OVCA AUSTRALIA (ACT & REGION)
The National Ovarian Cancer Awareness Network

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Parliamentary Inquiry into Gynaecological Cancer

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

Dear Sir/Madam

We are writing in response to the above Inquiry. We are a local ovarian cancer support group – OvCa (ACT & Region) – which is part of the broader OvCa Australia (National Ovarian Cancer Awareness Network).

OvCa (ACT & Region) was established four years ago to raise awareness of ovarian cancer among the medical profession and the general community, and to provide support to women in our region with the disease, and their family and friends. We are a small group of volunteers which receives no government funding.

Our activities are largely funded through donations and fund-raising activities and to date include, for example: hosting information sessions on ovarian cancer at the Canberra Hospital; organising smaller targeted sessions for local area networks of general practitioners; undertaking direct mail of information to GPs in our region; advertising on milk cartons and through television community service announcements; and general public relations/media activities.

We are writing specifically to provide the Inquiry with an insight into the personal experiences of women in this regon with ovarian cancer, and their families and friends. We will touch only briefly on the incidence and epidemiology of ovarian cancer, as we are sure that the larger national research organisations will go into further detail on such issues.

a. Level of Commonwealth and other funding for research addressing gynaecological cancers

We are unaware of the total research budget (i.e. Commonwealth/State Government and private research funding) for ovarian cancer, however we understand that the current Commonwealth research and awareness commitment is around $500,000 (*04-05 Federal Budget*). Given that ovarian cancer is the most lethal of gynaecological cancers – killing 1 Australian woman every 10 hours (Australian Institute of Health and Welfare, *Cancer in Australia* 1996) – and that there is currently no mass screening or early detection test for this insidious disease we believe this to be manifestly inadequate.

Given the high mortality rate and increased health costs associated with late diagnosis, we believe there would be a potential saving to the health budget from a substantially increased investment in research directed towards a better diagnostic test for ovarian cancer and the accessability of mass screening.

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

Like most cancers, if ovarian cancer is caught early enough there is a 90 per cent or more chance of cure or survival beyond five years. However, 75 per cent of women with this disease are diagnosed at an advanced stage and their five-year prognosis is poor. Some 80 per cent of these women will die within five years. This is overwhelmingly due to the fact that there is no early detection test or mass screening program for ovarian cancer. The development of such is the single most important factor in saving the lives of more than 800 Australian women each year.

Statistics have also shown that women treated by a gynaecological oncologist have far better survival rates than those treated by gynaecologists or general surgeons alone. There are currently no gynaecological oncologists in Canberra. While Canberra is well served by visiting gynaecological oncologists from Sydney, most women have to travel to Sydney for their surgery, placing them and their families under additional pressure during the most stressful of times. While we understand the complexity of health resourcing – and the fact that the incidence of gynaecological cancers in Canberra is comparatively low – a Canberra-based gynaecological oncologist could provide a service for a larger regional feeder area.

The presence of strong multi-disciplinary support is also considered to be critical for the treatment of women with ovarian cancer. In Canberra this could currently be described as patchy at best, non-existent at worst. Communication between gynaecological oncologists and the medical oncologists is often poor, with women being presented with opposing treatment options. There is also often no involvement of dieticians, counsellors etc. Women generally have to find their own way through a confusing system, with little or no external support

> *"I spend all of my time on the internet trying to find out a few answers – but it is very confusing. You are bombarded with a lot of information, but with no direction."* (Ovarian cancer patient, diagnosed in 2005 Stage 3C, rising CA125 level, but no current visible evidence of disease)

c. *Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds; and those living in remote regions.*

We have no direct experience in this area. However, given the inadequacy of services in what would generally be regarded as a large regional area, we can only imagine how difficult it must be for Indigenous women, those of different cultural backgrounds and those living in remote areas of this country.

d. Extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers.

The lack of an effective early detection test and mass screening programme for ovarian cancer remains the number one barrier to reducing the dreadful impact of this disease.

In the absence of such, a well-informed medical and general community remains our only real defence in the fight against ovarian cancer. Sadly, personal experiences suggest current medical knowledge in this area is far from adequate. Nearly every woman in our local support group was misdiagnosed by their general practitioner – including by a womens' health specialist – potentially robbing them of valuable time.

Wrong diagnoses included unspecified virus, giardia, irritable bowel syndrome, gall bladder problems and ectopic pregnancy. In many instances women were made to feel like hypochondriacs.

> *"I first went to my doctor in December with gastro-intestinal problems. I wasn't diagnosed until the following June and then it was 'by accident' while they were looking at another potential cause of my 'vague symptoms'. I had asked if I should have any tests, but was told that 'no unnecessary, invasive tests would be ordered'."* (Ovarian cancer patient, diagnosed in 2001 Stage 3C, currently being treated for third recurrence, including metastasis to spleen.)

While ovarian cancer affects women of all ages, statistically it is a disease which is more prevalent among older women. One older woman (aged in her late 70s) with many symptoms was told by her doctor that women her age don't need to worry about gynaecological problems anymore.

While ovarian cancer is difficult to detect, with symptoms often presenting late in the development of the disease, doctors must be educated to consider ovarian cancer first rather than last when a patient presents with vague abdominal/gastroenterological symptoms. While the symptoms of ovarian cancer are vague, they **are** there and they **do** tell a story. General practitioners must also be educated as to the best treatment path once ovarian cancer is suspected, i.e. that a gynaecological oncologist must be involved.

As mentioned in the introduction to this submission, OvCa (ACT & Region) has undertaken a range of activities within this region to raise awareness of the disease among women and the medical profession. While we have received a great deal of support from the medical profession we have also met some resistance, including the accusation that we are unnecessarily 'scaring' women. We believe it is far more frightening to be suddenly diagnosed with a potentially terminal illness about which you know nothing.

e. *Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers.*

Education of women and the broader community is critical, but the development and introduction of an early detection test/mass screening programme must be the key priority.

The difficulty in ‘selling the message’ about ovarian cancer is that there is no single, easy action that a woman can take to detect the disease or help prevent the further development of the disease, e.g. ‘have a regular pap smear’ or ‘if you detect changes in your breast have a mammogram’. Current diagnostic tools for ovarian cancer (e.g. CA125 test or vaginal ultrasound) are extremely unreliable, and by the time many women experience the symptoms of ovarian cancer the disease is well advanced.

Having said that until there is an effective test, education about the symptoms of ovarian cancer is our best, if not only, form of defence.

f. *Extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia.*

We are not in a position to be able to comment on this point.

In summary

In summary, OvCa Australia (ACT & Region) believes that the development of an early detection test and mass screening programme for ovarian cancer is urgent, and that a major investment of Australian Government funding to this end is critical.

We also believe that a designated health professional to coordinate a multi-disciplinary approach to the treatment of women in this region diagnosed with this disease or other gynaecological cancers is essential.

Finally, we would like to thank the Senate for establishing this important Inquiry and for giving us the opportunity to express our views on this issue. We would be happy to elaborate on any of the issues we have raised.

Yours sincerely

Jane Harriss
Director, OvCa (ACT & Region)

16 June 2006