GENERAL MEMBERSHIP MEETING MINUTES SUMMARY

Friday, November 19, 2010, 9:00am-3:00pm
Moffitt Cancer Center - Stabile Research Building

ATTENDEES

EXECUTIVE CCRAB COMMITTEE MEMBERS:
- CHAIR-Thomas George, MD-College of Medicine of the University of Florida
- Honorable Marti Coley-House of Representatives (By Phone)
- Honorable Eleanor Sobel-Member of the Senate
- Susan Fleming-Florida Department of Health
- Dorothy Parker-University of Miami Sylvester Comprehensive Cancer Center
- Brian M. Rivers, PhD-H. Lee Moffitt Cancer Center & Research Institute
- Gerald J. Robbins, MD-American Cancer Society
- Eric S. Sandler, MD-Florida Association of Pediatric Tumor Programs

CCRAB MEMBERS:
- Zenesha Barkley-Florida Nurses Association
- Michael Bolin-Agency for Health Care Administration
- Jeffrey Bubis, MD-Association of Community Cancer Centers
- JoAnn Carrin-General Public Acting as Consumer Advocate
- Rose Marie Cossick-General Public Acting as Consumer Advocate
- Ellen Daley, PhD-University of South Florida, College of Public Health
- Sharmine Dipnarine-General Public Acting as Consumer Advocate
- Benjamin Djulbegovic, MD, PhD-College of Medicine of the University of South Florida
- Steven N. Hochwald, MD-American College of Surgeons
- Pascal Jean-Pierre, PhD-School of Medicine of the University of Miami
- Helen Lewis-Florida Tumors Registrars Association
- Cathy Reed-Florida Department of Education
- Elizabeth Shenkman, PhD-University of Shands Cancer Center
- Rosemary Irene Sullivan-University of Shands Cancer Center

FCPC MEMBERS:
- Vanessa Rivera-Colen-H. Lee Moffitt Cancer Center & Research Institute, Program Manager Outreach Wellness Education & Resources
- Jeff Feller-Florida Department of Health, Northeast Collaborative
- Ann Fonfa-General Public Acting as Consumer Advocate
- Martha Gonzalez-University of Miami Sylvester Comprehensive Cancer Center
- Christy Harrison-Florida Department of Health, Northwest Collaborative
• Sue Higgins-Florida Department of Health Comprehensive Cancer Control Program
• Paul Hull-American Cancer Society
• Mary Lesperance-Mayo Clinic Florida
• Maureen Mann-Holy Cross Hospital
• Antoinette Meeks-Florida Department of Education
• Jane Parker-Florida Department of Health, Bureau of Tobacco Prevention
• Camilla Reid-Florida Department of Health, Southwest Manatee County Collaborative
• Heather Shelby-Northwest Florida Community Hospital’s Women’s Imaging Services
• Recinda Sherman-Florida Cancer Data Systems
• Megan Wessell-American Cancer Society

OTHER ATTENDEES:
• Jamie Wilson, Vice President, Government Relations, Moffitt Cancer Center
• Merritt Martin, CCRAB Executive Director, Moffitt Cancer Center
• Kimberley Buccini, CCRAB Coordinator, Moffitt Cancer Center
• John DeMuro, Federal Government Relations Director, Moffitt Cancer Center
• Sarah Henderson, Government Relations Intern, Moffitt Cancer Center
• Susan Derrick, Program Consultant for the Centers for Disease Control

WELCOME:
Dr. George, CCRAB Chair, welcomed those in attendance, noting a number of newly appointed CCRAB members and indicating this meeting represents the first time CCRAB and FCPC has convened a meeting together. He expressed the hope this can be the start of a productive collaboration between the two groups. The overall agenda for the meeting day was reviewed. All members in attendance introduced themselves with brief statements about their work.

LEGISLATIVE UPDATE & STATUTE REVISION:
Jamie Wilson, Vice President for Government Relations for Moffitt Cancer Center, gave an overview of the upcoming Florida legislative session, making the following points.

• The State of Florida is facing a severe budget shortage, so funding for new cancer initiatives will be tough to obtain.

• A major bill to overhaul the state Medicaid system will likely be passed this year, with implications for the treatment of cancer patients at lower income levels.

• Legislation to modify the CCRAB statute will be offered this year. Mr. Wilson indicated this presents a unique opportunity for CCRAB to re-define its mission and streamline its processes in order to magnify the group’s positive impact to Florida's public, private, and academic efforts to fight cancer.
SENATOR SOBEL OFFERED THE FOLLOWING REMARKS:

- A Medicaid "memorial" or message of intent was passed by the House of Representatives to indicate the House's top priorities for a Medicaid reform bill to come. Among other ideas, it set forth that all current Medicaid patients in Florida will eventually be shifted to some form of private, state-contracted managed care.
- Senator Sobel expressed concerns that a statement regarding "managed care" lacked specificity, leaving the status of special populations such as developmentally disabled Floridians, and those needing nursing-home care, unknown with regard to how "managed care" programs will cover key services.
- Senator Sobel expressed her support for legislation that would offer increased access to cancer screening and early detection as well as to regulate tanning salons.
- Senator Sobel indicated House and Senate leadership have indicated the intent to reduce the size of government and reduce costs-- which will have an effect on the type of legislation that will eventually approved. In order to achieve passage, any cancer initiatives, then, must have sound fiscal strategies that do not reduce state budgets, and also not be viewed as "mandates" that would restrict individual freedoms or increase government regulation.

REPRESENTATIVE COLEY OFFERED THE FOLLOWING REMARKS:

- Exhorted the group to always remember its mission of bringing comprehensive awareness in the State of Florida of all policy issues related to cancer prevention, treatment, detection and education.
- Recognized that while financial resources may always be limited, there is always room for good ideas when it comes to cancer policy, and it is the duty of CCRAB to develop and advance such ideas.
- Encouraged members to cultivate relationships with individual legislators in order to educate state leaders about the mission and priorities of CCRAB.

PAUL HULL OF THE AMERICAN CANCER SOCIETY SHARED HIS ORGANIZATION'S LEGISLATIVE PRIORITIES FOR THE UPCOMING GENERAL SESSION:

- Line-item appropriation for breast cancer screening and early detection.
- The allocation of $50 million from the 2009 Tobacco surcharge funds to the Bankhead Coley and King biomedical research grant programs.
- Continued funding for tobacco prevention through the Tobacco Settlement Trust.

LEGISLATIVE DISCUSSIONS AMONGST GROUP:
It was suggested that a mechanism to share information on cancer policy developments and how group members can take action would be helpful. Several ideas on improvements in membership communication were discussed and vetted.

Ann Fonfa suggested a legislative measure to address the high cost of oral chemotherapy and its impact on patients should be a top priority.
Dr. Sandler expressed last year's re-authorization of the Bankhead Coley and King Biomedical grant programs, and the Mary Brogan screening and detection programs represented a success of the combined advocacy of the American Cancer Society and CCRAB, but he said that these programs may be on the chopping block again this year.

**COMPREHENSIVE CANCER CONTROL PROGRAMS:**
Susan Derrick, Program Consultant for the Centers for Disease Control offered a detailed presentation on the Comprehensive Cancer Control priorities of the CDC and the resources made available to the state of Florida through her agency. A copy of her slide presentation can be available to all members. It contains Ms. Derrick's contact information. Ms. Derrick offered to serve as a resource. [CDC Comprehensive Cancer Control Program]

**FLORIDA CANCER PLAN UPDATE:**
Susan Fleming, Department of Health provided an update on the Florida Cancer Plan, which contained the following highlights:

- Florida Cancer Plan is in 10th Revision; Current version in its final draft. The Current version will be released in January 2011, with a 10th anniversary launch celebration being planned.
- Reviewed the history of CCRAB dating back to 1979.
- Reviewed the history of the Florida Cancer Plan and its mission: to form coalitions to reduce the burden of cancer.
- Recognized the decade of service of Dorothy Parker, who has chaired the FCPC for the past 10 years.
- Review of the FCPC collaborations currently active in the state of Florida
- Reviewed the goals of the 2010 planning process, notably the expansion of involvement and input opportunities.
- Showed how the Plan's strategies addressed 10 cancer sites, with specific action steps on each
- Indicated the overall plan offers a broader view of cancer policy needs in Florida and an incisive view of the challenges faced by collaborators.

**OPEN GOVERNMENT GUIDELINES:**
JoAnn Carrin, Governor’s Office, highlighted key considerations of Florida's Sunshine Law affecting CCRAB and FCPC:

- Meetings must be noticed and open to the public.
- Meeting minutes must be created and promulgated.
- Any meeting or conversation involving two or more members must be noticed publicly, same as a meeting.
- All Council records must be made available to the public.

[2010 Open Government Update]

**PRESENTATION ON MOFFITT’S TOTAL CANCER CARE:**
Dr. Rob Wenham of Moffitt Cancer Center delivered a presentation on Moffitt's Total Care, an initiative that:

- is enrolling more than 100 patients per day in 19 hospitals in 10 states in a
protocol that involves the donation and subsequent genetic profiling of tumor tissue;

- has created a large biorepository and database which inter-relates the molecular, clinical, and demographic data from enrolled patients;
- facilitates more rapid accrual in clinical trials and helps to identify genetic markers and other targets for development of personalized means to fight cancer; and
- creates an electronic health record for patient use, a decision-support tool for physicians, and a major resource for researchers to generate and test hypotheses.

Total Cancer Care-Our Approach to Personalized Medicine.pdf

PRIORITY FOCUS GROUPS

Dr. George divided the attending members into breakout groups which addressed statewide priorities in cancer control and prevention. The groups generated the following ideas for top priorities in these areas:

GOAL 1 - DEVELOPING CANCER CONTROL SYSTEM CAPACITY/COORDINATION

- Condense FCPC with CCRAB with embedding of collaboratives
- Identify disparate needs locally to maximize capacity already in place

GOAL 2 - PREVENTION

- Collaborate more closely with obesity prevention and tobacco control efforts
- Develop tool kit for school curriculum
- Partner with other organizations to develop a distribution list
- Work with MCC/FCPC on sun safety initiatives

GOAL 3 - TREATMENT AND ACCESS TO CARE

- Promote understanding of healthcare reform impacts as new delivery models emerge
- Promote access to care and clinical trials
- Formalize a program to reach minority groups

GOAL 4 - SURVIVORSHIP

- All survivors should receive a treatment summary after their care
- Educate medical professionals regarding survivorship care

CONCLUSION:

- A motion was made by the Chairman to merge CCRAB and FCPC membership for the purposes of meetings, membership, and mission -- and for reducing redundancy and streamlining publicly funded efforts. Dr. Sandler seconded the motion. All members in attendance agreed by a unanimous vote

Meeting was adjourned at 3:10pm. Next Meeting will be in the spring 2011 – TBD.