

16 June 2006

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

Dear Sir,

Re: Inquiry into gynaecological cancer in Australia

I refer to your letter of May 12th 2006, requesting a written submission addressing the above Inquiry. I welcome the opportunity to do so.

I will address each point individually.

(a) Level of Commonwealth and other funding for research addressing gynaecological cancer.

Broadly speaking, medical research can be divided into two components:

- (i) clinical research, which investigates the optimal approach to the diagnosis and treatment of cancer. This research is performed on patients, by clinicians, with help from statisticians;
- (ii) basic or laboratory research, which aims to develop new diagnostic tests and therapeutic agents. This research is performed by research scientists, who have no direct contact with patients.

(i) Clinical Research. With respect to clinical research, the most reliable results come from prospective randomized controlled trials. Many treatment centres need to be involved in these trials, so that large numbers of patients can be entered on the research protocol in a relatively short period of time, and statistically significant results achieved.

Four years ago, the Australian and New Zealand Gynaecological Oncology Group was established in Australia (ANZGOG) under the chairmanship of Professor Michael Friedlander. The group collaborates with other major trials groups around the world, including the GOG in the United States. The group is significantly unresourced, and needs a

major infusion of money, particularly for research nurses, travel expenses and data analysis. This would bring Australia into line with other developed countries, such as the United States, Canada and Europe.

Several major advances in the clinical management of patients have come from gynaecological oncologists in Australia, and we could offer our patients optimal care and more effectively influence world opinion, if we had a better funded ANZCOG. Major innovations which have come from our group at the Royal Hospital for Women in recent years include:

- (1) **defining the role of pelvic and paraaortic lymphadenectomy in the management of patients with advanced ovarian cancer.** An international prospective, randomized trial was initiated by the writer, but because of lack of adequate funding for data collection in this country, we had to use a data centre in Italy for the randomization of patients, and for the collection and analysis of data ¹.
- (2) **pioneering the use of small field pelvic radiation for patients with high-risk, node-negative cervical cancer** ². Our pilot data, published in 1999, showed that with this modified radiation treatment field, disease control in the pelvis was not compromised, and we postulated that significant morbidity would be decreased. Our data on pelvic disease control have recently been validated by Japanese workers using case-control studies ³, and the Japanese workers also confirmed that morbidity was decreased with this approach ⁴. For universal acceptance, the concept should be subjected to a randomized prospective study.

The group at the Peter McCallum Clinic in Melbourne is trialing this approach for patients with high-risk, node-negative endometrial cancer.

- (3) **pioneering the concept of nodal debulking rather than complete groin dissection for patients with vulvar cancer and bulky, positive groin nodes.** This concept, with supporting data, was presented at the International Gynaecologic Cancer Society meeting in Edinburgh in 2004, and should be subjected now to a randomized, controlled trial. Our pilot data showed that this approach significantly decreased the risk of lymphoedema, without compromising survival. ⁵

(ii) Laboratory research. The most effective basic research programs involve a collaboration between clinicians and research scientists. Clinicians supply tissue and blood specimens from cancer patients to the research laboratory, along with vital patient information, and in return, any new discoveries can be trialed on the patients in the clinic. This is the basis of the ovarian cancer research collaboration which we have between the Gynaecological Cancer Centre at the Royal Hospital for Women and the Garvan Institute of Medical Research.

At the present time, the most urgent need in gynaecological cancer research is to develop a blood test that could be used to allow population screening for ovarian cancer. In 2001, the last year for which national figures are available from the Australian Institute of Health and Welfare (AIHW), there were 1295 new cases of ovarian cancer in Australia (an increase of 44% over the past 20 years), and 857 deaths⁶. The 5-year survival for ovarian cancer in Australia is 40%, which compares very unfavourably with the 85% 5-year survival for patients with breast cancer.

Stage I ovarian cancer can usually be treated by surgery alone (without chemotherapy) and has a 5-year survival of about 85%. The reason for the poor overall survival for patients with ovarian cancer is that 70% of patients have advanced disease at the time of diagnosis. Such patients usually need more than one major operation, multiple courses of chemotherapy, and frequently prolonged hospitalization because of bowel obstruction.

There is presently no means of early diagnosis, because symptoms are vague and non-specific (such as indigestion, bloating, mild abdominal pain), and most of these symptoms are not caused by ovarian cancer. It is completely unrealistic to expect general practitioners to make a diagnosis of ovarian cancer in its early stages, so this disease will continue to have a very poor prognosis until a diagnostic screening test is developed.

In the 2005-06 Budget, the Federal Government allocated \$80m over 2 years for the treatment of patients with advanced, metastatic breast cancer with the targeted (gene) therapy Herceptin. This drug was rejected for PBS subsidy by the Pharmaceutical Advisory Committee, and costs \$66,000 per person.

Similar targeted therapies are already available for ovarian cancer. All such therapies are very expensive, and although they have been shown to significantly prolong life for a number of different cancers, they are not curative. Better value for money would come from spending \$80m on research to develop a screening test for ovarian cancer, so that the need for such therapies would be markedly reduced.

Development of a screening test for ovarian cancer has become eminently more feasible since the completion of the Human Genome Project in 2003. Our group has a small team of research workers at the Garvan Institute of Medical Research tackling this problem, but major financial support would enable our team, and others, to be expanded. It is no longer a matter of *if* a screening test will be discovered, it is only a question of *when*. The greater the investment in this research, the sooner population screening for ovarian cancer will be a reality. Early diagnosis of ovarian cancer would save hundreds of lives in Australia each year, and save millions of dollars in treatment costs.

The major cancers in women are breast, colorectal, melanoma, lung, non Hodgkin's lymphoma, cervix, uterus and ovary. With the exception of lung cancer, which is usually related to smoking, ovarian is the only cancer with a 5-year survival below 50%. Many cancers in women have survivals well in excess of 80%. Any dispassionate observer would have to conclude that there is an urgent need for dedicated funding for ovarian cancer research.

(b) Extent, adequacy and funding for treatment services, and for wider health support programs for women with gynaecological cancer.

There were 3886 gynaecological cancers in 2001, and this is expected to increase to 4488 by 2011, an increase of 14%. While ovarian, uterine, and vulvo-vaginal cancers are each expected to increase by about 25%, the number of cervical cancers is expected to decrease by 34%, because of the National Screening program⁶. The cervical cancer incidence is expected to decrease even further in later years after the introduction of the HPV vaccine.

Assuming the vaccine is effective, it is protective against only 2 high-risk viruses (types 16 and 18) which together account for about 70% of cervical cancers. There are about 20 other high-risk HPV viruses, so it will still be necessary to continue the National Cervical Cancer Screening Program, albeit with possible changes to the recommended age for initial screening and the recommended screening interval. The only reason the incidence of cervical cancer is so low in Australia is that a high quality screening program is in place.

Management of gynaecological cancer is better coordinated than any other solid tumour in Australia, because gynaecological oncology has been recognized as a subspecialty of Obstetrics and Gynaecology by the RANCOG since 1985. There is a specific 3 year training program, which can be undertaken after 5 years of basic training in Obstetrics and Gynaecology. This 3 year Fellowship training program leads to a written and an oral examination, following which successful candidates receive the Certificate of Gynaecological Oncology (CGO) of the RANZCOG.

There are presently 34 certified Gynaecological Oncologists in Australia, and a further 6 in training positions. Initial projections by the RANZCOG were that Australia and New Zealand required one gynaecological oncologist per 500,000 population. This has recently been revised to 1 per 400,000 population. With the latest census showing an Australian population of almost 19 million in 2001, we should have 48 gynaecological oncologists to adequately service the Australian population.

Management of gynaecological cancer should be carried out within multidisciplinary Gynaecological Cancer Centres, directed by a gynaecological oncologist. Members of the multidisciplinary team should include medical oncologists, radiation oncologists, gynaecological pathologists, palliative medicine specialists, specialized oncology nurses (including designated operating theatre teams), a psycho-oncologist, social worker, dietician and physiotherapists with particular expertise in the management of lymphoedema.

All capital cities in Australia, except Darwin, have established Gynaecological Cancer Centres, where the standard of care, in general, is excellent. There are 13 major gynaecological cancer centres in Australia, 4 in New South Wales, 3 in Victoria, 2 each in Queensland and South Australia, and one each in Western Australia and Tasmania. Most centres need some additional staff, and this will be addressed in the submission from the Australian Society of Gynaecological Oncologists (ASGO). Several Gynaecological Cancer

Centres, including our own, have recently had to employ another Staff Specialist, and now have no salary to employ a Gynaecological Oncology Fellow (trainee).

(c) Capability of existing health and medical services to meet the needs of indigenous populations, people of other cultural backgrounds, and those living in remote regions.

Although gynecological cancer care is generally well managed, and multidisciplinary gynaecological cancer centres are generally well resourced in capital cities, it is not so well organized in rural areas, including indigenous communities.

The appropriate management for all new patients should be determined by the multidisciplinary team in the gynaecological cancer centre, after central review of any pathology specimens. Major surgery should be performed in the gynaecological cancer centre, and the patient and a support person need to travel to the capital city for the operation. To avoid discrimination against rural patients, travel should be provided free of charge (at least for low income earners) and patients and carers need appropriate, cheap accommodation close to the hospital. Chemotherapy, and sometimes radiation therapy, can appropriately be delivered in large country towns.

Follow-up should ideally be carried out in the large country towns, by gynaecological oncologists who travel out from the city. Some low-risk cancer surgery could also be performed by gynaecological oncologists in country towns if operating theatre time was made available.

As an example of this, our centre has such an arrangement with The Canberra Hospital and with the Illawarra Cancer Centre. We travel to Canberra and Wollongong once every 2 weeks, and run half-day clinics. Once a month, we have a half-day operating list in Canberra. To adequately cover the needs of the ACT and Illawarra, we should be doing a weekly clinic in Canberra and Wollongong, and a fortnightly operating list in Canberra.

Other services that are lacking in rural areas are psychosocial support and access to palliative medicine experts. These issues will be the subject of other submissions. Gynaecological cancers are particularly distressing from a psychological perspective. For all women, there are issues such as sexual dysfunction and disturbed body image associated with a cancer of the female genital tract, while for pre-menopausal women, there are the additional issues of induced infertility and menopause.

(d), (e) Extent to which the medical community and the lay community need to be educated on the risk factors, symptoms, and treatment of gynaecological cancers.

There is a need for continuing medical education for general practitioners and gynaecologists on all aspects of gynaecological malignancies, as new information becomes available. For example, in the last decade, genes responsible for the hereditary forms of breast, ovarian and endometrial cancer have been identified, and genetic counselling and genetic testing are now

available. How to identify patients at risk of an hereditary cancer and how to manage such patients subsequently, are critical issues for all clinicians dealing with female patients.

Equally important is the continuing education of the medical and lay community regarding risk factors for the various cancers, any screening that may be available, and symptoms of early disease. An important issue for the lay person is where to get the appropriate help, if diagnosed with a gynaecological cancer.

I believe that all of these issues would be best addressed by the establishment of a National Gynaecological Cancer Centre (NGCC), along the same lines as the National Breast Cancer Centre (NBCC). There is presently a National Ovarian Cancer Centre, which is an appendage of the NBCC, but this centre does not address education, research, and management issues pertaining to endometrial, cervical, vulvo-vaginal or placental malignancies.

To link the gynaecological cancers to the NBCC is inappropriate, because they occur in sufficient numbers to stand alone. In 2001, the last year for which statistics are available in Australia, there were 40, 578 cancers in females, of which 3886 (9.6%) were gynaecological cancers. Numerically, gynaecological cancers were the third most common group of tumours, after breast (11,791; 29%) and colorectal cancers (5883; 14.5%). Melanomas were a close fourth, with 3861 cases (9.5%).

In the 2005-06 Budget, the Australian Government committed \$1.0m to improve support for those newly diagnosed with breast cancer, and \$4.0m to improve the early detection and management of breast cancer. There was nothing to help support or better detect and manage patients with ovarian cancer, and yet such patients have a far worse prognosis and are likely to be in need of even greater help than those with breast cancer. There is an effective screening test available for breast cancer. No such screening test is available for women with ovarian cancer, and hence the urgent need for funds to be dedicated to this research, and for gynaecological cancers to have an independent voice and advocacy group.

(f) Extent of representation on national health agencies, especially the recently established Cancer Australia.

Gynaecological cancers represent 9.6% of cancers in women, which should be sufficient justification for representation on national cancer agencies. It may be appropriate for the National Gynaecological Cancer Centre to be placed under the umbrella group Cancer Australia.

SUMMARY

Funding is urgently needed for the following:

- (1) to establish a National Gynaecological Cancer Centre to be responsible for education, research co-ordination, and advocacy for all gynaecological cancers.
- (2) to enhance basic laboratory research, particularly that directed at developing a blood test to allow population screening for ovarian cancer.

- (3) to guarantee the viability of the ANZGOG, which will allow proper Australian participation in clinical trials. This would bring Australia into line with the United States, where the GOG is the major trials group, and Europe, where the European Organization for Research and Treatment of Cancer (EORTC) has been long established
- (4) to bring staff levels at major Gynaecological Cancer Centres into line with RANZCOG recommendations, and to allow adequate training positions for future gynaecological oncologists in this country.
- (5) to better manage patients from rural and indigenous communities. This should include provision of more psycho-oncologists and palliative medicine experts in major country towns, and provision of more resources to allow patients and their carers to travel to gynaecological cancer centres for major surgery.
- (6) to introduce a HPV vaccination program into the Australian population.

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Yours Sincerely

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