SENATE INQUIRY INTO GYNAECOLOGICAL CANCER IN AUSTRALIA

The submission represents the opinions of the National Ovarian Cancer Network and that the submission has been reviewed and endorsed by the Board of Directors.

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1 Executive Summary

This submission to the Senate Inquiry into Gynaecological Health in Australia represents the opinions of the National Ovarian Cancer Network and has been reviewed and endorsed by the Board of Directors. This submission is primarily focussed upon Ovarian Cancers.

1.1 The Need

Gynaecological cancers account for the deaths of over 1400 women in Australia each year. Ovarian cancer is the most lethal of gynaecological cancers and accounts for over 57% of deaths due to gynaecological cancers, more than all other gynaecological cancers together.

The causes of ovarian cancer are not well understood and the survival outlook is poor for most women diagnosed with ovarian cancer. 50% of women are not appropriately referred to specialist Gynaecologic Oncologists reducing survival rates of this disease even further. Support groups for survivors, family members, friends and carers of ovarian cancer patients are limited.

Compared to other cancers, especially breast and cervix, gynaecological cancers receive substantially less funds for research and health promotion activities.

1.2 The Opportunities

Based upon the information presented within this submission, the National Ovarian Cancer Network has identified the following opportunities for exploration by the Senate Inquiry.

- Funding to enable opportunities for the development of new tests for early diagnosis are urgently needed.
- Additional funding is required to support existing organisations that currently provide screening programs, treatment services and wider health support programs for women with gynaecological cancer, particularly ovarian cancers.
- Women with gynaecological cancers require adequate and speedy access to specialist medical and support services. Therefore, there is a desperate need to fund and develop alternative care and support models, such as the use of videoconferencing, the internet or telephone networks to provide women with access to clinical experts, specialist staff and their peers regardless of geographical location.
- There is an urgent need to raise awareness and educate General Practitioners on symptoms, diagnoses and the treatment of ovarian cancers to improve chances of early diagnosis and appropriate referral of patients to ensure they are provided with access to best practice treatments for their disease.
- Greater Commonwealth support for the dissemination of reliable information to ensure women are reliably informed of the disease.
- Improved representation of gynaecological cancers with major agencies.

1.3 The Required Outcome

Reduction in the mortality rate and morbidity for patients with ovarian cancer.

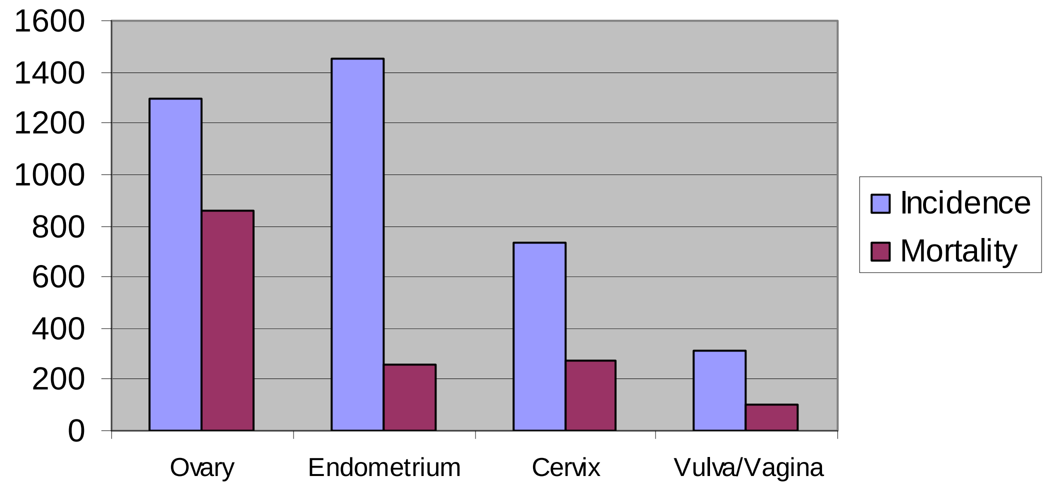
2 Background Information – Ovarian Cancer

This section presents key information on ovarian cancers, which is the primary focus of this submission.

2.1 Cancer Statistics

Gynaecological cancers account for the deaths of over 1400 women in Australia each year. Ovarian cancer is the most lethal of gynaecological cancers and accounts for over 57% of deaths due to gynaecological cancers, more than all other gynaecological cancers together (Fig 1).

Fig 1. Gynaecologic Cancers In Australia



Ovarian cancer is the fifth most common cause of cancer death in women in Australia (Table 1). Only breast, lung, colorectal, and pancreas cancers are responsible for more cancer deaths. It is far more prevalent than cervical cancer and more lethal. The risk of a woman developing the disease up to the age of 75 is 1 in 104.

Table 1. Most frequently occurring cancers in Australia (2001)

	New cases					Deaths				
Cancer site	**Number**	**% of all new cancer cases**	**ASR (A)**	**ASR (W)**	**Lifetime risk(c)**	**Number**	**% of all cancer deaths**	**ASR (A)**	**ASR (W)**	**PYLL(c)**
Breast	11,791	29.1	117.2	93.1	1 in 11	2,594	16.3	24.8	18.2	28,540
Colorectal	5,883	14.5	55.4	38.9	1 in 26	2,153	13.5	19.7	13.1	12,585
Melanoma	3,861	9.5	38.3	31.6	1 in 34	390	2.5	3.7	2.7	4,300
Lung	2,891	7.1	27.7	20.0	1 in 46	2,382	15.0	22.6	15.9	16,030
NHL	1,576	3.9	15.1	11.3	1 in 88	715	4.5	6.5	4.4	3,935
Unknown site	1,568	3.9	14.3	9.5	1 in 117	1,217	7.7	10.9	6.9	5,640
Uterus	1,537	3.8	15.1	11.7	1 in 77	299	1.9	2.8	2.0	2,225
Ovary	1,295	3.2	12.6	9.8	1 in 104	857	5.4	8.1	5.7	6,598
Kidney	944	2.3	9.1	6.8	1 in 142	386	2.4	3.6	2.4	1,923
Pancreas	900	2.2	8.2	5.5	1 in 207	865	5.4	7.8	5.1	3,908
All cancers	*40,578*	*100.0*	*393.3*	*300.3*	*1 in 4*	*15,902*	*100.0*	*147.8*	*102.2*	*117,545*

[Source: Cancer in Australia 2001, Australian Institute of Health and Welfare, 2004]

2.2 Risk factors

The causes of ovarian cancer are not well understood, however around 10% of cases are believed to involve a genetic predisposition that is also linked to increased risk of breast cancer (BRCA1 and BRCA2 gene mutations) and some forms of bowel cancer.

The oral contraceptive pill, as well as several full term pregnancies and breast feeding all seem to substantially lower the risk of ovarian cancer.

Increasing age, and possibly diet and lifestyle factors (high fat / dairy intake, smoking) increase the risk of developing ovarian cancer. The majority of cases of ovarian cancer occur in women over 45 – 50 years.

Therefore, information about lifestyle factors, familial risk and details about symptoms (see later) could provide women with the additional support they need to help reduce mortality of the disease.

2.3 Survival

The survival outlook is poor for most women diagnosed with ovarian cancer. At the time of diagnosis around 75% of patients have advanced disease, demonstrated through the spread of the cancer to other areas within the pelvis, abdomen and beyond. Diagnosis at this late stage of the disease drastically reduces the rate of survival. If diagnosis occurs when the cancer is still confined to the ovary, there is a far better chance of survival, with cure being possible in as many as 90% of patients.

Therefore, early diagnosis is believed to be a key factor in reducing mortality.

Radical surgery followed by cytotoxic chemotherapy is the standard treatment and offers many women a remission but often not a cure. Five year survivals for advanced ovarian cancer patients range between 15 – 50 % depending on degree of spread of the disease.

2.4 Diagnosis

There is no reliable early diagnostic test for ovarian cancer, and therefore no suitable approach for screening at this time.

Symptoms of ovarian cancer are vague and non-specific, associated with pelvic and abdominal disorders, as well as backache, fatigue etc. For this reason the majority of cases go undiagnosed for many months, resulting in more advanced disease and higher mortality.

Many women report undergoing multiple investigations for other conditions before a diagnosis of ovarian cancer is made. This is distressing and traumatic for the women involved and often generates anger and resentment at the lost opportunity to treat the disease at an earlier and potentially less lethal stage.

Sadly, many women with extensive disease report that during initial consultations with GPs and other specialists, no-one performed a simple physical internal gynaecological examination that may have revealed ovarian abnormalities.

Improving awareness and educating women and General Practitioners to raise the index of suspicion in cases of persistent pelvic / abdominal symptoms should better enable women with ovarian cancer to be diagnosed at an earlier stage of the disease and therefore obtain best practice treatment at the earliest opportunity, improving survival rates of the disease.

2.5 Referral

To improve patient outcomes, the treatment for ovarian cancer requires extensive, specialised surgery that should be performed by specialist Gynaecologic Oncology Surgeons. However, currently only about 50% of women diagnosed with ovarian cancer are treated by specialist Gynaecologic Oncologists and the outcomes for women with an inappropriate referral will more than likely be poorer than those referred to the right specialist.

Raising awareness and educating General Practitioners on symptoms, diagnoses and the treatment of ovarian cancers is critical to changing GP referral patterns of patients to specialist Gynaecologic Oncologists when ovarian cancer is suspected. This should enable diagnosis at earlier stages of the disease, thereby improving survival rates of the disease.

In addition, best practice for all cancer types dictates that treatment should be within a multi-disciplinary setting. However, these are not always accessible or available, especially in regional, rural and remote locations.

Appropriate referral pathways are identified in the *Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer 2004* and need to be disseminated further.

2.6 Support

Many women with ovarian cancer undergo extensive and invasive treatment, involving the removal of the uterus and ovaries. They often feel isolated, and support groups specifically for ovarian cancer (and other gynaecological cancers) are limited. The impact of the disease on these women can be extensive as it affects their sexuality, self-esteem and their psychological well-being.

Support groups for families, friends and carers of ovarian cancer patients are also limited. Ovarian cancer patients and their families require greater access to quality information about their disease, and broader psychosocial supportive care services (including peer-support groups, counselling etc).

2.7 Research

Opportunities to develop new tests for early diagnosis are urgently needed. A current Australian research study is examining whether specific biomarkers that are detectable in blood or urine may signal a developing ovarian cancer. This study is in an early stage of development.

Current tests such as imaging (ultrasound and CT) along with blood tests such as CA-125 are also being investigated for approaches to improve sensitivity and specificity, however early stage detection remains elusive.

Participation in clinical trails is a key strategy in the improvement of cancer treatments. However access to clinical trials is generally limited to metropolitan areas in Australia and the level of participation in trials is not high. Funding is required to address workforce constraints and to improve public awareness and participation in clinical trials.

2.8 Funding

Compared to other cancers, especially breast and cervix, gynaecological cancers receive substantially less funds for research (both clinical and basic scientific research) and for health promotion activities. For example, in the Commonwealth 2005-06 budget initiative “Strengthening Cancer Care” $189.4 million was allocated over five years to enable “the Australian Government deliver its election commitment to help reduce the burden of cancer.” Of this funding, $5 million was specifically allocated to breast cancer initiatives while other types of cancer did not receive any block grants. Organisations for other forms of cancer were only able to apply for seeding grants of up to $90,000.

Currently the largest scientific study in Australia is the Australian Ovarian Cancer Study which has been substantially funded by a grant from the US Department of Defense, although more state-based Cancer Council funding has been forthcoming recently.

Commonwealth Government support has supported the Ovarian Cancer Program at the National Breast Cancer Centre ($500,000 over three years). However, this is a very small amount in comparison to support of breast and cervical initiatives.

3 Responses to Inquiry Terms of Reference

3.1 Level of Commonwealth and other funding for research addressing gynaecological cancers

To the knowledge of the National Ovarian Cancer Network there are several significant Australian research organisations that are pursuing the development of effective test protocols for the early diagnosis and potential screening of women for ovarian cancers. The funding for these endeavours has been primarily from philanthropic sources and public donation. There is little evidence of significant funding for core research efforts by either Commonwealth or State Governments in Australia.

The largest research project for ovarian cancer in Australia is principally funded through the US Department of Defense. The fact that the Australian Ovarian Cancer Study was able to win a large overseas grant is testimony to the quality and capability of this Australian research team. However again this reflects poorly on Commonwealth priorities for funding of research into ovarian cancers.

Participation in clinical trails is a key strategy in the improvement of cancer treatments. However access to clinical trials is generally limited to metropolitan areas in Australia and the level of participation in trials is not high. Funding for cancer clinical trials is desperately needed within Australia to:

- to improve regional and rural participation in trials (through initiatives such as videoconferencing between local clinicians and cancer experts); and,
- address workforce constraints (limited number of clinical trial research nurses and technicians);
- to enable the establishment and operation of a greater number of clinical trials.

Furthermore, true integration of research, education and clinical services is needed to ensure all cancer patient outcomes are optimised. This can only be achieved through appropriate policy development and funding.

3.2 Extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer [Terms of Reference (b)]

The National Ovarian Cancer Network believes there is a clear need for additional funding and support to be provided to organisations that currently provide screening programs, treatment services and wider health support programs for women with gynaecological cancer, particularly ovarian cancers. It is possible that new organisations may also be required to address service or care gaps, however funding of existing organisations is insubstantial and must be increased to enable improved awareness and education of women and General Practitioners with the aim of improving the survival rate of ovarian cancer patients.

The Network has been able to provide a range of health support program through depending upon the goodwill of the community, philanthropic sources and recently upon a small Commonwealth grant. The programs provided and programs in development are explained in further detail below.

The National Ovarian Cancer Network expects to receive approximately $22,000 through the Patient Services Support Grant awarded by the Department of Health and Aging for the provision of patient support services over the past 12 months. This grant awarded as part of a new initiative during 2005 and is the only funding provided by the Department specifically for Ovarian Cancer support (the grant is worth a total of $90,000 over 4 years).

The grant has allowed the National Ovarian Cancer Network to develop and distribute a new information DVD for patients and families. The DVD was produced with the help of several clinicians and primary care professionals, and provides comprehensive details in an easily understood format for ovarian cancer patients.

The Network has designed and developed a prepaid post card to enable patients to contact the Network easily and receive additional information and support.

A third project that is currently underway is to develop information sheets for patients covering the following areas:

1. Ovarian Cancer – What is it?
2. Understanding Terminology
3. Chemotherapy – what to expect and tips for coping
4. Treatment for Ovarian Cancer
5. Good health and well being
6. Complementary Therapies
7. Support information

Through funding by public donation and commercial sponsorships, The National Ovarian Cancer Network has established peer support groups through their own facilities in Melbourne and is currently expanding this initiative through to Western Australia and Queensland. The Network provides the accommodation for patients to meet, along with a facilitator to provide a secure and welcoming environment for patients.

In addition the Network has opened its website to provide patient forums. This online resource enables patients and families to make contact with others, regardless of geographic location. The forum provides the opportunity to share information and has been the catalyst for many ongoing supportive friendships. This has been vital element in overcoming isolation for many patients.

3.3 Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions [Terms of Reference (c)]

Women with gynaecological cancers require adequate and speedy access to specialist medical and support services. Access to those within regional and remote areas is limited and in many cases not existent.

The treatments for ovarian cancers often require lengthy and repeated chemotherapy and radiotherapy sessions. For women in remote communities this requires extensive travel and time away from home and families which may not often be practical.

It has been common, for example, for women with ovarian cancer in the Northern Territory to have to travel to Adelaide for treatment and follow-up due to the lack of facilities and expertise in NT.

Women with gynaecological cancers are often isolated as cultural and social issues are a barrier to the discussion of cancer in general, gynaecological cancers and gynaecological issues in general. There are no support groups for women with Gynaecological Cancers in remote areas. The conventional models of support groups are unlikely to succeed in remote areas because of the tyranny of distance.

There is a desperate need for alternative support models, such as those using videoconferencing, the internet or telephone networks to provide women with access to clinical experts, specialist staff and their peers regardless of geographical location.

3.4 Extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers [Terms of Reference (d)]

The National Ovarian Cancer Network receives too many reports from women diagnosed with ovarian cancer, for whom the diagnostic process has been long and several incorrect diagnoses given, which effectively delays treatment and reduces survival rate for these women.

The symptoms of ovarian cancer are relatively non-specific and can be confused with general gastrointestinal and pelvic disorders.

Gynaecological (and especially ovarian) cancers symptoms are often not recognised by General Practitioners in the first instance. Delays in referral have a devastating effect on the patient's likelihood of survival and on their family.

To improve patient outcomes, the treatment for ovarian cancer requires extensive, specialised surgery that should be performed by specialist Gynaecologic Oncology Surgeons. However, currently only about 50% of women diagnosed with ovarian cancer are treated by specialist Gynaecologic Oncologists and the outcomes for women with an inappropriate referral will more than likely be poorer than those referred to the right specialist.

There is an urgent need to raise awareness and educate General Practitioners on symptoms, diagnoses and the treatment of ovarian cancers to improve chances of early diagnosis and referral of patients to ensure they are provided with access to the most appropriate treatments. There is a further need to ensure that the clinical management guidelines are disseminated and more information needs to be provided to General Practitioners.

Recent examples of targeting of General Practitioners is demonstrated in the activities of the Ovarian Cancer Program at the National breast Cancer Centre, which have attempted to address issues around diagnosis of non-specific pelvic disorders and the value of procedures such as the CA-125 test.

3.5 Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers [Terms of Reference (e)]

The success of the correct diagnosis and treatment of ovarian cancer is dependent on intervention at the earliest possible opportunity. Early stage disease, treated by a specialist team has proven to give the best outcomes for the patient.

There are a number of myths that are common community beliefs that can cause women to delay seeking medical advice:

- It is a common belief that the Pap test detects all gynaecological cancers and therefore protects against them. It is not unusual for a women diagnosed with ovarian cancer to comment that they are surprised as they only recently had a Pap test. Pap tests do not provide an indication of the presence of ovarian cancer.

- Gynaecological cancers are perceived as ‘rare’, and the substantial improvements in prevention of cervical cancer can create a false sense of security with respect to other gynaecological cancer sites.

- It is generally believed that ovarian cancer is a disease of older women. It is true that the incidence rises with age (as with many other cancers), but the risk of ovarian cancer starts to rise significantly from the age of 45. In addition there are still many much younger women who develop the disease, and in younger patients the disease can be much more aggressive.

The presentation of factual information to the broader community will hopefully result in better outcomes for women. Behaviours that can significantly alter the risk for ovarian cancer include:

- Taking the oral contraceptive pill
- Having several full term pregnancies
- Breast feeding their children

Dietary influences such as avoiding high fat diets and maintaining a good intake of green vegetables have also been identified as potentially beneficial in reducing risk.

Risk factors that need to be understood by women who may be at higher risk due to genetic predisposition include the importance of a family history of breast and ovarian cancers at an early age as well as some types of bowel cancers.

Where there is suspicion about a family history it is important that those women seek advice from familial cancer specialists.

Information to ensure women are reliably informed is vital and the sources of that information need to be credible and verifiable. Greater Commonwealth support in this area would assist the dissemination and reliability of such information.

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

[Terms of Reference (f)]

To our knowledge there is very little representation for Gynaecological Cancers within major agencies.

The single most, strongest representation is demonstrated through the Ovarian Cancer Program within the National Breast Cancer Centre. The National Ovarian Cancer Network is very keen to see extensions of the work at the National Breast Cancer Centre and further funding is clearly required to meet those needs.

Appendix A Terms of Reference

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

The Senate Community Affairs References Committee is undertaking an inquiry into Gynaecological Cancer in Australia. This inquiry will pursue issues raised in the Committee's response earlier this year to a petition on gynaecological health that had been presented to the Senate.

The Committee will particularly be inquiring into the:

(a) Level of Commonwealth and other funding for research addressing gynaecological cancers;

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

(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;

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

(e) Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and

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

The reporting date is 19 October 2006

Written submissions are invited and should be addressed to:

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

Closing date for the receipt of submissions is 16 June 2006.

The Committee prefers to receive submissions electronically as an attached document - email: community.affairs.sen@aph.gov.au

Submissions become Committee documents and are made public only after a decision by the Committee. Publication of submissions includes loading them onto the internet and their being available to other interested parties including the media. Persons making submissions must not release them without the approval of the Committee. Submissions are covered by parliamentary privilege but the unauthorised release of them is not protected.

Following consideration of submissions, the Committee will hold public hearings. The Committee will consider all submissions and may invite individuals and organisations to give evidence at the public hearings.

Information relating to Senate Committee inquiries, including notes to assist in the preparation of submissions for a Committee, can be located on the internet at http://www.aph.gov.au/senate/committee/wit_sub/index.htm

For further details contact the Committee Secretary, Phone: (02) 6277 3515, Fax: (02) 6277 5829.
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