13 June 2006

The Secretary
Senate Community Affairs References Committee
Parliament House
Canberra ACT 2600

Dear Senators,

Re: INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

The care of women with gynaecological cancer in Australia has the potential to be regarded as the yardstick against which other countries should be measured. There were many areas within this disease spectrum where the Australian infra-structure and care has been a world leader but over time we have failed to keep pace with some of the changes that are occurring in basic scientific and translational research, psycho-social aspects of care, organizational structure for equitable care and work force requirements.

Gynaecological Oncology was established as a recognized subspecialty of the Royal Australian College of Obstetricians and Gynaecologists (RACOG, now the RANZCOG) in 1988. To be a recognised Gynaecological Oncology Unit the following criteria had to be in place

- ~ Minimum annual caseload
- ~ Dedicated Gynaecological Oncology nursing and inpatient ward
- ~ Multi-disciplinary care and treatment planning meetings
- ~ Involvement in research

To be a Certified Gynaecological Oncologist (CGO), 3 years of subspecialty training in recognized Units had to be undertaken prior to completing subspecialty exams. This program was the first nationally coordinated training in Gynaecological Oncology available outside of North America and many trainees from Europe and Asia have spent time training here because of the high level of expertise available in this country.

The basic infrastructure for the provision of exemplary care is already in place but this infrastructure has not been built upon since it was established 15-20 years ago. Changes over this time have left the provision of care to women with this disease below what should be expected and what is possible. The areas of particular concern fall largely into the following areas

1. **Research**
   The funding of basic scientific, translational and epidemiological research is inadequate despite many of the centres undertaking this research being regarded as world leaders in their area. There appears to be a deficiency in the co-ordination of research priorities and funding allocation. The establishment of a national Gynaecological Oncology body with adequate research funding specifically within the area of ovarian or gynaecological cancers should be a priority.

   The incorporation of the many diverse and competing interests in this area research under one umbrella will give opportunities for less duplication of infrastructure and easier co-ordination of co-operative studies.

2. **Training and workforce requirements**.
   The aging Australian population, the increasing complexity of care provision and the need to provide outreach services to women outside major metropolitan centres means that there is a need for more gynaecological oncologists within Australia. Training positions can be made available within the currently recognized training centres in Australia but there is inadequate funding for these positions in most states and more importantly no funding for employing these new subspecialists within the Gynaecological Oncology Units.

   The estimated workforce requirements for Gynaecological Oncology are 1 sub specialist for 400,000–500,000 population which means that for adequate care of Australian women we require between 40-50 specialists in clinical practice. There are currently 33 CGO's in Australia and 5 trainees but 25% of the workforce is 55 years or older.

   As the Australian population ages there will be an increase in the number of women presenting with ovarian cancer and other gynaecological malignancies (AIHW data) that will further increase the need for specialists in this area. There is a need for more funded training positions but this has to be supplemented by adequate funding for these sub specialists to be employed in Gynaecological Oncology Units.

3. **Data Management**
   Improved data management is essential for the appropriate provision of cancer services to women. Most gynaecological oncology units managing women with ovarian cancer have a data management system but the data recorded is variable and there is no capability to share or pool data. This means that within Australia we have no clear measure of

- The number of women currently being managed by, or in conjunction with, Gynaecological Oncology Units
- The number of women not given the option of optimal care
- Outcomes of treatment
- Treatment related morbidity and complications

Improved data management is an essential tool in the ability to quantify what is currently being done, to look at outcome measures and then to improve our service delivery. Not only is the funding for data managers inadequate, the systems available for collection and analysis of accurate information appear to be basic and largely ineffectual.

Data management is also an important part of the research and clinical trials undertaken to improve the care of women with gynaecological cancer. While some trials are industry funded there are many clinical trials that require research nurses and data management support for which funding cannot be secured.

There is an urgent need for the development of appropriate data management systems and for the provision of data manager/research nurse time to accurately record the information.

4. **Psycho-social support.**

Following the diagnosis of gynaecological cancer many women and their families experience major degrees of psychological distress. Appropriate referral to support services is frequently unsuccessful because;

- The support service is not available
- The support service is overbooked
- The support service is geographically inaccessible
- The support service is not affordable

These comments were the common theme heard at the Ovarian Cancer Consumers forum held in Melbourne in February 2006.

The feedback from women with this illness suggests there is a major deficiency in the provision of psychological support services and this aspect of care is as important to these women as the medical and surgical components of true multidisciplinary care.

5. **Teaching.**

The recent publication of ‘Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer’ has been an important initial step in coordinating care for one gynaecological malignancy. There is no information yet available on the impact of these guidelines for the treatment of women with this cancer and unfortunately there are no such guidelines available for other gynaecological cancers.

Ongoing support of clinical guideline development combined with infrastructure and research funding will ensure that Australian women with gynaecological cancer can continue to have world leading care and that this care can be made available to a significant number of women who currently fall outside of the multidisciplinary framework.

Thank you for considering this submission.

Yours sincerely

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