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

GENERAL MEMBERSHIP MEETING MINUTES SUMMARY

Friday, June 10, 2011, 10:00am-4:00pm Moffitt Cancer Center - Stabile Research Building

ATTENDEES

EXECUTIVE CCRAB COMMITTEE MEMBERS

CHAIR-Thomas George, MD-College of Medicine of the University of Florida

Susan Fleming-Florida Department of Health

Lance F. Grenevicki, DDS, MD, FACS-Florida Dental Association 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
Joanne L. Bujnoski, MD, DO-Florida Osteopathic Medical Association
JoAnn Carrin-General Public Acting as Consumer Advocate
Robert H. Cassell, MD, PhD-Florida Society of Clinical Oncology
Ellen Daley, PhD-University of South Florida, College of Public Health
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
Naushira Pandya, MD-Southeastern College of Osteopathic Medicine
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-WellFlorida Council, North Central Florida Cancer Control Collaborative

Phil Fusca-Aventura Comprehensive Cancer Center, Southeast Collaborative Co-Chair

Travis Greenman-Tallahassee Memorial Hospital, Northwest Florida Collaborative Co-Chair

Sue Higgins-Florida Department of Health Comprehensive Cancer Control Program

Paul Hull-American Cancer Society
Maureen G. Mann-Holy Cross Hospital
Jane Parker-Florida Department of Health, Bureau of Tobacco Prevention
Recinda Sherman-Florida Cancer Data Systems
Megan Wessell-American Cancer Society

OTHER ATTENDEES

Center
Merritt Martin, CCRAB Executive Director, Moffitt Cancer Center
Kimberley Buccini, CCRAB Coordinator, Moffitt Cancer Center
Laura Lenhart, CCRAB Liaison, Moffitt Cancer Center
Malcolm Klein, MD-James A. Haley Veterans' Hospital-(Guest)
Youjie Huang, MD-Florida Department of Health
Monique Hernandez, PhD-Florida Cancer Data Systems

Jill Mackinnon, MD-Florida Cancer Data Systems

Jamie Wilson, Vice President, Government Relations, Moffitt Cancer

CCRAB MEMBERS NOT PRESENT

Honorable Marti Coley-House of Representatives
Honorable Eleanor Sobel-Member of the Senate
Michael Bolin-Agency for Health Care Administration
Jeffrey Bubis, MD-Association of Community Cancer Centers
Rose Marie Cossick-General Public Acting as Consumer Advocate
Sharmine Dipnarine-General Public Acting as Consumer Advocate (By Phone)
Cathy Reed-Florida Department of Education

WELCOME

Dr. George, CCRAB Chair, welcomed those in attendance, both CCRAB and FCPC members. He suggested that every member in attendance take the opportunity to go around and introduce him or herself, and provide a brief synopsis of their field. Once the introductions were complete, Dr. George reviewed the agenda for the day.

Elizabeth Shenkman, PhD-University of Shands Cancer Center

LEGISLATIVE UPDATE

Merritt Martin, in coordination with Jamie Wilson, and Paul Hull gave the legislative update, detailed below in addition to comments made by each of the formally listed authorities on the subject.

Funding Allocations for Cancer Control

During the 2011 legislative session nearly \$115.1 million was appropriated by the Legislature to continue advancing cancer control and research efforts.

Biomedical Research

The King Biomedical Research Program and the Bankhead-Coley Cancer Research Program were both funded for fiscal year 2011-2012. However, both programs received reductions of \$15 million and \$10 million from last year's funding. Allocations were designated in \$5 million increments to Moffitt Cancer Center, UF-Shands Cancer Hospital, and UM-Sylvester Cancer Center. The Governor signed the bill that mandated these changes, HB 5303, into law on May 31, 2011. The latter allocations will be placed into statute, in addition to a \$5 million designation from annual tobacco surcharge proceeds to the King and Bankhead-Coley Programs. Below is a break down of how the biomedical research appropriations were distributed.

Bankhead-Coley Biomedical Research Program	\$10 Million
King Biomedical Research Program	\$7.2 Million
Moffitt Cancer Center	\$5 Million
UF-Shands Cancer Hospital	\$5 Million
UM-Sylvester Cancer Center	\$5 Million

Ms. Martin explained the split in allocations, and the struggle that they were faced with in retaining the Biomedical Funding during this year's legislative session. Mr. Wilson and Mr. Hull reiterated her point in saying that this should be something all members are away of going into the 2012 legislative session as the state's budget will continued to be full of constraints, and to also be mindful that legislative session will begin early this year due to redistricting.

Tobacco Control

SB 1430, Regulation of Smoking, authorizes school districts to restrict smoking on school district property. The bill was sponsored by Sen. Altman, and was signed into law by the Governor on June 2, 2011. Additionally, the Comprehensive Statewide Tobacco Prevention and Education Program received full funding with an allocation of \$62.3 million.

There was immediate interest in this bill by the group as a whole because of the potential for possible CCRAB supported legislation in the upcoming year to apply this restriction to college campuses, Dr. Eric Sandler sighted the University of

Florida as a model because the campus recently become completely tobacco free.

Prostate Cancer

Name:

HB 137, Prostate Cancer Awareness Program, expands the purpose of the Prostate Cancer Awareness Program and transfers all duties and responsibilities for implementing the Program to the University of Florida, Prostate Disease Center. The House bill was sponsored by Rep. Renuart, and the Senate companion was sponsored by Sen. Oelrich. The Governor signed the bill into law on May 31, 2011.

Dr. George was able to speak to this bill directly as he provided the group with a proposed list of members to serve on the advisory council. The list is below:

Affiliation/Organization:

Angela Adams, PharmD Patient Advocate - Orlando, Florida

B. Thomas Brown, MD Community Urologist - Daytona Beach, Florida
Thomas Crawford, MBA Chief Operating Officer – UFPDC, Gainesville, Florida

Linda Delo, DO Florida Osteopathic Medical Association - Port St. Lucie, Florida

Edward Droste Patient Advocate - Clearwater, Florida
*Denise Grimsley State Representative - LaBelle, Florida

Sue Higgins, MPH Florida Department of Health - Tallahassee, Florida
Paul Hull Vice President, American Cancer Society - Tampa, Florida

David Most, PhD Prostate Cancer Survivor - Jupiter, Florida

James Mule, PhD Vice President, Moffitt Cancer Center - Tampa, Florida
Alan Pollack, MD Radiation Oncologist, University of Miami - Miami, Florida

*John Thrasher State Senator - Jacksonville, Florida

Johannes Vieweg, MD Executive Director – UFPDC, Gainesville, Florida

Michael Wehle, MD Mayo Clinic - Jacksonville, Florida

To be determined Florida Medical Association Representative

As noted above, several of the proposed members have not been contacted; again, this is only a proposed list. Susan Fleming interjected that the proposed group may not contain enough diversity given that a larger percentage of men afflicted with prostate cancer are African American men, this was noted and considered by the group.

Ovarian Cancer

HB 1085, Women's Health, creates the Kelly Smith Gynecologic and Ovarian Cancer Education and Awareness Act within the Department of Health, and also adds one member from the Florida Ovarian Cancer Alliance Speaks Organization to C-CRAB. The House bill was sponsored by Rep. Plakon and it's Senate companion was sponsored by Sen. Storms.

Ms. Martin pointed out that this bill is of significant importance to the membership of CCRAB as it calls for an additional member representing the Florida Ovarian Cancer Alliance Speaks Organization. She also indicated that steps were being

^{*} Have not been contacted to discuss his/her willingness to serve on the Advisory Council.

taken internally to connect with the Governor's appointment office to identify the new member.

Florida Center for Brain Cancer Research

HB 7079, OGSR/Florida Center for Brain Cancer Research, modifies and reenacts the public records exemption for the Florida Center for Brain Cancer Research, and also extends the public records exemption repeal date from October 2, 2011, to October 2, 2016. The bill was sponsored by Rep. Bileca and has been enrolled.

Mr. Wilson provided the group with an explanation of OGSR, open government sunset review, and the unique public records exemptions held by institutions of the like.

Pain Medications / Palliative Care

HB 7095, Prescription Drugs, or "The Pill Mill Bill", provides an inclusive scope, addressing the epidemic of prescription drug abuse throughout the State of Florida. As part of the bill's comprehensive approach, activities by physicians, pain management clinics, pharmacies, and wholesale drug distributors will be regulated. In the final version of the bill, language that would have infringed upon the ability of terminally ill patients to receive appropriate amounts of pain medication was eliminated. The bill was sponsored by Rep. Schenck, and signed into law by the Governor on June 3, 2011.

Mr. Hull and Ms. Martin explained that the potentially damaging language in the bill was a dosage unit limit that a pharmacy in a hospital like Moffitt's would have capped out at during a period of a day and a half. The unit dosage limit was eliminated in a partial strike-all of the bill. However, in the final version of the bill, there was a call for a research study to be conducted by DOH to survey pharmacies throughout the state to gauge the volume of narcotics typically distributed.

CCRAB Statute

No changes were made to statute 1004.435 during this year's legislative session. However, there was a bill, SB 720 sponsored by Senator Gaetz and it's House companion HB 377 sponsored by Rep. Coley, which intended to make a few changes to the statute. Some of the proposed changes included: staggering member terms, defining the exclusive purpose of the research programs, and implementing a new and more rigorous approach when reviewing and considering grant applications. Despite full passage from the Senate, the bill died in messages.

Group discussion was had speculating as to why the bill died. Mr. Hull presupposed the reason for the bill dying was because of its perceived connection to DOH and the current climate of the legislature. The body seemed

to agree, and also agreed that this would be an actionable item that the Goal I Committee assumed this year, with a proposed language change.

To conclude the legislative update, Mr. Wilson briefly summarized and reiterated the importance of the Council's membership in participating in supporting the ongoing efforts to restore the biomedical trust fund monies to the King and Bankhead-Coley programs. Additionally, reiterating that session will begin early in 2012 and that it would another tight budget year for the legislature.

FLORIDA CANCER DATA SYSTEM PRESENTATION & DISCUSSION

The Florida Cancer Data System Presentation was given by, Dr. Youjie Huang, Florida Department of Health, Director of Cancer Registry Operations and Dr. Jill MacKinnon ,University of Miami Miller School of Medicine, Florida Cancer Data System.

Enhancing Florida's Cancer Surveillance-Cancer Registry Data

The presentation provoked insightful conversation about how the data gleaned from the Florida Cancer Data System can be converted and used as evidence to support more access to data and promote better patient care.

LUNCH AND LEARN

Lunch and learn was conducted with Dr. Pascal Jean-Pierre and he presented the group with a presentation on Cancer Patient Navigators. The primary discussion that arose from Dr. Jean-Pierre's presentation were the many different names given to patient navigators, a few examples being, community health workers, lay health workers, patient advocates, etc...

Patient Navigation Application Across the Cancer Care Continuum

SUB-COMMITTEE UPDATES AND PRIORITIES

Laura Lenhart, who acts as the CCRAB Liaison between Moffitt Cancer Center and the Department of Health, gave the sub-committee update and priorities presentation. The presentation briefly outlined the outside initiatives of each Goal Committee.

CCRAB Committee Update

SUB-COMMITTEE WORKING GROUPS AND FALL LEGISLATIVE PRIORITIES

Following the sub-committee update, the group split up into their perspective Goal Committee groups and discussed actionable items of each committee to address during the upcoming year. Also, each group identified one legislative priority for the 2012 legislative session.

Goal I: System Capacity and Infrastructure

- CCRAB/FCPC COLLABORATIVE NETWORK (GOAL I LEGISLATIVE PRIORITY)
 - Must maximize communication and awareness (unified) between CCRAB & FCPC
 - Continue moving forward with the CCRAB/FCPC revision in FS.1004.435
 - Improved dissemination of information between CCRAB, FCPC, and Regional Cancer Collaborative

BIOMEDICAL APPROPRIATIONS

 Continue supporting the appropriations to King & Bankhead-Coley Research Programs

ADVOCACY

 Increased advocacy efforts, awareness, and exposure of our organized efforts; continue to gain visibility and educate.

FCDS EXPANDED STATE SET

- Using information to build evidence to drive policy
- Their ask of CCRAB was a letter of support support is also wanted for when they approach hospitals for more data
- We could ask them to draft us a letter telling us what would be most helpful to them.

Goal II: Prevention

- PROMOTE & ADVOCATE FOR A BILL SIMILAR TO SB1430, REGULATING TOBACCO USE ON COLLEGE CAMPUSES. (GOAL II LEGISLATIVE PRIORITY)
 - Indentify potential bill sponsors

OBESITY/SCHOOL GARDENING UTILIZATION

- Possibly including a person from the Department of Agriculture on the next call?
- REPLACE DOE CCRAB MEMBER

- VENDING MACHINES IN SCHOOLS
 - Inquire about revenue from the proceeds of vending machine sales in schools
 - o How is this contributing to obesity in school age children?
- ANN SCOTT'S OBESITY INITIATIVE
- SUN SAFETY

Goal III: Treat and Access to Care

- Community Health Workers/Navigators
- IDENTIFY AND SUPPLEMENT CURRENT INFRASTRUCTURE
- IDENTIFY CIRRICULUM FOR CHW/NAVIGATORS
- ESSENTIAL ELEMENTS AND ROLES FOR NAVIGATORS
- LEGISLATION AND SUSTAINABILITY FOR NAVIGATORS (GOAL III LEGISLATIVE PRIORITY)

Goal IV: Survivorship

- EDUCATE PATIENTS ON HOW TO RESQUEST THEIR TREATMENT SUMMARIES (CONSUMER USAGE) (GOAL IV LEGISLATIVE PRIORITY)
- GENERATE/IMPROVE FLORIDA SPECIFIC SURVIVOR COMMUNITY RESOURCES
- REFINE TREATMENT SUMMARY CONTENT TO LEAST-COMMON DENOMINATOR
- MONITOR FOR NEW MODELS/SCHEMA & EBM

The group discussed all of the points and collectively chose the points that would be best to pursue as legislative priorities.

CONCLUSION

Dr. George briefly recapped the day, and felt that the group had made great strides in a very short amount of time. Dr. George made a motion that the body rise, and Dr. Sandler seconded the motion. All members in attendance agreed by a unanimous vote.

Meeting was adjourned at 4:10pm. Next Meeting will be in the October 2011, date TBD.