

**Breast Cancer Research Council Meeting Minutes
November 30, 2001
Santa Monica, California**

Members Present: Teresa Burgess, Irene Linayao-Putman, Tammy Tengs, Anna Wu, I. Craig Henderson, Sandy Walsh, Hoda Anton Culver, Diana Chingos, Florita Maiki, Elaine Ashby, Robert Carlson.

Members Absent: Akua Jithadi, Ellen Mahoney, Sue Blalock, Lauren John

Staff Present: Marion Kavanaugh-Lynch, Charles Gruder, Katherine McKenzie, Walter Price, Laurence Fitzgerald, Roslyn Roberts, Janna Cordeiro.

I. Call to Order and Introduction

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

II. Approval of October 19, 2001 Minutes

Motion: A motion from Terri was made to approve the minutes with no corrections. The motion was seconded by Hoda Anton-Culver and Craig Henderson and passed unanimously.

The minutes were approved with no corrections.

III. Director's Report

Mhel began her report with an update of the Cycle VIII Call for Applications. A total of nine CRC Concept Papers were received compared to eighteen from the year 2000. All other applications are due in January. Review committees are scheduled to begin the third weekend in March and will continue through the last weekend in April. She reiterated the need for council members to disseminate information about the Program and its funding.

Portions of the 2002 Advances in Breast Cancer and the 2001 Annual Report have been distributed to Council members to edit and comment. The official annual report is scheduled to be completed by the end of the year and the Advances in Breast Cancer report is targeted for distribution during the 2002 Breast Cancer Symposium in March, 2002.

Laura Talmus and Associates has been selected as the Programs fundraising and marketing consultant. Mhel summarized the firms' proposal for the initial phase which consists of the planning and development of a detailed fundraising and marketing plan. Betsy Krugliak of The Pacific Group,

a media firm subcontracting with Talmus and Associates, will become more involved in outreach and media advertising for the symposium and the Tax Check off Program. Other focus areas include the development of a major donor campaign and enhancing the BCRP website by offering suggestions on design and essentials which would make the website more assessable to the general public. Details of these projects will be provided to the Council as they become available.

Strategic Health Concepts provided a revised framework for priority setting along with their proposal on how to proceed with the process. Mhel stated that although the council was in agreement that the process should be allocated more time spread over a longer period, the timeframe suggested by Strategic Concepts was unrealistic. This will be discussed further by the Committee and the Council in the future.

Mhel was extended an invitation from the Health Research Science Board to assist in the assessment of the effectiveness of the Board's strategies and facilitation of best-practices research grant administration. As an advisory body to the New York State Department of Health, the Board solicits grant proposals and administers meritorious research and education projects financed by the Breast Cancer Research and Education Fund. Mhel's presentation of the research granting programs sponsored by the California Breast Cancer Research Program will afford information and guidance to the Board.

Secondly, Patricia Buffler, Professor of Epidemiology at UC Berkeley, received funding from the University of Berkeley and the Centers For Disease Control to do a summit on developing a research agenda on environmental causes of breast cancer. Mhel was invited to serve on the steering committee to plan this process and to implement the results. The summit is scheduled for May 22-25, 2002 and although billed as an international summit, she projects that 90% of the attendees will be from California. One of the challenges is to obtain input and disseminate things more widely before and after the conference.

Mhel and Janna have developed a one-page sheet on the charge to the Industry Relations Committee and have identified members to serve on the committee. A conference call is scheduled in December with a face-to-face meeting scheduled in February.

Presentation on BCEDP

Georjean Stoodt gave an overview of the CA Department of Health Services Cancer Detection Section and its growth and diversification over the last three years.

Responsibilities specific to breast and cervical cancer include saving lives, reducing the burden from breast and cervical cancer and reducing disparities. The Program is accountable for outcomes and effective resource deployment. Georjean is particularly pleased with the watershed development of the long-sought treatment funds.

The BCEDP and BCCCP are multi-faceted components including clinical services, public education and outreach, professional education, quality assurance and improvement, regional cancer detection partnerships, evaluation and surveillance and the Breast and Cervical Cancer Advisory Council.

Some of the key issues faced by the Cancer Detection Section as the programs mature involve more integration and coordination of BCEDP and BCCCP. Both are targeted and oriented to women at or below 200% of the Federal poverty level with the federal funding program (BCCCP) being for cervical cancer as well as breast cancer. With two different funders and sets of accountability and history of how they are structured and administered, the question is how best to integrate them. Expansion into detection of additional cancer types/precursors and questions of how to better use technology for communication, enabling them to reach a variety of Stakeholders and target populations including Health Care Professionals are current challenges. The timely entry into treatment will prove to be an interesting observational experiment as the new treatment program comes into effect. Adherence to administrative requirements (HIPAA and public contract codes), along with balancing program growth and adequacy with resources and the stability of those resources will be challenging.

Clinical services have progressively increased in demand since inception of the two programs serving a cumulative total through June, 2000 of 267,790 women (BCEDP) and 91,169 women (BCCCP).

Georjean encouraged council members to review the BCEDP Brochure and marketing campaign materials available to review. She pointed out that the 800 number is a key element in outreach and ability to connect women to providers.

The Safeway/Von's collaboration is an example of emerging collaboration where 500 stores located in underserved areas set up displays disseminating educational materials and contact information. They also collected donations to fund local community groups. A mock check of \$170,000 was presented at a media event with Director Bonta and Lieutenant Governor Bustamante. Asian media production is another example of collaboration along with locally delivered, focused public education and outreach efforts such as The Beauty Shop Project and "Tell a Friend".

The Program has four tools especially developed in professional education. The program is working not only on clinical breast examination training but the next phase of exporting CBE Curriculum and knowing how to others to reach more providers. A CBE brochure for women has been developed to create an expectation for a quality exam.

A Quality Assurance Project is underway, for which CDS has contracted with San Diego State University to do medical record abstraction (6,600 records) for breast and cervical to develop interventions based on the findings. Timely entries into treatment along with a data-based approach to decision-making are among the outcomes being measured.

Georjean stated that regional partnerships were a vital component of the program in achieving outcomes. The scope of work falls into four areas; coalition-building, clinical access and quality, public education and outreach and professional education. The regional partnerships compliment the direct clinical providers.

Data from the BCCCP is very extensive. The Program is pursuing electronic HIPAA-compliant system for billing and data collection.

IV. Committee Reports and Discussion

A. Collaboration with BCEDP Committee *(Attachment 9)*

Walter Price reported on BCEDP Committees' decision to focus on two areas:

(1) Communication and dissemination of information, and (2) Intervention to highlight possible areas of research that would further BCEDP's mission and to try to broaden the scope of research ideas that can arise from the partnerships.

With respect to communication, there are four main constituencies in the BCEPD: the state administrative and policy structure, the partnerships, the providers and the target population. The committee must decide: (1) whether and to what extent we should work directly with one or more of the Partnerships, directly with the state only, or both, and (2) in what way, if any, we can define research issues and communication packages relevant to providers and the client population. We need to develop a specific "package" or product, that is, to define the issues which we want to communicate and research findings we want to disseminate.

Recommendations:

1. Council should consider discussing the merits of developing a database inventory (or issuing an RFA to develop such a database) for use by California investigators doing research in areas of health policy, earlier detection, medical care access and so on. Included would be:

data items and their limitations, population and data covered, availability, contact people, etc. Perhaps this could be done in collaboration with another agency such as the Public Health Institute.

2. Identify issues seen by scientists as needing study which are relevant to both BCEDP and BCRP's mission and goals. Do we need a new specific priority issue, or "bullets" under existing issues? We need to identify the BCEDP relevant issues that BCRP can address.
3. Encourage research around the new treatment program.
4. Consider research on the impact of new technologies on health policy affecting BCEDP, e.g., issues around genetic screening and screening of high risk women based on family history/genetic testing.
5. Try to build capacity in selected Partnership(s) in an attempt to broaden the realm of issues partnerships may consider when applying for a CRC Research Grant.
6. One issue, as outlined in Georjean Stoodts' presentation, is how to disseminate information to convince the partnerships and practitioners to incorporate the best practices for their service area.
7. There will be a number of specific research questions emerging on which BCRP could potentially focus. For example, the new state and federal breast cancer treatment program will generate policy and quality control issues, as will new screening & diagnostic technology. Identifying and quantifying unmet access needs may also be areas that the BCRP could encourage research in.

Hoda. Anton Culver questioned whether the Committee's objective was to compliment the state program or augment it. It would be complimentary to attempt to drive policy by the research that BCRP supports. With this being the objective, she pointed out that a more focused approach would be to identify areas in which we would like to encourage research which would drive policy at the state level. If the Program feels that augmenting the aim of the state program is our primary mission, the implications are that we may well be doing all that we can now, as our research funding is in support of our missions, which overlap.

Tammy Tengs pointed out that the Program does not encourage research that involves modeling, either the development of new models or application to breast cancer of existing models, and this is an area we might want to target.

B. Evaluation and Priority Setting Committee *(Attachment 10)*

Evaluation

Anna Wu reported on the Committee's accomplishments which included the creation of evaluation models and the design and completion of a pilot study (Post Doc Study). The committee has worked extensively on the development and revision of an overall evaluation plan, focusing on specific evaluation projects for the future.

Anna went on to outline the Committee's evaluation plan. The purpose of the evaluation plan is to help inform and guide staff and committee members. Some components incorporated in the plan include evaluation approaches used by other agencies such as the NIH, DOD, etc., The Plan also outlines design and methods to be involved in evaluating the program including process vs outcomes, evaluation (logic) models, and the types of methods and/or tools available. Finally, the Committee must ensure that products derived from the evaluation process such as the Post Doc Study are utilized, incorporating recommendations and following up on those recommendations and implementation. Results from the Evaluation will feed back into the priority setting process.

The Breast Cancer Research Program undertakes seven major program activities (i.e., funding innovative and transitional research, identifying gaps). For each activity, a logic model was devised to identify the short, mid and long term outcomes which could be measured to evaluate whether that particular activity was achieving its goal. The models, having very specific outcomes, are then used to design the evaluation study. The models focus the evaluation questions, survey development, and the findings to determine whether goals are being met.

Evaluation tools include surveys conducted by e-mail or phone. A prime example is the Post Doc Study, where investigators were interviewed with targeted questions that addressed specific expected outcomes. Other tools include citation analysis, peer review and case studies. Existing tools include reviewer and symposium surveys that could be utilized as is or redesigned adding new questions

In the upcoming year, the committee will oversee 2 major evaluation studies including an evaluation of the IDEA Awards and the New Investigator Awards. Additionally, an evaluation of the symposium will be conducted. The IDEA Awards study will focus on the IDEA 1 awards looking at innovation, funding leveraged, and success of the grants. The New Investigator Awards study will focus on the retention of investigators, career development, funding leveraged, and publication/citations. A subcommittee

has been formed for both the IDEA awards study and the New Investigator study to design the tools to answer questions on expected outcomes identified in the logic models.

Priority Setting

Mhel reported that the criterion in the revised Organizing Framework submitted by Strategic Health Concepts was ready to be adopted; however, the Information Questions and the Proposed Process required more work from the committee.

In reviewing each criterion and information questions, the committee realized that, due to the wording, the council focused on priority issues and not award types. Currently, it reads ***“The Research Priority does*”**. In an effort to remain focused on award types and priorities issues when setting priorities, the committee recommended changing the wording of each criterion to read ***“The priority issue and/or award type does.....”***.

With regard to the Information Questions, Mhel pointed out that the idea of the priority setting process is to have criteria to use to set priorities. In order to set priorities using those criteria, information is needed to make educated decisions. The Committee felt some of the questions posed by SHC were useful and appropriate, edited and deleted others, and additional questions were added.

The Committee agreed that the priority setting process proposed by Strategic Health Concepts was unrealistic. Mhel will edit the proposed process to shorten it. For example, Strategic Health Concepts gave a considerable amount of time to reviewing the mission statement and reaffirmation of the nine priority criteria but the Committee felt that it could be accomplished in one to two hours during a full council meeting. Other steps can be accomplished in a shorter time period by trimming down the steps in the process, spreading it out over a longer period of time and by assigning segments to committees with the committees presenting summaries to the full council. Two suggestions were made to change the proposed process:

- **Make priority setting a 2-tiered process: each year review the grants received and identify ways to solicit more quality grants in areas that are under-represented.**
- **Conduct a full priority setting process every 2-3 years, similar to Strategic Health Concepts’ suggestion, but over a longer period of time.**

The committee will continue working on the information questions and present suggestions on the types of data which should be collected in order

to set criteria and establish a new priority setting process, establishing more reasonable timelines.

C. Outreach Committee (*Attachment 11*)

Terri outlined the plan for the Dissemination Committee including a name change to the "Outreach Committee".

A draft mockup of the proposed BCRP Brochure was distributed to council members to review the brochure and provide feedback to Katie in two weeks.

Terri reported on the 2002 Symposium. The Pacific Group, a media firm subcontracted by Laura Talmus and Associates, will assist the committee in advertising for the symposium. The program is essentially the same as the one planned for September. Mhel distributed a mock up of the program for councils' review. Terri emphasized the council should focus on identifying emerging concepts and research areas for the 2003 symposium and for Priority Setting in 2002 and beyond.

Discussion regarding the 2003 Symposium included tentative dates, September 12-14, 2003 or September 19-21, 2003 and logistics. Locations suggested were San Diego, Orange County or Los Angeles. Council members preferred the September 12-14, 2003 dates and the San Diego location.

The BCRP Newsletter is scheduled for distribution during the BCRP Symposium in March. Articles should be completed by February 1, 2002 with the newsletter to the printer by February 15, 2002. The September newsletter would include a report focusing on the previous symposium with the article deadline scheduled for August 1, 2002.

Content for the March newsletter include postdoctoral evaluation, interviews, messages from the Chair and Director, symposium highlights, BCRP Program updates, etc. Future content would include summaries of hot papers by BCRP researchers, researcher of the month, analysis of funded grants, tax check-off history and value, call for applications and award announcements, symposium presentation highlights and symposium advertisements. Terri encouraged council and staff to contribute to the content of the newsletter.

Terri proposed the distribution of the BCRP newsletter articles (3 length versions) to other breast cancer organizations and newsletters for re-publication. The newsletter would also be distributed at the 2002 symposium, mailing lists and an E-mail announcement on the web site.

D. BCRP Diversity Award

Terri presented a proposal for the BCRP Diversity Award. A variety of barriers face students at the beginning of their scientific careers that prevent or discourage pursuit of breast cancer research. The award supports BCRP's mission by offering the career development of students and mentors and encourages diverse researchers and research on diverse populations.

The objective of the Diversity Award Supplement is to provide funds to BCRP-funded Principal Investigators to mentor promising students demonstrating a high potential for and an interest in breast cancer research. Eligible Principal Investigators, undergraduate and graduate students may receive awards of up to \$10,000 per year for undergraduates and up to \$20,000 per year for graduate students.

Tammy suggested having a rolling application deadline making the point that a PI may find a student to mentor at any time during the year and if they have to wait for a once yearly deadline, the PI could easily lose that student. It was decided that for this first round, we would send out the announcement, go through the process with a single deadline, evaluate it, and then decide how to handle the deadline. Since this isn't an award type but rather a supplemental award, we do have more flexibility in deadlines, etc. Janna will now pass the award through the UC lawyers for their approval and we expect that it will be ready to send out to the eligible PI in late February.

Motion: Chair Terri Burgess motioned to accept the BCRP Diversity Award Proposal. The motion was seconded by Elaine Ashby and approved unanimously

V. Brainstorming

A. Priority-Setting (*Attachment 5*)

Mhel began by stating that the Committee identified ways to use the symposium in the priority setting process. One piece of the data to be collected for this process is obtaining input from stakeholders attending the symposium. Although there is no time to do a formal stakeholders meeting, Mhel suggested using a poster that has all the current priority issues and award types. Registrants will receive dots with their packets and be requested to place the dot on the issues they deem most important. A related idea is to have a blank poster where registrants would write down new suggested priorities for the Program. Third, there is an open slot of time right before the reception where council members and staff could host a "town hall meeting". It was suggested to advertise the forum as "BCRP Listens" focusing on obtaining feedback on what is emerging and what is

changing in the field, specifically around setting priorities. Council member suggestions included advertising the session by sending out special invitations to symposium attendees, making an announcement in the morning session, and make flyers to promote it. Advertising for this session could also be in the upcoming newsletter.

Another suggestion offered to elicit input from stakeholders is to have a bulletin board on the BCRP web site. It was suggested that we could establish the site as a guest book where people would post their comments. Staff would assess the comments and make decisions on what gets posted. This could be an ongoing project to be launched at the symposium with the results of various meetings and the bulletin board comments featured in future newsletters.

B. Industry Relations

The Council engaged in a lively brainstorming and open discussion about the creation of a BCRP Industry Relations Committee. Mhel began by identifying committee members and describing the purpose and intent of forming the committee. She noted that although for profit corporations doing research are encouraged to submit grants as outlined in the Call for Applications, the Program has only received one or two proposals each year. One of the main tasks the Industry Relations Committee is charged with is to devise creative ways in which BCRP can collaborate with private industry to accomplish our mission. It was suggested that awarding grants may not be the most effective way to harness that pool of expertise found in the corporate environment.

Some ideas that emerged during the discussion include:

- Private Industry often needs access to patients for clinical trials. Corporations such as Bristol-Myers have partnered with community-based organizations to promote clinical trials. Gentech also has an advocate liaison.
- Funding Orphan Drugs. With orphan drugs, there is little incentive for private industry to invest in bringing the drug to market regardless of the usefulness of the drug. If the product is off patent and there is no possibility for the company to own the Intellectual Property of the drug, then there are no incentives. The federal government currently has a special program that offers companies incentives if they develop orphan drugs including tax incentives and longer patent protection.
- Hoda suggested that Industry could co-sponsor a junior investigator with BCRP. Industry could provide matching funds to promote

research project and/ or provide time on machines or access to expensive agents.

- Industry has high quality biostatisticians that academia could benefit from. Perhaps there is some way to share resources. Some members felt that it could go both ways because some of the smaller biotech companies need assistance from academia.

Tammy made the point that it is important to fund research that would not occur otherwise. BCRP does not want to fund something that will get funding any way.

VI. Announcements

There were no announcements for this council session.

VII. Adjournment

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