center-Outreach Wellness Education & Resources (FCPC)
- Recinda Sherman, Florida Cancer Data System (FCPC)
- James G. Schwade, MD, Florida Medical Association (CCRAB)
- Rosemary Irene Sullivan, Florida Society of Oncology Workers (CCRAB)
- Vanessa Vicente, Leukemia & Lymphoma Society of Southern Florida, Co-Chair Southeast Collaborative (FCPC)
- Monique Whan, Consumer Advocate
- Rob Whan, Consumer Advocate
- Laura Lenhart, Moffitt Cancer Center
- Kimberley Buccini, Moffitt Cancer Center
- Ali Polsky, Florida Department of Health

NON-ATTENDEES

- Sharmine Dipnarine, Consumer Advocate (CCRAB)
- Dewey Painter, MD, Southeast Native American Indian Council (FCPC)
- Elizabeth Shenkman, University of Florida Shands Cancer Center (CCRAB)
- Honorable Eleanor Sobel, Member of the Senate (CCRAB)
- Megan Wessell, American Cancer Society (FCPC)

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. Once the introductions were concluded, Laura Lenhart provided the Council with an update on the status of new members awaiting appointment, and provided an update regarding current member's re-appointment statuses. The Governor's appointment office is currently going through reorganization, which is an attributing factor to the delay in appointments. Communication with the appointment's office is on going.

Legislative Update

Representative Marti Coley provided a legislative update by phone with regards to the CCRAB statute revision bill filed during the 2012 Legislative Session, HB1073/SB1350 – Relating to Cancer Control. Representative Coley explained that there was difficulty getting the bill scheduled in its first committee stop. Overall, the difficulty was attributable to a lack of understanding among certain House members as in the two years that the bill has been filed, the content has differed. Representative Coley urged all members of the Council to build relationships with their local Representative and Senator to educate them on CCRAB.

Ryan Reid, who attended in place of the American Cancer Societies CCRAB member Paul Hull, provided the Council with a broader update from the 2012 Legislative Session. During the 2012 Legislative Session the Legislature allocated \$107,427,597 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	\$7,150,000
Bankhead-Coley Biomedical Research Program	5,000,000
UF Shands Cancer Hospital	7,500,000
UM Sylvester Cancer Center	7,500,000
Moffitt Cancer Center	5,000,000
Sanford-Burnham	3,000,000
Comprehensive Statewide Tobacco Prevention and Education	64,289,944
Mary Brogan Breast and Cervical Cancer Program	1,236,436
Minority Health	3,134,044
Rural Primary Care Residency Expansion	3,000,000
La Liga (League Against Cancer)	117,173
UF McKnight Brain Institute	500,000
TOTAL CANCER-RELATED ISSUES AND ACS PRIORITIES FUNDED	\$107,427,597

In addition to reviewing these budget allocations, Mr. Reid reiterated the need for the Council to build relationships with their locally elected officials. Moreover, in response to the Council's desire to be more proactive in this coming year's legislative session, he conveyed that it will be essential to get to work early on getting ahead of the biomedical funding issue, insuring that the Mary Brogan Breast and Cervical Cancer Program becomes a reoccurring budget allocation, and continue working to protect the tobacco education/prevention allocations.

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

Bill	Outcome
HB 655/SB 616 Relating to Biomedical Research	HB 655: Approved by Governor on 3/23/12
HB 1073/SB 1350 Relating to Cancer Control	HB 1073: Never heard in committee SB 1350: Died in budget *Bill was amended on to SB 1646, but died in Senate Budget.
HB 143/SB 746 Relating to Florida Clean Indoor Act	HB 143: Died in Community and Military Affairs Subcommittee SB 746: Died in Community Affairs (2 nd stop)
HB 723/SB 886 Relating to Community Health Workers	HB 723: Died in Health and Human Services Access Subcommittee SB 886: Died in Health Regulation
HB 623/SB 1066 Relating to Cancer Chemotherapy Treatment Parity	HB 623: Died in Health and Human Services Quality Subcommittee SB 1066: Died in Banking and Insurance
HB 1043/SB 1044 Relating to Tanning Bed Facilities	HB 1043: Died in Business and Consumer Affairs SB 1044: Died in Health Regulation
SB 1842/HB 1049 Relating to Surcharge on Cigarettes	HB 1049: Died in Finance and Tax SB 1842: Died in Regulated Industries
HB 1051/SB 1116 Relating to Human Papillomavirus	HB 1055: Died in Health and Human Services Quality SB 1116: Died in Budget

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

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.

Oncology Drug Shortage Update

Kelly Markey, PharmD, BCOP, Clinical Pharmacist at Moffitt Cancer Center, provided the Council with a presentation on the National Drug Shortage. The presentation defined appropriate terminology,

provided reasons for the drug shortage, identified trends in national medication shortages, and specifically identified drugs that are in short supply, addressed the multifaceted impact of the drug shortage, and supplied potential solutions. [National Drug Shortages](#)

Dr. Thom George inquired as to whether or not there was anything that CCRAB could do to advance awareness of the issue, and possibly promote a solution. Dr. Eric Sandler suggested that the Council advocate with each members perspective legislators on a national level to support any current legislation in Congress with regards to the issue. Dr. George also asked if CCRAB should draft a position statement regarding any current legislation. The Council felt that a one-page position paper could be beneficial, and that other organizations associated with CCRAB could already be working on a similar document. With other organizations in mind, the Council could solicit suggestions.

Action Items: One Page Position Paper; Identify Bills/Bill Sponsors; Possibly use CDC DL to distribute; Goal III.

Update from Collaborative Chairs and DOH: CCC Funded Programs

Each Collaborative Chair or Co-Chair in attendance provided a Collaborative update.

Jeff Feller, North Central Florida Collaborative Chair, the North Central region is comprised of eleven counties 11. The collaborative has received funding from the American Cancer Society for a Lay Educator program focused on breast cancer education in African American churches in Alachua County, membership is slowly growing, and the Collaborative is working toward expanding into two more counties. Additionally, in June the Collaborative will be launching a searchable and printable resource guide on their website for hospital and navigator information.

Camilla Reid, Southwest Florida Collaborative Chair, provided an update for the region that she represents. The South West Collaborative has developed a webpage, but would like to have an independent server host other than the department of health. The collaborative also developed a cancer patient resource guide with the American Cancer Society; fifteen thousand have been printed and have been translated into Creole and Spanish. The Collaborative is currently trying to make the resource guide available online. Additionally, the Collaborative is putting on a huge community event for national cancer survivor day.

Phil Fusca, Southeast Collaborative Co-Chair, provided an update on the region. The Collaborative has a new/updated website and also a new Facebook page: SoFlaFightsCancer. Additionally, the Collaborative has used their Department of Health funding to create a Speaker's Bureau Directory that will be community based, applicants to the speaker's bureau will be review by the committee, and the project will be live in June 2012. The Collaborative has also created a publication, "What's next for my life after cancer treatment?" The document will be distributed to member organizations to be provided upon the conclusion of treatment.

Jerry Lang, Southeast Native American Indian Council, introduced himself and his organization. The Council is a chartered 501c3, and welcomes anyone with Native American heritage to join, or anyone who would like to be supportive. The Council comprises Native American tribes who are not federally recognized with the goal of working towards recognition.

Dr. Joanne Bujnoski, Northwest Florida Collaborative Co-Chair, provided an update for the region. The Northwest region is presented with a precarious challenge as the area is split into two time zones: eastern standard and central. The collaborative currently has a student receiving her master's degree from University of West Florida updating the Collaborative website to make it more interactive.

The update will be complete in June 2012. Both Collaborative Chairs will be attending a leadership collaborative workshop in Panama City next month.

Susan Fleming provided updates on the five components of the Department of Health's CDC grant proposal. Those components include initiating an integrated element between departmental programs and describing how they obtain and sustain cohesiveness between programs. Additionally, the grant focuses on supporting local, preventative cancer activities, including collaborative efforts with local health councils. Moreover, educating providers on systems change, increasing screening rates for breast and cervical cancer, especially in minority populations, and partnering with the Office of Minority Health are among issues being included in the grant application. Finally, the application includes a component to sustain funding for the cancer registry.

Subcommittee Updates & Priorities

The subcommittee chairs for each committee provided an update of the happenings in each committee since the October 2011 meeting.

Goal I: Develop System Capacity

Chair: Dr. Thom George

- Identified Action Items from October Meeting
 - Statute Revision – minimize coordination by DOH
 - Biomedical Resources
 - Dollars from CDC to support Comp Cancer Control
 - Collaborative Grants for Redistricting
 - Position statement for NON-ACA funds for BRFSS
- Additional Action Items & Progress
 - Revision of Bylaws (in progress)
 - Consideration of creation of a Communications Plan
 - Bill language for statute revision
 - Letter to Legislature urging an amendment to HB 1263 to preserve the essential functions of Florida Cancer Data Systems
 - Letter to Legislature regarding bills that CCRAB supported during 2012 Legislative Session.
 - Development of "How Can CCRAB Help Your Organization" Form.

Goal II: Prevention

Chair: Susan Fleming

- Identified Action Items from October Meeting
 - Support HB 143
 - Letters from CCRAB to Committee Chairs and Co-Chairs
 - Promote and advocate for a bill similar to SB1430 relating to tobacco use on community college campuses.
 - Letters to other state universities recommending that they follow the University of Florida's lead in adopting a tobacco free campus.
 - Seek out a representative from the Department of Agriculture to participate in Goal II activities.
 - Support total ban regarding the use of tanning beds for minors.
 - Continue promoting HPV vaccinations
 - Talk to DOH regarding HPV vaccination statistics

- What is DOH's position if a school district asks about HPV vaccination?
- Additional Action Items & Progress
 - Letter to universities and colleges in Florida congratulating those who have adopted tobacco free policies, and encouraging other colleges and universities to do so also.
 - "Tobacco & Cancer" fact sheet to accompany letter is in the process of being developed.
 - Letter and fact sheet will be sent to each county's Tobacco Free Partnership and will be accompanied by a press release for distribution.
 - Development of "tobacco and cancer" House and Senate district specific fact sheet for distribution.
 - Consideration of a "back-to-school" initiative aimed at boys and girls receiving the HPV vaccine.

Goal III: Treatment and Access to Care

Chair: Dr. Brian Rivers

- Identified Action Items from October Meeting
 - If there is legislation including Community Health Workers (CHW) our group will review and recommend to CCRAB if we are in agreement.
 - Navigation becomes a subgroup of the Community Health Worker Coalition
 - Define group within Florida CHW Coalition focused on navigation
 - CCRAB recommends an advisory group be established that will recommend a path toward standards, certification and reimbursement – sustainability should come through legislation.
- Additional Action Items & Progress
 - Researching navigator practices throughout Florida and other state's for presentation on May 18th call.
 - Working toward expanding committee size through inviting navigators from throughout Florida to join the committee.
 - Through invitation of navigators the committee hopes to gain education on the needs of navigators throughout the state, facilitate networking, and infrastructure development.

Goal IV: Survivorship

Dr. Eric Sandler

- Identified Action Items from October Meeting
 - Brochure:
 - Content Lead: Eric
 - Format Lead: Sue Higgins
 - Treatment Summary Database
 - Travis Greenman
 - Tara Hylton
 - Education: Speakers Bureau and Webinar
 - Hope Wood
 - Advocacy – Support Others - ACS
- Additional Action Items & Progress
 - Brochure is completed and is awaiting distribution.
 - Speaker's Bureau letter and questionnaire are finalized.
 - Pilot project with Nemours and FCDS is underway.

Subcommittee Working Groups & Review Identified Fall Priorities

Time was provided for each of the committees to break-out into their perspective groupings to identify actionable items for the fall.

Goal I: Develop System Capacity

1. 2012-2013 Priorities/Strategies Revision
 - a. Third Point – Goal I: "Educate and inform elected and appointed officials and the public on effective strategies to reduce the burden of cancer."
2. Statute Revision
 - a. Revise with the intent to include more stakeholders from around the State
 - b. Finalization of language at Fall meeting
3. Update Bylaws
 - a. Executive Council
 - b. Vice Chair
 - c. Nominating Process
 - d. Voting Procedures
4. Taking a proactive approach: "How Can CCRAB Help Your Organization?" Form
 - a. What do we do with the form?
 - b. Internal vetting procedures
 - c. Executive committee could review the request and assign whatever the task may be to the appropriate committee.

Goal II: Prevention

1. Tobacco
 - a. One Pager
 - b. Disseminate Letter
 - c. Tobacco Free Hospitals: Survey or Send Letter
 - d. Consider Native American Populations – culturally sensitive education
2. HPV (newest priority strategy)
 - a. Pediatricians
 - i. Partner with Merck
 - ii. Schools/back to school
 - iii. Position Statement
 - iv. Piggy back on USPSTF vaccine
 - b. Partner with Merck (Gardasil) on education efforts
 - c. Create educational posters on HPV specific cancer prevention
3. Skin/Sun Safety
 - a. Mole Patrol – Support through identification of dermatologists who would be willing to volunteer
 - b. Tanning Bed – support legislation in 2012 Legislative Session
4. Healthy Weight
 - a. Follow up with green ribbon schools

- b. Follow up with US Healthy School Challenge
- c. Follow up with CATCH/SPARK Training

Goal III: Treatment and Access to Care

1. Summarize (definition/resources) the existing scientific evidence regarding patient navigation.
2. Map Resources for patient navigation in Florida.
 - a. Core elements of navigation
 - b. Training by Dr. Harold Freeman in State of Florida.
 - c. Levels/tiers of navigation
3. Identified models of certification/training for patient navigators nationally.
4. Consider development of legislation for Florida; identify examples from other states.
5. Sustainability models/funding considerations.

Goal IV: Survivorship

1. Distribution of Brochure
 - a. ACOS, ACS, FLASCO, ONS, FSOSW, and Collaborative Networks
2. National Cancer Survivorship Day – 6/5/12
 - a. Joint Resolution/Proclamation
3. Speakers Bureau
 - a. Four in 2013: 3 professional, 1 community based
4. New Members
 - a. ACCC

Overarching Action Items

- Creation of a “one-pager” addressing the drug shortage problem on a National level
 - Identify bill numbers/sponsors
 - Tasked to Goal III
- Assist the registry in creation of a Task Force to identify meaningful metrics and needs

Miscellaneous

Dr. Brian Rivers provided a brief update on the recent meeting of the Florida Prostate Cancer Advisory Council. CCRAB will continue to work with the PCAC to promote statewide prostate cancer education, awareness, and resources during the upcoming legislative session.

Conclusion

The meeting concluded with each of the subcommittee chairs reporting out on their committee’s goals until the Council meets again in the fall. CCRAB’s chair, Dr. Thom George, tentatively set the fall meeting in November in Tallahassee. The committee would like to coordinate their fall meeting with the first meeting of the legislature after this year’s election cycle. The meeting was adjourned at 4:00pm.