

Australian New Zealand Breast Cancer Trials Group

ABN 64 051 369 496

ANZ Breast Cancer Trials Group Limited

CFN 10881

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BACKGROUND – ANZ BCTG CAP

Consumer representation and involvement is a critical part of any successful clinical trials research organisation. The inclusion of consumers, in the planning and conduct of clinical trials, enhances the quality and relevance of patient information and the acceptability of clinical trials participation to women.

The ANZ BCTG first began involving consumers in its research governance structures in 1994. Two consumers were invited to join the ANZ BCTG Scientific Advisory Committee and their role was to contribute to new clinical trial protocols and patient informed consent documents, plus represent a consumer's perspective on external committees, in the media and in other forums.

By 1998, the ANZ BCTG Board resolved that more should be done to address low participation rates in breast cancer clinical trials, and the lack of awareness about clinical trials amongst patients and the community. The Board decided to increase consumer involvement within the ANZ BCTG by establishing a Consumer Advisory Panel (CAP), under the leadership of Professor Linda Reaby AM, consisting of women who have had breast cancer and who have participated in a clinical trial.

The CAP, as with all ANZ BCTG committees, is governed by a Terms of Reference which includes but is not limited to:

- Purpose;
- Guiding Principles;
- Roles;
- Duration;
- Structure (Chair, Membership, Executive, any sub-committees);
- Meetings;
- Reporting Lines;
- Delegation Rules;
- Conflict of Interest;
- Performance Indicators;
- Administrative support and Resourcing

The goals of CAP are to:

- improve recruitment to breast cancer clinical trials;
- advocate for women who may participate, or who are participating in breast cancer clinical trials; and,
- provide the ANZ BCTG with a consumer perspective on relevant issues about clinical trials including recruitment, patient information for informed consent, new trial protocols and ethical issues.

The CAP also raises community awareness of breast cancer clinical trials and research, and represents consumer views on behalf of the ANZ BCTG in government, community, consumer and research funding forums.

CAP members include women from most States and Territories in Australia and from New Zealand who have had breast cancer. Each CAP member brings a unique perspective gained through their own experience and understanding of breast cancer issues, and their personal commitment to increasing participation in quality research activities.

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CAP also supports an initiative of the ANZ BCTG called 'IMPACT' - 'Improving Participation and Advocacy for Clinical Trials'. This programme is for women who have participated in an ANZ BCTG clinical trial and it acknowledges the contribution these women have made to breast cancer prevention and cure.

'IMPACT' aims to: recognise the important contributions made by women to ANZ BCTG clinical trials research; increase participation in breast cancer clinical trials; provide women with reliable up-to-date information about breast cancer clinical trials research and research in general; educate women about the science of breast cancer and the processes of clinical trials so they can become effective advocates for clinical trials research; educate the wider community about clinical trials research; lobby for increased infrastructure funding for breast cancer clinical trials research; and enhance links between health professionals and women who have participated in clinical trials research.

IMPACT currently has more than 1,850 members from all states and territories of Australia. Membership is free and benefits include: a biannual newsletter; information sessions; regular email contact; and the opportunity to participate in the ANZ BCTG IMPACT Advocate Program.

It is hoped that 'IMPACT' will enable interested women to become effective advocates for breast cancer clinical trials in the wider community, which will in turn lead to increased participation in breast cancer clinical trials and further funding support for clinical trials research.

MEMBERSHIP - ANZ BCTG CAP

Consumers interested in becoming a CAP member are usually sourced by existing CAP members and must submit a membership application which details:

1. Their experience of breast cancer and clinical trial participation.
2. Their involvement with other consumer groups or breast cancer organisations.
3. Their reasons for wishing to join the ANZ BCTG Consumer Advisory Panel (CAP).
4. How they envisage they will be able to contribute to the CAP and how whether they are willing to be involved in the promotion and understanding of clinical trials research?
5. Their Curriculum Vitae.

All new CAP members are advised of the following key elements of membership:

Essential Criteria

The essential criterion for a member of the ANZ BCTG Consumer Advisory Panel is to give unqualified support to the concept of clinical trials; of every woman's right to information concerning trials and her right to make a personal, informed choice. As consumer advisers they are not asked for, nor do they necessarily have the expertise to comment on the scientific/medical merits of a trial. Whether they personally like or dislike a particular trial is irrelevant. Their role is to advise the ANZ BCTG on issues which may affect women participating in the trial.

Duration of Appointment

Membership of the Consumer Advisory Panel is for a three (3) year period. At the end of that time membership of the CAP may be renewed after reapplication, up to a maximum of three terms.

Confidentiality and Conflict of Interest

CAP members contribute because of their personal experience with breast cancer and as clinical trial participants and not as members of any other group. CAP members must respect the confidentiality requested by the researchers when reviewing documents, and must disclose any conflict of interest in any matters being considered by the Panel.

Expectations of Members

The ANZ BCTG invests resources into supporting and maintaining the CAP. Of course, it is recognised that CAP members are volunteers with professional and family commitments, however, CAP members are all asked to be conscientious regarding their participation in CAP activities and meetings.

CAP meetings are usually held four (4) times per year and all CAP members are expected to attend the Annual Scientific Meeting (ASM) of the ANZ BCTG. Availability to attend and/or give presentations at other relevant meetings, forums and conferences is desirable.

Members' timely responses to various proposals, protocols and documents will also be sought throughout the year.

All new CAP members are also required to sign a Confidentiality Agreement and Standing Notice of Interest (updated annually) and are furnished with an Orientation Pack, which includes:

1. CAP Terms of Reference
2. CAP member contact details
3. Recent CAP minutes
4. Relevant ANZ BCTG operational and personnel information
5. ANZ BCTG Annual Report
6. List of ANZ BCTG Clinical Trials
7. List of commonly used abbreviations
8. Any other pertinent information