Elton Humphery Committee Secretary Australian Senate Community Affairs References Committee Parliament House Canberra ACT 2600

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Dear Sir,

#### Response to petition on gynaecological health issues

Thank you for the opportunity to comment on the above petition. I have provided some details specific to the issue of ovarian cancer and the need for greater public and professional awareness, along with appropriate funding into research for early diagnosis.

#### **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).



Ovarian cancer is the 5<sup>th</sup> commonest cause of cancer death in women (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.

	New cases					Deaths				
		% of all								
		new					% of all			
		cancer	ASR	ASR	Lifetime		cancer	ASR	ASR	
Cancer site	Number	cases	(A)	(W)	risk(c)	Number	deaths	(A)	(W)	PYLL <sub>(c)</sub>
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

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

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

#### **Risk factors**

The causes of ovarian cancer are not well understood, but 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.

## Survival

Survival outlook is poor for most women diagnosed with ovarian cancer. Around 75% of cases are advanced disease at the time of diagnosis, with spread of the cancer to other areas within the pelvis, abdomen and beyond. Radical surgery followed by cytotoxic chemotherapy is the standard treatment and offers many women a remission but often not a cure. 5 year survivals for advanced ovarian cancer patients range between 15 - 50% depending on degree of spread of the disease.

Diagnosis when the cancer is still confined to the ovary usually results in a much better outlook, with cure being possible in as many as 90% of patients.

Early diagnosis is believed to be a key factor in reducing mortality.

# 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 many 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 would have revealed ovarian abnormalities.

Education of women and General Practitioners to raise the index of suspicion in cases of persistent pelvic / abdominal symptoms should enable women with ovarian cancer to obtain treatment at the earliest opportunity.

## Referral

Currently only about 50% of women diagnosed with ovarian cancer are treated by specialist Gynaecologic Oncologists. As the treatment requires extensive, specialised surgery, the outcomes for many women will be poorer if not referred appropriately.

In addition, best practice dictates that women should be treated within a multidisciplinary setting. However, these are not always accessible, especially for women in rural or 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.

## 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 (and other gynaecological cancers) are limited. The impact of the disease on these women can be extensive, and affects their sexuality, self-esteem and their psychological well-being. Ovarian cancer patients and their families require greater access to quality information about their disease, and broader support services (including peer-support groups, counselling etc).

## Research

Opportunities to develop new tests for early diagnosis are sought, with current research seeking biomarkers detectable in blood or urine that may signal a developing ovarian cancer. 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, but early stage detection remains elusive.

Participation in clinical trails is a key strategy in the improvement of cancer treatments. Access to multinational clinical trials is crucial for delivering best practice treatment to Australian women.

## Funding

Compared to other cancers, especially breast and cervix, gynaecological cancers receive substantially less funds for research (both clinical and basic scientific research).

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.

#### Conclusion

Gynaecological cancer in Australia lags behind many other areas of cancer in terms of funding for research, treatment, prevention and support.

Greater emphasis needs to be placed on education and awareness of risk factors, prevention, symptoms and treatment options.

I hope the above provides the Committee with the information that it is seeking. I am happy to provide more information or discuss these issues further.

Yours faithfully,