

ANZGOG Consumer and Community Committee

Who are ANZGOG:

ANZGOG was established to foster and support collaborative research throughout Australia and New Zealand and to improve outcomes for women with gynaecological malignancies through randomized clinical trials. The group was formed in late 2000 and shortly after was accepted to join the US GOG, the pre-eminent US based collaborative trials group and at the same time joined the Gynecological Cancer Intergroup (GCIg). ANZGOG has opened a number of clinical trials within Australia and New Zealand and is participating in a growing number of pivotal international trials. The important links that have been forged with international groups, recognized for their contribution to our current clinical practice in gynaecological malignancies, are essential as gynaecological cancers are a global problem and require collaborative efforts to improve outcomes. More than 500 women have joined these trials since inception.

Objective of the Consumer and Community Committee.

The ANZGOG Consumer and Community Committee (ANZGOG CCC) is a new initiative by the Executive for 2008 and reflects the needs of the gynaecological cancer community to seek guidance and input from consumers to better represent the needs and expectations of gynaecological cancer consumers. The ANZGOG CCC will consist of advocates across all gynaecological cancer disciplines and geographical areas to act as an interface between consumers and clinicians. Advocates will share their insight and provide recommendations to clinicians as to how consumers can better understand the purpose of and engage in ANZGOG clinical trials. ANZGOG will utilise the skills of the ANZGOG CCC for Consumer representation on clinical trial processes and information delivery.

Responsibilities for Committee members

- Status on the ANZGOG CCC is a volunteer position, however all candidates will be required to apply for membership to ANZGOG officially, to be included in the public liability policy.
- All volunteers are expected to attend at least one, possibly two face to face meetings representing the ANZGOG/CCC per year. The cost of this representation will be fully borne by ANZGOG.
- To attend one teleconference per quarter, or 4 per annum, to discuss strategies and issues that may arise.
- Will have had either personal experience with gynaecological cancer or have been in a primary carer's role for a family member diagnosed with a gynaecological cancer.
- Will be provided induction training on ANZGOG core values and purposes and kept updated as to new clinical trials being undertaken.

9 ANZGOG CONSUMER/COMMUNITY COMMITTEE

- 10.1.1 The Consumer/Community Committee shall assist ANZGOG achieve its objects and purposes by acting as an interface between people who have been touched by gynaecological cancer and the wider community and by providing guidance, support, information and advice by contributing to discussion and reporting to the ANZGOG Executive.
- 10.1.2 The Chair of CCC shall be appointed by the Executive
- 10.1.3 The committee shall consist of the
- a) Chair,
 - b) Deputy Chair (appointed by the committee),
 - c) Chair Elect
 - d) Past chair
 - e) a representative of each of the States and Territories of Australia and New Zealand where ANZGOG clinical trials are conducted.
- 10.1.4 The appointments to the CCC shall be approved of by the Executive.
- 10.1.5 Members of the CCC can be nominated by any existing ANZGOG member/supporter
- 10.1.6 Should nominations exceed positions a list of candidates names in alphabetical order shall be presented to the committee for voting and then approval by the Executive.
- 10.1.7 The CCC shall with the approval of the Executive nominate one of their members to hold the position of CCC Chair elect. This person so selected shall hold office only until the next following Annual General meeting where such position shall be ratified by being subject to the election process. Such a person will hold office for a period of two (2) years and will be formally elected to the roll of Chair CCC at an Annual General Meeting held when the current chair's term of office is concluded.
- 10.1.8 The retiring chair of the CCC shall remain on the committee for a period of two (2)years after such retirement.
- 10.1.9 The Chair of the CCC will serve on the Executive
- 10.1.10The Chair of the CCC will provide a report to the Annual General Meeting on the activities carried out by the CCC

Members of the ANZGOG Consumer/Community Committee

Name: Karen Livingstone – Committee Chair

Location: Melbourne, VIC

Category of Interest: Carer, CEO Ovarian Cancer Australia

Name: Stephanie Alvarez.

Location: Perth, WA.

Category of Interest: Carer, Qualified Pharmacist & Ovarian Cancer Australia board member

Name: Helen O'Neil

Location: Newcastle NSW

Category of Interest: Survivor

Name: Pennie Stoyles

Location: Melbourne VIC.

Category of Interest: Survivor

Name: Rachel Coates

Location: Auckland NZ

Category of Interest: Carer, Chair Silver Ribbon Foundation NZ

Name: Loryn Einstein

Location: Brisbane QLD

Category of Interest: Survivor

Name: Sally Barron Hay

Location: Sydney

Category of Interest: Clinician

Name: Nicole McCarthy

Location: Brisbane

Category of Interest: Clinician