

Breast Council Research Council
Humphrey=s Half Moon In
San Diego, California
February 28, 1996
Minutes

ATTENDEES:

Members Susan Claymon, William Comer, Jacquolyn Duerr, J. Patrick Fitch, Patricia Ganz, Deborah Johnson, John Link, Carol MacLeod, Andrea Martin, Carol Pulskamp, Susan Shinagawa, Carol Voelker, and Barnarese Wheatley.

Staff: Larry Gruder, Mhel Kavanaugh-Lynch, Mary Kreger, Walter Price

Guest: Carolene Marks

ABSENT

Members Lisa Bailey, Chris Benz

Staff: Annette McCoubrey

The meeting was called to order at 9:15am by the Chair, Susan Shinagawa.

I. GENERAL COUNCIL MATTERS

A. REVIEW OF MINUTES

Minutes from the December 15th Meeting were reviewed, and it was suggested that Awith Barbara Friedman≅ be included in the description of the meeting that was held discussed in Sacramento. With this addition the minutes of the December 15, 1995 meeting were unanimously accepted.

B. CONFIDENTIALITY AND CONFLICT OF INTEREST AGREEMENT

The latest draft of the proposed confidentiality and conflict of interest agreement for Council members was discussed. Topics included the definition of conflict of interest and the limits on the assistance that Council members could offer grant applicants in preparing grant applications or others who could potentially benefit from said assistance without violating the agreement. Staff also reviewed some of the history that lead to this drafting of the agreement and which meetings and documents would be considered confidential. They also outlined how the public right-to-know/open meeting laws could be impacted from this new

proposed agreement.

Chair Shinagawa suggested that these additions be made to the Confidentiality Agreement, and the Council review it once more. It was made clear that the standard of practice that the Council had adopted was that meetings and materials are open to the public **unless** a particular meeting, or portion of a meeting (and related materials), were otherwise designated confidential. Such meetings and materials are declared confidential only when the subject matter includes confidential information, as defined in the confidentiality agreement (largely, review of grant applications and formulation of priorities and mechanisms for a future granting cycle, the latter being made public only after the call for applications has been released). Suggestions were made to clarify the above issues within the Confidentiality and Conflict of Interest agreement. The Council requested that, once these changes are made, the draft agreement be mailed to members for approval or further suggestions.

C. UPCOMING COUNCIL OPENINGS:

Staff presented a list of the 5-7 seats which will be vacated on July 1, 1996 and the one seat (private industry) which is currently open. The Council discussed the composition/configuration of the Council in the future, the terms of the service, and how and when past members may return to serve the Council again. There was also considerable discussion of the orientation of new members to the Council.

Council member Martin noted that all terms will now be three years (terms for members appointed in the first year were staggered from 1 to 3 years to ensure future continuity within the Council). Council member Ganz stated that it is very important to stagger membership and to inform potential members of the large amount of work involved in Council service.

Staff suggested designing an orientation for new members and a mentoring program for them, as well. Newer Council members were consulted as to what they felt was successful for them and what could be improved in the integration of new Council members. Council member Comer suggested that the orientation include: (1) meet with staff in person or by conference call (2) overlapping meeting between Anew \cong and Aold \cong members.

The Council discussed the need to fill the current vacancy for an industry representative quickly, so that the industry sector would be represented by more than one person at the next two meetings (at which the funding priorities and mechanisms for Cycle III will be determined and the funding decisions for Cycle II will be made). Staff pointed out that there was not enough time before the next meeting to solicit, receive and review

nominations, prepare a panel of qualified individuals and obtain Council vote, and appoint a new member.

MOTION:

Carol Voelker moved that the standing procedure for appointing Council members be waived in this situation to quickly fill the vacant seat. The staff will review previous nominations for private industry representatives and prepare a slate of candidates to be sent to Council members for a mail vote, with the intent of filling the currently vacant position prior to the March 15 Advisory Meeting.

The motion was seconded by Carol MacLeod and passed unanimously.

II. Presentation from Carolene Marks from the Office of Alternative Medicine.

Carolene Marks serves on the Advisory Council for the NIH Office of Alternative Medicine. Ms. Marks noted that she is a survivor of Breast Cancer and the wife of a California State Senator, Milton Marks. She is delighted with the BCRP legislation and the fact that advocates are recruited and serve on the Council. She said she would like to explore the possibility of co-funding research with funds coming jointly from the Office of Alternative Medicine and Breast Cancer Research Program. She highlighted these points regarding the Office of Alternative Medicine.

- ☞ The Advisory Council reports directly to the Director of NIH.
- ☞ The Advisory Council does not make funding decisions, but instead develops policy issues and helps to determine priority issues.
- ☞ The Office of Alternative Medicine has funded two cycles of three year grants.

Ms. Marks presented the recommendations of the NIH Office of Alternative Medicine on how the BCRP can best invest the research dollars, based on the priority of funding high quality, innovative, creative and non-duplicative research (see attachment).

Ms. Marks also discussed some of the issues facing alternative medicine on a regional level including the alternative medicine insurance proposals in Washington and the challenges funding different kinds of innovative research. She concluded by giving the Council the contact information for NIH:

Geoffrey P. Cheung Ph.D.; Director
Office of Alternative Medicine
Acting Program Office for Extramural Funding and Administration,
9000 Rock Field Pike, Bldg 31, Corner Room 5B3B, Mailstop 2182,
Bethesda Maryland 20892
(301) 594-2013

III. UPDATE ON MARCH ADVISORY MEETING

The revised agenda for the March 15th Advisory Meeting, and the list of invitees,

was presented and discussed. The meeting will consist of invited speakers in the morning and break-out groups in the afternoon. Each break-out group will include one of the speakers, advocates, scientists, clinicians and industry representatives, as well as a facilitator. They will be brainstorming on priority issues and funding mechanisms for Cycle III. The meeting will conclude with a plenary session in which the entire group will discuss the ideas which arose in the breakout sessions. It was clarified that only invited participants will be asked to participate in the breakout sessions, in order to ensure balance in representation and keep the group size optimum for interactive discussion. The plenary sessions, however, will be open to the public.

Materials that the speakers and participants will receive were discussed, and the following were decided upon:

- Cycle I and II Call for applications
- Cycle I Compendium of Awards
- Outline Summary of the 1994 National Advisory Meeting
- Questions for the Speakers
- Letter of Instructions
- (Newsletter has already gone to them)

IV. STAFF REPORT

A. Potential Impact from Current Legislation

Legislative bills introduced in the current session of the State Legislature that may have an impact on the BCRP were discussed.

AB 2915 proposes to change name of the State Department of Health Services Program from the Breast Cancer Control Program (its current name in legislation) to the Breast Cancer Early Detection Program (the name by which it's commonly known). Many Council members voiced concern that this could have an impact on the program since it will still be referred to by its former name in other legislation and in the revenue and tax code.

The second bill codifies the current BCRP enabling legislation and makes a number of amendments: 1) characterizes the Council members from private industry as having, A a demonstrated commitment to, ≡ rather than Aan interest in, ≡ breast cancer research and control; 2) adds the stipulation that Council members shall be ineligible to receive BCRP funding during their term; 3) excludes Californians from sitting on review panels; 4) adds breast cancer advocates and survivors, clinicians and persons from the science, high technology or health care sector to reviewers that the Council participates in identifying and recruiting; 5) assorted other miscellaneous corrections. Chair Shinagawa noted her concern in the phrasing of the industry representative member to the counsel. She said that under this definition, Bill Comer would not be allowed to be on the Council because his company does not deal with

breast cancer.

Staff went on to discuss the third bill (SB 1832), which will create a new account in the BC fund to finance the administrative efforts of the State Board of Equalization in relation to the BC programs. The Council requested an administrative assessment to explain the amount requested and the exact process for the creation of the new account. It was also suggested that this request can go to the Budget Office.

B. UPDATE ON BCRP Audit

Staff reported to the Council on the progress of the audit, which is expected to be completed shortly.

C. UPDATE ON CYCLE II PROCESS

Staff reported that there were 250 applications received in Cycle II. These have been assigned to 8 Review Committees, which will be meeting during the period March 26 - April 15.

Staff discovered while reviewing the Cycle II applications that some of the proposals that should have been considered under the Innovative Treatment and Models of Care Award (the only mechanism in which treatment issues were invited) were submitted under other funding mechanisms. In order to fairly address this, staff proposed the following:

Reviewers will be asked to determine the one priority area to which each application is most responsive. If they decide that the application is most responsive to the priority area of treatment, it will be discussed by the entire review committee at the meeting and a vote will be taken. An application that is determined in this way to be most responsive to the priority area of treatment will be changed at that time to the Innovative Treatment and Models of Care Award. It is possible that this will require reductions of the requested budget and duration of the project in order to comply with the guidelines of that award.

The Council endorsed this solution.

D. UPDATE ON ANNUAL REPORT

Photographs of Council members were taken during the meeting to include in the Annual Report.

Staff reported that the draft Annual Report has been formatted, and distributed copies of the new draft for review. Council members were asked to return comments within 2 weeks.

Meeting was adjourned at 4:00 P.M.

