Breast Cancer Research Council Meeting Minutes November 20, 2003 San Francisco, CA

Members Present: Dorothy Bainton, Kathryn Phillips, Georjean Stoodt, Michael Figueroa, Kim Pierce, Diana Chingos, John Morgan, James Ford, Christine White, Vicki Boriak, Carol D'Onofrio, Debra Oto-Kent, Kathy Walters

Members Absent: Jacqueline Papkoff, Elaine Ashby, Janet Howard-Espinoza

Staff Present: Mhel Kavanaugh-Lynch, Katherine McKenzie, Larry Fitzgerald, Walter Price, Charles Gruder, Roslyn Roberts, Janna Cordeiro, Lyn Dunagan

Guests: Peggy Reynolds, Ngina Lythcott, Robert Millikan, Musa Mayer

I. Call to Order and Introductions

The meeting was called to order at 9:15 a.m. by Chair Debbie Oto-Kent. General introductions followed.

II. Approval of 10/17/03 Minutes

The October 17 minutes were unanimously approved as written.

III. Priority-Setting Presentations, part I

a. Introduction

The annual and tri-annual priority-setting process establishes and re-examines goals for the CBCRP's future funding directions. These presentations are designed to help inform the council's decision-making.

b. Peggy Reynolds – Highlights from the California Cancer Registry's *Breast Cancer in California* Report

A forthcoming monograph from the California Cancer Registry (CCR) applies a variety of data to questions like changes in breast cancer incidence and mortality.

c. Musa Mayer – Treatment and Outcomes for High-risk and Metastatic Breast Cancer in California: An Inquiry into Disparities and Research Needs

Recommendations include studies of the experiences of women with poor prognosis or metastatic breast cancer and what treatments they are receiving, what support they are getting, both inside and outside the hospital.

d. Robert Millikan – Maximizing the Impact of the California Breast Cancer Research Program: Studying Environmental Influences and Breast Cancer A regionally-focused, comprehensive study of breast cancer and the environment could build on existing databases, encourage new collaborations, and capitalize on California's rich population diversity.

e. Ngina Lythcott – Continuing to Reduce the Excess Burden of the Incidence and Mortality Caused by Breast Cancer among California Women

Incidence and mortality rates vary, prompting questions about access to available services, barriers to timely detection/treatment, and accurate population measurements (race, ethnicity, SES, and disease stage).

f. Questions and Discussion

The council discussed the research community's awareness of the Program, the available pool of researchers, and the lack of responsive applications in particular areas. The CBCRP conducts outreach and communicates its desires with clearly-written RFAs and published funding percentages. How can the Program increase the number of responsive proposals in the areas that the Council has identified as important?

IV. Old Business – Reports from Committees

a. Outreach

Kim Pierce reported on the proposed Susan Love Breast Cancer Course for Researchers collaboration, for which the Outreach Committee is partnering with the Collaboration Committee.

The Outreach Committee is looking for a site in Northern California for the 2005 Symposium

The next newsletter is underway—articles are welcome from any council member, and should be submitted to Katie by February 15.

The committee suggests that the Priority-Setting Committee consider inviting someone from NCI to present to the Council in the future, discuss goals & priorities, and help the Council consider new directions.

b. Priority-Setting

Debbie Oto-Kent reported that the following speakers will comprise a panel addressing the translation information questions at the January Council meeting: Anna Wu, Bob Irwin, Roland Newman, Mitch Golant, Mort Lieberman, and C. Benz (invited but not confirmed).

Also at the January meeting, CBCRP research administrators will present data to inform the collaboration priority-setting criterion. They will present the number of collaboration awards funded by CBCRP, with case studies of successful and not so successful collaborations, and interview grantees to share their experiences.

The committee is discussing—and Debbie asked for the council's input—how to synthesize and make relevant the data presented in the past 2 Council years. The 10 priority criteria were split amongst the committee

members; they will each review staff-developed summaries of all information presented and develop recommendations for the Council to consider at the priority-setting retreat scheduled for March 2004 in Santa Barbara.

c. Evaluation

Diana Chingos reported that evaluating the IDEA awards has hit a slow spot because of the difficulty in quantifying results of high-risk research. Most awards are just too recent to gauge their success or to know what translational, meaningful outcomes may result. Janna is talking with the DoD staff to see what they are doing about evaluating their IDEA awards.

Marj Plumb is working on the CRC award evaluation, studying the impact of the completed CRC awards. Marj expects to begin the study in the spring.

d. Collaboration

Vicki Boriak reported that the committee has a new stated purpose, which she will include in next meeting's packet, which includes: review requests for collaboration on conferences and symposia of related groups and make recommendations to council; promote the CRC award mechanism by developing plan for outreach, education, and evaluation; promote other unique research collaborations with multi-disciplinary fields through outreach, meetings, publications, etc.; continue to promote collaboration with DHS, Every Woman Counts, regional partnerships and cancer registries, and track progress of committee activities through collaboration with the Evaluation Committee.

The Collaboration Committee is pursuing the CBCRP's participation in the Breast Cancer Course for Researchers with the intent for greater input and participation by the CBCRP, if the course can become a "think tank".

Vicki will contact the Expedition Inspiration Foundation, which has an international think tank in British Columbia, to see how they do it and what they learned, with the goal of applying that knowledge to the Breast Cancer Course for Researchers.

The committee will also work with staff on the CRC outreach and technical assistance project. They will provide advice on outreach and technical assistance for the proposed 12 workshops, help determine the scope of the workshops, and they will also look at adding Translational Research Collaboration and Scientific Perspectives Research Collaboration award types to the Program's outreach efforts.

V. Priority-Setting Presentations, part II

a. Marj Plumb – Does the California Breast Cancer Research Program Fund Research that Drives Policy?

Both traditional and community researchers were aware that their research *could* impact policy; however, the community researchers are usually

more comfortable, skilled, motivated, and involved in taking research results to policy makers.

b. Janna Cordeiro – New Priority-Setting Handouts: the funding allocations by CSO sub-category

The CSO handout in the packet compares data between the NCI, DoD, and CBCRP.

c. Questions and Discussion

The council discussed its expectations and definitions of "driving policy in both the private and public sectors," successful policy vs. research relevant to policy, and the timeframe within which policy is made and its impact is felt.

VI. Director's Report

Cycle X Timeline: Mhel briefly reminded the council to review the timeline to see where we are in the process. Council members were again encouraged to spread the word and encourage people to apply. Staff can provide any necessary support materials, and we encourage applicants to call us for information.

CRC Concept Papers: We received a record number (28) of concept papers on November 6. Council members were provided with a list of the titles and institutions, and were reminded of the confidentiality of the material. The concept papers will be reviewed December 13-14. The applicants will receive feedback, and full applications are due in February and will be reviewed in April.

California Endowment Grant: We received a grant to support the CRC outreach efforts. The grant starts November 1; however, the paperwork has not yet been finalized. A one-page description of what is being supported is in the council packets. Some of the new items funded by this grant include staff and technical assistance.

Publications: We are preparing a lay-friendly version of the California Cancer Registry's monograph; the booklet will include an explanation of the data used to reach the study's conclusions. The council discussed the relevance of supporting a report with old data—despite the disparity between 1990 and 2000 census data, and despite the time it takes to collect and analyze data and process the monograph through the approval stages, council members generally felt that the monograph's results were still relevant. A draft of the document was included in the council packet.

We are producing a publication based on the "10 Years of Progress" presentation from the Symposium.

Fundraising: The revenue from the state's voluntary contribution program on the Form 540 income tax forms dropped this year. Last year, 65,000 people donated a total of \$736,000 to the CBCRP; this year, 58,000 people donated a total of

\$638,000. Although we are well above the minimum \$250,000 required to remain on the state tax form, we spent a lot of time and money marketing the Tax Check-Off Program. We decided to step back and do some market research. The market research, performed through the consulting firm Lake, Snell, & Perry, will take place in three phases: (1) six focus groups studying existing marketing material, (2) a telephone survey of 800-1000 people, and (3) a second round of focus groups studying messaging created as a result of the first two phases. We also decided not to continue working with Laura Talmus Associates when her contract ends in January, though we may re-engage her at a future date. Some items of interest from the first round of focus groups:

- People do NOT like donating money on their taxes
- People are very cynical towards the government
- As they heard more about the CBCRP, they liked the Program more
- They like that the Program is big, innovative, and that we are spreading the money around ("nearly \$150 million to 569 grants at 62 institutions...")
- They like that 95 percent of our money goes to research & education
- They do not like to talk about taxes
- They did not respond well to politicians or actors

Joining Forces Conference: "Preclinical Trials for Breast Cancer" was a Joining Forces award. Held November 1-5, 2003, the meeting brought together the international community for discussions focused on hastening the application of mouse models of human breast cancer in preclinical trials. The conference encouraged cooperation and collaboration by presenting the perspectives of basic scientists, clinicians, industry, and government, and emphasized the translational objective of preclinical trials by including the active participation of clinicians and breast cancer advocates.

VII. Review of Calendar and Announcements

• The 2003 – 2004 meeting calendar was briefly reviewed.

VIII. Adjourn

The meeting was adjourned at 4:02 p.m.