Breast Cancer Research Council Meeting Minutes October 19, 2001 Oakland, California

Members Present: Susan Blalock, Teresa Burgess, M. Ellen Mahoney, Irene Linayao-Putman, Tammy Tengs, Anna Wu, I. Craig Henderson, Sandy Walsh, Hoda Anton Culver, Diana Chingos, Florita Maiki, Elaine Ashby, Lauren John, Marion Kavanaugh- Lynch (via teleconference).

Members Absent: Robert Carlson, Akua Jithadi

Staff Present: Charles Gruder, Katherine McKenzie, Walter Price, Laurence Fitzgerald, Roslyn Roberts, Janna Cordeiro, Sarah Bradley.

Guest: A.J. Trudy, Programmer/Analyst – Department of Health Services – CDIC-CDS-BCCCP/BCEDP

I. Call to Order and Introduction

The meeting was called to order at 9:30 a.m. by Chair, Terri Burgess

II. Approval of June 1, 2001 Minutes

Sandy Walsh pointed out page 2, paragraph 4 should read "that the offer be extended" was corrected to read "that the offer not be extended". In addition, paragraph 6 of page 2 read "Terri stated that the council should here from the Committee. The minutes were corrected to read "Terri stated that the council should hear from the Committee"

Motion: A motion from Terri was made to approve the minutes as corrected. The motion was seconded by Hoda Anton-Culver and Craig Henderson and passed unanimously.

III. Director's Report

Mhel presented a synopsis of the BCRP staff roles along with a list of publications produced by the BCRP staff. She discussed the Cycle VIII Call for Applications and timelines encouraging council members to disseminate information about available funding and the Programs' interest for next year.

Laura Talmus and Associates have been selected as fundraising consultants. Their major efforts will include increasing statewide exposure for the tax check off program and increasing the tax check off revenue. The pending renewal of the tax check off initiative by the state legislature is an opportunity to add language which would mirror the state of New York to include a tax check off for Corporate taxes,

which California does not have. The ideal scenario is for Senator Speier to introduce the re-authorization of the tax check off adding a Corporate Check Off option to the legislation. Corporations willing to simultaneously commit to supporting the initiative would be solicited, the entire process would be covered by the media. The outcome would be twofold; Corporations would donate funds generated through their taxes in addition to advertising the personal tax check off option to their employees.

Another fundraising project BCRP will embark on is the development of a major donor program. A fund raising advisory group to include current and past council members along with others to be identified. The five-year goal of the fund raising effort is to ensure a steady twenty million-dollar per year revenue for BCRP within one to three years and secondly, to increase that revenue to forty million per year. This is based on the assumption that we raise four to six million per year to guarantee the Program twenty million, taking into account the declining tax revenue.

Mhel gave an update of the Annual Report and the Advances in Breast Cancer Research Report stating that Judy Mac Lean has begun the process. Drafts will be circulated to the council for review and comment. The official annual report to the legislature is scheduled for completion by December 15th and the text for the Advances Report finalized in February.

IV. Understanding the Impact

Janna Cordeiro, BCRP Program Evaluator, and Sarah Bradley, BCRP Evaluation Intern, gave a presentation of the highlights from the evaluation study assessing the outcomes from the first four funding cycles of the postdoctoral fellowship award program. Council members received a copy of the report prior to the meeting. Planning for the study began in February of this year with the guidance from the evaluation and priority setting committee as well as from the RAs and Mhel. Implementation occurred in the late spring and summer. Janna and Sarah tracked down and interviewed 39 of the 42 eligible respondents. Interviews were conducted over the phone or via email. Highlights from the study include: 67% of the respondents are still doing some type of breast cancer research; over 70% of the respondents felt that the BCRP award gave them the opportunity to do work relevant to breast cancer research that they would not have otherwise been able to do; all reported career gains as a result of the BCRP award; 82% of the respondents published at least one paper as a result of the BCRP award totaling 108 papers; and for every dollar BCRP invested in the postdocs during cycles 1-4, respondents and their colleagues obtained an additional \$12 for breast cancer research.

V. New Business

A. 2001-2002 Work Plans/Goals for the Year

Chair, Terri Burgess presented the 2001-2002 work plan and goals. She outlined a collaborative project involving all council members working through committees reporting to the council on action items and final decision making.

Communication - The first item was a continued effort to maintain communication between staff and council members. As a result of this effort, the Chair, Vice Chair and Program Director has scheduled conference calls for the first of each month. During these calls Mhel will provide reports on the activities within BCRP in an effort to stay connected with main issues.

Priority Setting/ Evaluation Process - One of the major responsibilities for the Breast Cancer Research Program Council is to identify priorities for funding on an annual basis. Terri explained that part of the problem is that there is no process defined to set priorities. Council should decide the next task to be evaluated. Hoda pointed out that the process would be very helpful in articulating the prioritization process.

Industry Collaboration – Designed as an attempt to maximize the industrial component of the Breast Cancer Research Program by developing a collaborative effort with industry to further the Programs' Mission to have a larger impact in California. Corporations have a lot of money but are basically focused on profits. The Councils' task is to focus on a creative means to leverage this concept.

Hoda suggested using the NIHs' SBIR Program (the industry/university combination of the CRC where a proposal has both industry and a university or an academic institution having one proposal coming in. The program is specific with the process by academic and industry. This could be used as a model where the Breast Cancer Program could co-sponsor research between industry and an academic institution where the industry provides some funding.

Terri stated that she is involved in international groups attempting to set up funding between industry and academics. It is challenging to think outside the box because typically, industry is interested in funding short-term projects focusing on profits, where the academic or medical researcher is more interested in the fundamental biology.

Dissemination – Terri stated that although the symposium was a high priority this year, the committee would like to move beyond that and focus on other projects, specifically the newsletter. She stated that the newsletter was a good tool for disseminating information through various methods. She also emphasized the need for more public awareness of the Program and specifying our identity.

Fundraising – Terri stated that Mhel would elaborate more on this topic.

Stakeholders' Meeting – Developed as a component to program evaluation and the priority setting process based on solicitation from the community on the Programs' effectiveness. The plan was to schedule a stakeholder' meeting within the year 2002.

B. Report from Committees on 2000-2001 Accomplishments

Collaboration with BCEDP – Walter related the committee's goal to review the BCEDP Partnerships and establish the collaborative role of the Breast Cancer Research Program. Water stated the committee's responsibility is to identify the most salient issues presented by the BCEDP and determine which areas could be addressed by the Breast Cancer Research Program and initiate a plan of action.

Hoda raised the question of cultural barriers that would prevent various groups to participate in studies or clinical trails and what actions the Program could take to assist in these efforts. In general, the council determined that increasing awareness or access to mammography is not something that BCRP wishes to invest in and that increasing screening rates in California was not identified as a priority issue for the coming year.

A number of points were raised on how the programs could interact and assist one another. Irene suggested that the council would be a good source of disseminating information about BCEDP's training sources to survivor and advocacy networks. It was suggested that Georjean Stoodt do a presentation to the council on the BCEDP database along with the Program's accomplishments, demographic profile, etc.

Dissemination Committee - Katie gave a brief overview of projects the committee was involved in last year. The committee identified the different groups of stakeholders that needed to be reached including breast cancer advocates, researchers, clinicians, and the California public as well as people that could provide BCRP with additional funding streams. Outreach efforts for the past year included public service announcements for the tax check off fund, a planned event that would have introduced (or re-introduced) BCRP to California state legislators and their staff (which was postponed due to the energy crisis), and the bi-annual breast cancer symposium. The committee also began work on operationalizing the BCRP newsletter.

Program Evaluation - Janna Cordeiro reported the purpose of the Evaluation Committee is to create a systematic and on-going evaluation plan that will enable BCRP to assess its progress towards reaching its mission. During this year, the committee met in person and in conference calls to develop goals for the year,

evaluation models, a pilot evaluation study, and a revision of the evaluation plan written last year by the program evaluation intern.

Sue Blalock described the purpose of the evaluation models, which is to identify short, intermediate and long-term outcomes that are expected from the 7 BCRP program activities. The evaluation models will help to guide the entire program evaluation.

The committee also decided to conduct a pilot evaluation study focusing on the outcome from the first four years of the postdoctoral fellowship award program. The committee, along with the BCRP staff, was involved in all aspects of the pilot study including study design, questionnaire development, data analysis and production of the written report. The committee also worked to revise the evaluation plan written last year.

Priority Setting - Mhel stated the purpose of the Priority-Setting Committee is to develop a data-driven priority-setting process for the Council. The committee works closely with the director, the program evaluator, research administrators and priority-setting consultants.

Accomplishments for 2001 included contracting with consultants, Strategic Health Concepts, who assisted in planning a strategy for the development of the priority setting process. The decision was made to extract the existing information and to develop a feasible process utilizing its results in a pilot test.

A retreat was scheduled in April where the council offered input to the design of a pilot priority-setting process by setting the framework, criteria and desired outcomes for the program criteria and for looking at priorities that matched those desired outcomes. Strategic Health Concepts then collected data that gave information about our desired outcome and obtained feedback from council members on the draft framework criteria and desired outcome.

In June, Strategic Health concepts presented the data collected in the context of the criteria established in the April meeting. That data and criteria was used in the development of priorities for the Cycle VIII Call for Applications.

In September, Strategic Health Concepts solicited feed back from council members on the pilot priority-setting process. A draft of the Priority Setting Pilot Test was distributed to council members requesting them to revise the framework, desired outcome and criteria and by working in the committee, develop a proposed process to go forward with.

C. Committee Composition

Committee compositions are as follows:

Priority Setting/Evaluation:

Janna Cordeiro, Terri Burgess, Hoda Anton-Culver, Susan Blalock, Tammy Tengs, Anna Wu, Irene Linayao-Putman, Diana Chingos, Sandy Walsh.

Dissemination:

Katie McKenzie, Terri Burgess, Ellen Mahoney, Akua Jitahadi, Lauren John, Diana Chingos,

Collaboration with BCEDP:

Walter Price, Florita Mackie, Sandy Walsh, Irene Linayao-Putman, Georjean Stoodt.

Stakeholders:

Anna Wu, Diana Chingos, Elaine Ashby

Industry:

Terri Burgess, Elaine Ashby, Hoda Anton-Culver, Larry Fitzgerald

The "Fundraising" Committee has yet to be defined and will be solicited for at a later date.

D. Discussion of Committee Meetings

Terri suggested that committee meeting should be scheduled the night before the full council meeting to avoid taking up time during the regular council meeting. She invited new council members to select a committee to participate on.

E. Committee Reports on 2000-2001 Accomplishments/ Goals for 2001-2002

BCEDP Committee

Walter reported for the BCEDP Committee and focused on issues raised from committee discussions. It was determined there are four data bases which are available to researchers throughout California but are not publicized, nor are they fully incorporated in the priority setting process. The committee will do presentations on these databases at a future council meeting. The committee intends to meet via a teleconference to set a series of goals and action items for dealing with the collaborative efforts of the committee, establishing plans and creating a plan of action.

Dissemination Committee

Terri Burgess, Dissemination Committee Chair, reported that the Committee is now composed of members with expertise in newsletters, information, press releases

and communication; issues the dissemination committee would like to focus on in the upcoming year.

Discussions included identifying new business relating to the 2003 Symposium including the date and venue.

The newsletter was determined to be a priority for the committee this year. Terri stated that a decision must be made on the feasibility of having a newsletter published and distributed by March, 2002. Ellen Mahoney mentioned that there were a number of newsletters released by various advocacy groups within California which are hungry for content. She stated that BCRP could provide information such as the history and value of the tax check off, an analysis of funded grants and encouragement to these groups to learn of the CRC awards.

The committee noted that BCRP did not have a brochure. Mhel stated that she has developed a draft for a brochure that would be distributed to the committee for review. Mhel intends to involve the fundraising consultant in this effort and expressed hope of having the contract completed and the consultants involved by the November 30th council meeting.

The committee also expressed interest on developing a plan of action to disseminate information about the 2002 Symposium. Terri stated that the committee would like to explore ways to advertise the event via a press conference, press releases and/or media coverage.

Priority-Setting Process/Program Evaluation

Janna Cordeiro gave a brief overview of the accomplishments and goals for the committee. They included following up on recommendations from the post doc study, finalizing and presenting an evaluation plan to the full council at the next meeting, prioritizing the next evaluation study, and conducting at least one evaluation study.

F. Discussion of the Stakeholders' Meeting

Terri began the discussion with an overview and history of the stakeholders' meeting. She then opened the discussion to suggestions on the development of the next meeting.

Janna suggested conducting focus groups at the March symposium with various stakeholder groups as a way to gather data to create an effective stakeholders' meeting to be scheduled in the fall of 2002.

Hoda inquired about the proposed Ad-Hoc committee and suggested some focus points for the committee that included identifying stakeholders, the desired outcome of a stakeholders' meeting and providing a progress report from the last meeting.

Anna Wu will organize a conference call with the BCRP staff to outline a plan of action to obtain information in the development of a priority setting process for the next five years focusing on scientific priorities and innovative opportunities.

G. Review of 2001-2002 Calendar

VI. Announcements

There were no announcements for this council session.

VII. Adjournment

A motion was made to adjourn the meeting. The meeting was seconded by and adjourned at 3:45 p.m.