

BREAST CANCER RESEARCH COUNCIL

Lakeview Club, Kaiser Building

Oakland, CA

02/07/97

MINUTES

Part A - Open Meeting

ATTENDEES

Members Present: Shelley Adler, Arlyne Draper, Robert Erwin, Patrick Fitch, Marco Gottardis, Bobbie Head, Liana Lianov, Andrea Martin, Carol MacLeod, Maria Pellegrini, Carol Pulskamp, Carol Voelker, Suzette Wright,

Staff: Mhel Kavanaugh-Lynch, Larry Gruder, Walter Price, Katie McKenzie, Larry Fitzgerald, Mary Kreger, Patricia Hinkel

Members Absent: Beverly Rhine, Lisa Bailey, Susan Love

Guests: William Wright, California Cancer Registry (during Open Sessions only)

I. Welcome and Introductions

The meeting was called to order at 9:10 AM by the Chair, Carol Voelker.

At Arlyne Draper's suggestion, a moment of silence was observed in memory of the recent loss of 3 California breast cancer advocates.

New BCRP Staff members, grant officers Katie McKenzie and Laurence Fitzgerald, were introduced by Director Mhel Kavanaugh-Lynch.

New Council Member Bobbie Head introduced herself.

II. Review of 11/15/96 Minutes

Addition of a guest present - Jackie Gordon of the San Diego/Imperial Counties BCEDP Partnership.

The minutes were approved as corrected.

III. Unfinished Council Business

A. For-Profit Reimbursement of Awards

Bob Erwin reported for the ad hoc committee (members Andrea Martin, Beverly Rhine, Carol MacLeod, Bob Erwin) formed 11/15/96 to draft language for inclusion in the Conditions of Awards and at the end of the Statement on For-Profit Reimbursement of Awards prepared by the subcommittee.

It is the goal of BCRP to discover new information which can lead to the prevention, control and eradication of breast cancer. Hence, it is anticipated that some BCRP grant recipients will conduct clinical trials and ultimately develop profitable products or services from work funded in part or in whole by the BCRP. The Program strongly encourages, but does not require that, such individuals or institutions/companies consider:

- *Donating to BCRP to further advances in breast cancer research.*
- *Making experimental therapies available on a compassionate access protocol during clinical trials.*
- *Providing assistance to low-income women in gaining access to therapy.*

This statement conveys that, although there is no requirement for reimbursement of awards if profits are later obtained from products developed during the research, the BCRC encourages those who profit in this way to consider options for donations.

Discussion followed.

MOTION: *Arlyne Draper moved to accept the draft language. Shelley Adler seconded the motion, which passed unanimously.*

B. PR/Mechanisms for Reporting Research Results

Carol Voelker reported that the BCEDP Partnerships are producing wonderful newsletters, and displayed that of the Orange County BCEDP partnership, which contains information on the BCRP. Carol Voelker added all BCRC members to the mailing lists for the Partnerships and they should be receiving newsletters. Updated BCRC rosters will be mailed to all 14 BCEDP Partnerships for inclusion on their newsletter mailing lists.

C. Dialogue/Slide Presentation Announcement

Marco Gottardis has not yet started on this project. He will work with Susan Love (slides), Lisa Bailey (slides) and Pat Fitch (dialogue) and provide this to Council members as a tool for talks. The presentation will be about 20 minutes in length. An expected completion date was not established.

D. 1997 Meeting for Reporting Research Results

Carol Voelker presented the revised Committee Recommendations for the 1997 Meeting for Reporting Research Results (see Attachment I), and these were discussed.

The date has changed to Tuesday, September 16, 1997, 9:30 AM - 6 PM.

Mary Kreger has surveyed the proposed site - the Sacramento Convention and Visitors Center, and found it to be ideal for the meeting, newly redecorated with plenty of space for all of our planned activities and for 300-500 attendees. Thirty rooms at a nearby hotel will be reserved for 9/15/97.

Proposed titles were discussed and “1997 California Breast Cancer Research Symposium” was chosen.

Funding for costs of Cycle I awardees to attend the meeting was discussed. These individuals were not required to budget for travel to this meeting. Mhel Kavanaugh-Lynch suggested that the least complicated method of encouraging Cycle I awardees to attend is for the Program to pay their airfare directly. The Council agreed to this.

Notification: A letter will be sent in the next month to all PIs informing them of the date of the meeting. In March, another letter will be sent providing details on submitting abstracts for presentation. The abstracts will be those submitted in the Annual Progress Report (due May 15). The abstracts will be printed in a book to be provided at the meeting.

The selection of Keynote and Lunchtime Speakers was discussed. Two Keynote speakers are planned - 1 scientist and one advocate. The role of each of these speakers was discussed and agreed upon:

Scientist – (may or may not be from California) to speak for 40 minutes on the current status of research on breast cancer in lay language and stress challenges for the future; nominees include Mina Bissell, Judy Campisi, Mary Claire King, Susan Love, Craig Jordan, Monica Morrow. Marco Gottardis agreed to collect other nominations from the Council, prioritize them, include a short bio and submit them to the Council for approval. Program staff will issue the invitation.

Advocate/Activist - to present, in 40 minutes, an overview of the national breast cancer advocacy movement, where we are and where we need to go and what activists can accomplish, emphasizing necessity of such programs by using a personal story. Nominees include Susan Claymon, Ernie Bodai, Bobbi de Cordova Hanks, Harold Freeman, Lovell Jones, Susan Lay. Bob will collect nominations and prepare a prioritized list to present to the Council. Program staff will issue the invitation(s).

The Lunch speaker(s) will present the legislation/challenges in getting the bill passed and meaning of the BCRP. It was agreed that Barbara Friedman will be invited to host this session and introduce the other speakers (she could also be invited to emcee the morning session and/or be honored at the reception). A California advocate who was involved in lobbying for the legislation which created the BCRP will be invited to speak on the history of the BCRP. Suggestions were Susan Claymon, Andrea Martin. One or more other politicians may be invited to discuss legislation on breast cancer - where we are and where we are going. Nominees include Gayle Wilson, Pete Wilson, Dede Alpert, Sandra Smoley. Mhel Kavanaugh-Lynch suggested that she work with UC Legislative Affairs Office to identify and invite this speaker(s) (NOTE: 2 speakers may be invited for partisan equity). Program staff will issue the invitation(s)

The recommendations from the Subcommittee, along with the above additions and modifications, were adopted unanimously by the Council.

IV. New Council Business

A. The California Cancer Registry and the California Teacher's Study: Research Resources

Dr. William Wright, Chief of the California Cancer Surveillance Section and PI of the California Teachers Study presented the roles and activities of both Programs, and the types of data available for future studies by investigators in the State. The Cancer Registry has collected statewide data on cancer cases since 1988. Products available include: statistics for ACS Booklet on cancer statistics in CA, Compendium of breast cancer statistics for CA, Research Utilizing the CA Cancer Registry, Targeting Breast Cancer Interventions (coming soon!). There are 10 regional registries who report data to the central registry. Requirements for use of regional data include: peer review, human subjects approval, adequate funding support, coordination with other studies, feedback if patient requests no further contact by researchers. Of the 148 research projects the registry has been involved in since 1988, 43 (30%) are directed toward breast cancer.

B. Cycle IV Research Priorities and Funding Mechanisms

The Council discussed the Cycle IV Research Priorities and Funding Mechanisms in closed session.

C. Joint Meeting: BCRC & BCEDP Partnerships

Carol Voelker and Liana Lianov will confer regarding a joint meeting of the 2 state level advisory councils.

D. BCRC/Review Committee Attendance

Carol MacLeod proposed that Council members (especially those who have never been involved in grant application reviews) be allowed to attend one Review Committee. Reasons for the Council deciding not to do so in previous years in order to avoid any possible conflict in members' bringing extra information obtained during the Review Committee to bear on the funding decisions was discussed.

MOTION: *Marco Gottardis moved that Council members be allowed to attend one Review Committee as a silent observer and retain the right to vote on the funding model. Carol MacLeod seconded the motion and it passed unanimously.*

Council members were given the dates of the Review Committee Meetings and were asked to contact Mary Kreger if they wished to attend. They were advised to attend on the first day of any 2-day meetings. Council members will receive the abstract book in advance of attending a meeting.

E. Frequency of Council Meetings

It was suggested that the Council meet more frequently to maintain momentum. After discussion, five meetings per year, with one being on a Saturday, was agreed upon. 6 members voted that 2 of these be held in Southern CA, 2 voted that 1 be in Southern CA, and

2 members abstained. It was requested that meetings not be held during the month of October or between 11/15-1/1.

V. Coordinator's Report

A. Cycle III Update

1. Review Committees

Mhel Kavanaugh-Lynch presented Program staffs' plan to implement the recommendations of the Council to incorporate a "reader" in the review process and to further diversify representation on Review Committees (in terms of health care and public health practitioners, industry).

2. Applications received

A summary of the number of applications received for Cycle III in each priority area and funding mechanism was reviewed.

3. BCRP Staff Proposals

Two proposals developed by staff were presented: "Wild Card" grants and "White Paper Award."

The Wild Card proposal is designed to identify especially novel, exciting proposals which have easily fixed flaws (which prevent them from receiving competitive scores from the Review Committee), and to provide a mechanism for applicants to fix the flaws and receive funding in the same cycle. This is expected to be a rare event, applicable to only a small number of proposals each cycle. Review Committees would be asked at the end of a meeting to identify any such proposals, and the specific flaws to be fixed. Staff would then facilitate this process with the applicant. It was argued that bypassing the two-tier review process in this manner could be unfair to other applicants. The counter argument was that identifying especially innovative and exciting proposals, and funding them, is one of the goals of the Council, and it is fair to ask the Review Committees to assist the Council with this goal.

MOTION: *Arlyne Draper moved to implement the wild card proposal. Carol Pulskamp seconded the motion, which passed with 10 affirmative votes and one negative vote (by Marco Gottardis, who requested that his vote be recorded).*

The White Paper would be a commissioned paper that would serve to publicize the Program, to stimulate an in-depth analysis of an issue important to the Council, and to serve as the basis of an RFA. Several issues of implementation which have not been worked out were discussed (how would author be chosen, would it have to be a person within the state). A decision was deferred until the next meeting.

B. Cycle III Audit

Mhel Kavanaugh-Lynch reported on the upcoming State audit of BCRP's Cycle III. As previously reported, we had encouraged the State auditors to initiate the audit while the Cycle is in progress so that they could observe elements of the process first-hand, rather than only collecting information after the process was complete. The auditors accepted this suggestion and will be in the BCRP starting later this month.

C. 1996 Annual Report

A draft is in process and will be circulated to Council members for comment once it is in more complete form.

D. Donations

Mhel Kavanaugh-Lynch reported that BCRP has received a number of donations in name of a woman who recently died from breast cancer and whose family requested donations to BCRP (at the suggestion of Suzette Wright). Such donations will continue to be accepted, but will not be actively sought.

E. WWW Home Page

This was deferred for the next meeting.

VI. BCEDP Update

Liana Lianov provided a brief status report on the BCEDP. Service provision has increased remarkably, with an estimated 120,000 women to be served this year. The down side is that this represents more money than the Program has to provide services. A Resource Allocation committee is helping Program staff make decisions about priorities as dollars become tighter. For this reason, emphasis is now shifting from outreach and drawing in more women, to a focus on regular screening for those who have already been served by the Program and quality control of services. A question was asked about the data that is being collected on the women served. Liana reported that the data is not, at this time, useful for studies because it is raw data that has not been confirmed or "cleaned up." DHS is now confirming data on women who have been diagnosed with breast cancer and placing this data in a different file. "Controls" (women who do not have breast cancer) are not being pursued at this time, but may be some time in the future. As far as accessibility to this data for research, there are no consents to use this data for research (thus it is not accessible for this purpose without going back and obtaining consents from the women).

VII. Announcements

A. Line 52 Breast Cancer Tax Check-Off

Arlyne Draper reported that Senator Dede Alpert has proposed legislation to re-authorize the Breast Cancer Tax Check-Off program. In this new legislation, the CA BCRP is designated as the administrator of these funds, rather than DHS. The legislation also requires tax preparers to inform their clients of these tax check-off funds at the time the tax form is prepared.

B. 33 cent stamp

Suzette Wright provided information packets from Ernie Bodai on the national 33 cent stamp effort. CA has strong legislative support for this proposal, but other states are lagging behind. Federal legislation will be introduced in the next few weeks. Conservative estimates of the amount of money that could be raised for breast cancer research through this mechanism is \$300 million.

C. Next Meeting May 16-17, Oakland

The meeting was adjourned at 5:00 P.M.