

BREAST CANCER RESEARCH COUNCIL MEETING
December 15, 1995
Kaiser Center, Oakland, California
MINUTES

***Present:** Lisa Bailey, Chris Benz, Susan Claymon, William Comer, J. Patrick Fitch, Patricia Ganz, Carol MacLeod, Andrea Martin, Carol Pulskamp, Carol Voelker*

***Absent:** Jackie Duerr, Sam Ho, Deborah Johnson, Liana Lianov, John Link, Susan Shinagawa, Barnarese Wheatley*

***Staff:** Mhel Kavanaugh-Lynch, Mary Kreger, Annette McCoubrey, Walter Price*

***Guests:** Scott Bain*

The meeting was called to order at 9:45 a.m. by Mhel Kavanaugh-Lynch.

I. General Council Issues:

Mhel spoke about the use of Robert's Rules of Order and stated that Susan Shinagawa suggested that there be formal votes and the votes recorded. Lisa Bailey made the following motion:

Motion: Robert's rules of Order will be followed in the making of motions and taking of formal votes.

Carol MacLeod seconded the motion, and the motion was passed unanimously.

Attendance:

A discussion was conducted regarding Council members' attendance at meetings. Members discussed the difficulty of conducting Council meetings when individual members are absent, and when specific sectors of the breast cancer community are unrepresented. Andrea Martin made the following motion:

Motion: For current and new members, the Council requires that individual members attend four of six regular meetings per year, assuming advance, adequate notice of the meeting. Any member who misses two of these meetings in a year will be reminded. If the member misses a third meeting, the Program staff will bring the issue to the Council and the Council will decide about the individual's continuing membership on the Council and make a recommendation to the Program staff.

Lisa Bailey seconded the motion. There were seven yes votes, and one no vote.

Open Meeting Policy

Options for conducting Breast Cancer Research Council meetings were listed as follows:

1. Open meetings without notification of the public
2. Open meetings with notification of the public
3. Closed meetings

Legal Council has stated that advisory committee (i.e., the BCRC) meetings are not required by law to be open, but the Council does desire public input into the Program and is concerned about

the perceptions around closed meetings. Discussion on this topic followed and Susan Claymon made the following motion:

Motion: Council meetings will be open with the following provisions: (1) certain portions of meetings or (whole) meetings will be closed; (2) individuals who wish to attend must reserve a place in advance; and (3) meetings will be publicized on the Web and in the newsletter.

Carol Pulskamp seconded the motion. There were six ayes and two abstentions.

Minutes

Carol Voelker moved that:

Motion: Minutes of any meeting will be considered approved, if additional corrections to the minutes are not made within ten working days from the date of mailing.

This motion was seconded by Susan Claymon, and approved unanimously by the Council.

The minutes of the October 24 meeting were approved by seven members of the Council with one member abstaining.

Communication Issues

Mhel Kavanaugh-Lynch stated that the program is still working on obtaining an 800 number for the Program. Carol MacLeod suggested using e-mail to contact those members who are on the e-mail network instead of faxes. Several members stated that e-mail is a more effective mechanism for their communications. Council members were enthusiastic about the recent edition of the newsletter, thought it read well, and was nicely done.

II. Update on Cycle II

Requests for applications for Cycle II are still coming in. Council and staff members discussed the information meetings, which had approximately 72 attendees at all locations. The lower turnout, compared to last year, was probably because many people have information about the Program and did not feel the need to attend. It was suggested that for the next cycle there would be only one information meeting per city and fewer meetings in the Bay Area. Carol MacLeod suggested having a meeting in Orange County to draw the Riverside and Orange County researchers.

Mhel Kavanaugh-Lynch said that in the evaluation that is handed out at the information meetings, some researchers said they liked the LOI process because it saved time. The LOI process may be worthwhile and may be revisited at another time. Discussion included the fact that some researchers will submit an LOI but not have the time to develop a full-blown proposal. Reviewer recruitment is in process. The National Breast Cancer Coalition is sending a list of the Project LEAD-trained reviewers to the Program. Staff are seeking more reviewers from industry and policy research.

Council members were asked to review the draft review committee manual and return comments by December 22.

Discussion followed about the most effective ways of recruiting reviewers. It was decided that the Program will supply its current list of potential reviewers, broken down by area of expertise to the Council members, who will forward comments on particular reviewers who they know to Program staff.

It was also mentioned that the reviewers are among the strong supporters of the Program, and that the Program influences reviewers' attitudes. Mhel Kavanaugh-Lynch stated that there is a ripple effect caused by the Program as advocates and reviewers in other states are now looking into the possibility of funding such a program in their states. This is occurring in Georgia, Virginia, Texas and New Hampshire.

The decision that California advocates will sit on the study sections as observers was reiterated from the last meeting. This is important because it is another way for the Program staff and Council to evaluate the fairness of the study sections. A subcommittee was formed to establish the role and responsibilities of the California advocates and develop the orientation materials and questionnaires. Andrea Martin, Susan Claymon and Carol Pulskamp volunteered to join the subcommittee.

III. The Annual Report

An expanded outline of the annual report was distributed. It is organized around the priority areas identified by the Council, to help address one requirement: that the annual report explain how each funded project addresses the goals of the Program. It is envisioned that each priority area be introduced in a few paragraphs, explaining the following issues: (1) Where is the field? (2) Why haven't we solved this problem? (3) Why was this area chosen by the Council? (3) How do the funded projects relate to this goal?. It was suggested that these introductions, as well as other parts of the Annual Report, could be written by Council members. The Council agreed that this would add to the document.

Members were requested to review the topics that they were assigned to, and to let Program staff know if they felt they could not or should not write the respective section. Council members are requested to have their introductions for the annual report to the Program by February 1. It was also suggested that the introductions be written as a stand alone document for a lay audience.

IV. Legislative Issues

Mhel Kavanaugh-Lynch reported that she, Larry Gruder, Susan Shinagawa, Scott Bain, and Sandra Michioku met with Barbara Friedman and her staff in Sacramento, and discussed the Program and allegations that have been raised about it. Barbara Friedman indicated she planned to hold legislative hearings in January, February or later in the legislative session. The hearings will include the Breast Cancer Research Program and the Breast Cancer Early Detection Program and will evaluate how each program is fulfilling its intended purpose. Additionally, issues raised regarding the Breast Cancer Research Program in Cycle I will be addressed. It was also noted that the legislature appropriates funds for the Program annually. Andrea Martin asked what would be involved in the hearings, and Scott Bain responded that they would ask questions about the Program and its achievements, as well as about the allegations that have been made. He also said that there would be an opportunity at the end of the hearing for public input. There will be a staff document prepared prior to the hearings.

There was further discussion of the charges that the Council investigation was tainted by the fact that the chair of the subcommittee, Susan Shinagawa, is a UC employee. Bill Comer spoke to the fact that the subcommittee consisted of others than Susan Shinagawa - namely, Patti Ganz, Susan Claymon, Lisa Bailey, Bonnie Wheatley, Adeline Johnson Hackett, and himself. Susan Shinagawa became the chair of the subcommittee only after Lisa Bailey declined, due to her

heavy work load. The original allegations were that there was mismanagement during Cycle I, and now the subcommittee is accused of covering up because Susan Shinagawa was chair of the subcommittee while also a U.C. employee. Bill Comer and Patti Ganz said these allegations are unfounded because the whole subcommittee made decisions and recommended actions. Discussion continued about the University's role in administering the Program. Susan Claymon and Andrea Martin noted that U.C. was chosen originally because it had the expertise and existing infrastructure to administer the Program, obviating the need to create a new infrastructure. In addition, the California Public Health Foundation was not equipped to run the program. Members also discussed that the Council members serve without compensation, cannot apply for grants, and the University does not get overhead on grants that are awarded to U.C. campuses. If the Program is administered elsewhere, there would be eight to ten million fewer dollars available for research grants because U.C. campuses would receive overhead. Additionally, the California Public Health Foundation charges a 20 percent overhead to administer grants, whereas UC receives a maximum of only 5% for the administration of the Program. Other services that U.C. provides at no charge to the Program are services from legal counsel, auditors, risk management, and research administration. Scott Bain noted that Barbara Friedman's office is gathering written information about the Program and the subcommittee reports. Barbara Friedman's office will consider issues about who is eligible to be a member of the Council, how members are appointed, the LOI process, and issues regarding the number of women getting screened under the early detection program. Bill Comer stated that the Council welcomes the legislative oversight, and wants feedback on the Program. Mhel Kavanaugh-Lynch stated that Barbara Friedman had asked the Council to consider an external audit of the allegations. The Council discussed whether an outside audit should be conducted. It was pointed out that, to date, no evidence had been offered or found to substantiate the allegations. Given the lack of such evidence, despite a great deal of effort to uncover such evidence, members felt it was a waste of resources to hire an external auditor.

Carol MacLeod made the following motion:

Motion: The Council welcomes legislative oversight of the program and similarly would welcome documentation of any malfeasance in the LOI or research proposal review process. The Council would like to have this information in writing so that they can adequately address these issues.

The motion was seconded by Chris Benz, and passed unanimously.

Mhel Kavanaugh-Lynch asked that the Council think about how to evaluate the Program. Short of finding a cure for breast cancer, how do we define success for the Program? Chris Benz suggested reviewing the annual progress reports submitted by grant recipients. A question was raised by Barbara Friedman about whether we should send the Compendium of Awards to an outside reviewer to evaluate the grants funded. Andrea Martin suggested the possibility of an outside advisory group. Chris Benz said that the direction of the Program may be evaluated by analyzing the journals in which PI's publish, the number of publications, and external funding obtained. (These measures do require the passage of time before evaluation can occur.) Chris Benz stated that having an outside review is duplicative of the process that has just occurred with the peer reviewers. Patti Ganz suggested that the number of funded industry researchers is an

accomplishment, and Bill Comer said that whatever we suggest should be passed by Barbara Friedman for her input. In this way, the Council can incorporate her ideas. Patti Ganz noted that types of journals, number of publications, getting new investigators into breast cancer research, and yearly progress reports are all measures of success. Also, young postdoctoral fellows have been brought into breast cancer research who would not otherwise be funded in the field. Patti Ganz also noted that alliances with industry and integrative approaches are areas that could be evaluated. Bill Comer stated that the Program has identified areas of work that would be unique and would produce results, but that it takes years to get answers. Members noted that any program requires an initial start up phase

The Council briefly discussed Carol Pulskamp’s simultaneous membership on the Council and another group which has made allegations against the Program. Carol Pulskamp said that she would make a decision regarding this issue soon.

Council Membership Appointments

At the last Council meeting, Debbie Johnson proposed that two to three candidates for each open Council seat be chosen by the Program, that the Council provide input on these candidates, and that UC then appoint new members. Currently, UC solicits nominations widely from program stakeholders, including current Council members, and then appoints new members. After discussion of the pros and cons of several different processes, including maintaining the appropriate levels of confidentiality, the following motion was made by Carol Voelker:

Motion:

<i>Action</i>	<i>Responsible Unit</i>
1. Discuss general needs of Council	Council
2. Get nominations from many sources	UC
3. Screen the CVs	UC
4. Conduct a screening telephone interview to determine nominee’s willingness to serve and to inform them of the conditions of membership	UC
5. Provide a slate to the Council with a one paragraph biosketch including the individual’s name.	UC
6. Vote for more people than there are open slots. The votes will be yes, no, abstain. Comments can be written on the ballots.	Council
7. UC apppoints members from among the top grouping of nominees.	UC

Susan Claymon seconded the vote, and it passed unanimously.

VI. Public Advisory Meeting

The goal of this meeting is to obtain advice for Cycle III. It was suggested that input regarding scientific priorities and issues should be solicited in a separate meeting from a meeting to make

presentations about the Program to interested members of the public. Several members suggested that community presentations should be made in locations around the state.

Carol Voelker reported that the subcommittee planning the meeting recommended that the first day include a review of the Program's accomplishments and panel presentations. Breakout sessions would be held in the morning on the second day. Industry representatives, advocates, and researchers would be invited to participate.

It will be difficult to find 20 scientists who could adequately represent the diversity of the scientific community or 20 advocates who could adequately represent the diversity of the advocacy groups. Other suggestions were that participants be paid stipends, and that low-income persons be invited to the meeting. Chris Benz suggested discussion groups be formed around key invited participants, who will be asked to address questions of interest (e.g., the most effective ways to reach underserved populations). Andrea Martin expressed the desire that a balance of perspectives be represented. She would also like to receive information about research areas that are currently underfunded to assist the Council in deciding on priorities and appropriate funding levels. Chris Benz suggested defining the issues within broad categories so that the Council can determine whether there are issues that BCRP has missed and areas in which there is innovative work that is not currently being adequately funded. This process will permit the Council to determine whether BCRP should issue Requests for Applications (RFAs) on specific topics, or to give higher priority to certain areas. The following suggestions and comments were offered:

- 👍 Choose topic areas
- 👍 Choose experts and provide them with three or four questions, which would be framed by the advocates
- 👍 Discuss potential ways of addressing these problems
- 👍 Consider including the possible benefits of collaborative research, including new investigators, and a mentoring process
- 👍 Raise questions about the impediments in the various fields of research. (This could include collaborative research and might be a good topic for a breakout session.)
- 👍 Consider time constraints if this one meeting is to provide both scientific and public input.
- 👍 Consider videotaping the meeting.
- 👍 The meeting to set Cycle III priorities should be open, with approximately 100 participants.
- 👍 Consider scheduling simultaneous sessions, with participants choosing among them.
- 👍 Ask participants to address issues the Program has not yet addressed, and those that it should include in the future.
- 👍 Identify new award mechanisms to add or current mechanisms to change or drop.
- 👍 Consider asking new questions that are likely to provoke new thoughts and challenge paradigms.
- 👍 Make the morning session a plenary session.
- 👍 Structure each breakout session to have a speaker, a recorder, and a facilitator.

- ☝ Include the following in the plenary session: introductions, the plan for the day, a short summary of the work to date, the BCRP and Council, and highlights of the July 1994 advisory meeting.

- **Schedule**

9:00 am - 12:00 pm	Plenary session with chair, panel, and 6 experts. Discuss challenges, impediments, and plans. Audience response.
12:00 pm - 1:00 pm	Lunch
1:00 pm - 3:00 pm	Breakout sessions with experts. Each session needs a facilitator/recorder, an expert, and participants. Participants would choose their breakout sessions in advance.
3:00 pm - 4:00 pm	Plenary session with 5 - 8 minutes per report on the discussion at each breakout session.
4:00 pm - 4:30 pm	Wrap up.

Invitees

16 Council Members

6 Facilitators

6 Experts

14 or 20 - 30 Community Advocates Advocate Council Members

5 Industry representatives Attendee Subcommittee

5 Academic representatives Attendee Subcommittee

5 Clinical representatives Attendee Subcommittee

Attendee subcommittee: Bill Comer, John Link, Carol MacLeod, Patti Ganz, Chris Benz, Lisa Bailey

Chosen by

Mhel

Advisory Meeting Subcommittee

Mhel Kavanaugh-Lynch asked the Council members if they would be willing to meet for one day in February, two days in March, and two days in May. They agreed.

The meeting was adjourned at 6:00 p.m.