The Senate

Community Affairs References Committee

Response to the petition on gynaecological health issues

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Senator Penny Wong	ALP, South Australia

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RESPONSE TO THE PETITION ON GYNAECOLOGICAL HEALTH ISSUES

The petition is referred

1.1 On 7 December 2005 the Senate, on a motion of Senator Allison also on behalf of eight cross-party Senators, referred a petition tabled on 6 December from 2 887 signatories relating to the management and prevention of gynaecological cancers and Sexually Transmitted Infections (STIs) to the Committee for response to the Senate by 30 March 2006.

1.2 The issues raised in the petition, a copy of which is at Appendix 1, include:

(a) immediate increase in research funding for the development of a screening test for ovarian cancer;

(b) increased funding for the needs of women with gynaecological cancers in the Indigenous population and other cultural backgrounds;

(c) increased research funding to increase awareness and prevention of all gynaecological cancers to the same level of cervical cancer;

(d) increased education of gynaecological cancer symptoms with GPs and primary care workers to ensure timely diagnosis and treatment;

(e) recognise the need for, and fund accordingly, psychosocial and psychosexual care for patients and families affected by gynaecological cancers; and

(f) increased funding for research and prevention of STIs and their links with gynaecological cancers and infertility, especially human papilloma virus vaccine funding and Chlamydia prevention.

Conduct of investigating the petition

1.3 The petition was not referred for a formal enquiry, rather the Committee sought to ascertain information on the issues raised in the petition to formulate a response to the Senate. The Committee wrote to interested individuals and groups inviting a response to the issues raised in the petition. The Committee received seven written responses addressing gynaecological health issues. A list of the individuals and organisations that provided a response is at Appendix 2.

1.4 The Committee convened a Roundtable discussion on Friday 3 March 2005 in Canberra. In organising participants for this discussion, the Committee endeavoured to include participants who represented major organisations as well as those who represent or support individuals with gynaecological health issues. A short discussion paper based on the information provided in the written responses was prepared as an 'agenda' for the participants at the Roundtable. A list of the participants of the Roundtable discussion is in Appendix 2.

1.5 The Roundtable discussion was valuable and provided a unique opportunity for the Committee and participants to discuss issues in an informal and flexible manner.

Gynaecological Health Issues

1.6 The Committee, through its investigations, gained valuable information and insight into the issues detailed in the petition.

Immediate increase in research funding for the development of a screening test for ovarian cancer

1.7 The non-specific nature of symptoms of ovarian cancer makes it extremely difficult to detect the disease in its early stages. Approximately 70 per cent of women who initially present with ovarian cancer are in an advanced stage.[1] Given the advanced stage at diagnosis, the survival rate for ovarian cancer is poor with a 40 per cent 5 year survival compared with 80 per cent 5 year survival for breast cancer.[2] Screening can result in the detection of ovarian cancer in its earlier stage when treatment is more likely to be successful and a complete cure is a possibility.

1.8 A recent story on ovarian cancer, titled *Lifesaver* aired on the 60 Minutes television program on 12 March 2006. This story commented:

> Ovarian cancer takes lives. It kills one woman every 11 hours. Of those diagnosed with this horrible disease, 85 percent will die. The death rate is so high because most women don't know they have it until it's too late…What makes this so cruel is if caught early enough, women have a 90 percent chance of surviving ovarian cancer. The problem is, the symptoms are so vague, most sufferers aren't diagnosed until it is too late. They're simply not given a chance.[3]

1.9 Professor Neville Hacker informed the Committee that research breakthroughs via the human genome project will assist in the development of an ovarian cancer screening test. By looking at individual genes in the human genome, approximately 350 abnormal genes, out of a potential 40,000 genes, have been identified in patients with ovarian cancer. Professor Hacker stated:

> It should be possible, with a concentrated effort, to find a test for this disease. It may not be a single test, because there are several different types of epithelial ovarian cancer, but the commonest is the so-called serous type of cancer, and we are concentrating our efforts on looking at those serous cancers. So, unlike the situation five years ago, where this was like looking

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[1] *Response 2*, p.1 (Gynaecological Cancer Centre).

[2] *Response 2*, p.1 (Gynaecological Cancer Centre).

[3] http://sixtyminutes.ninemsn.com.au/sixtyminutes/stories/2006_03_12/story_1596.asp [accessed: 16.03.06]

> for a needle in a haystack, we now have the wherewithal to come up with a test, but obviously it takes a lot of time, effort and money.[4]

1.10 The Gynaecological Cancer Society provided the following statement:

> We need, if we can, an ovarian cancer-screening test because it kills a lot of people. It is very expensive, and we can do it. There is the talent in this country to develop that test. It is going to cost some money and it is going to take some time, but it just simply needs to be done. The emotional cost to patients and their families is incredibly high, and the outcomes are awful. It is something we need to do.[5]

1.11 The Department advised that over the period 2000 to 2005, the Commonwealth has provided $15.1 million for research into ovarian cancer. A further $5 million is expected to be expended in 2006 for ovarian cancer research.

Increased funding for the needs of women with gynaecological cancers in the Indigenous population and other cultural backgrounds

1.12 Cervical cancer is the leading cause of death from cancers among Aboriginal and Torres Strait Islander women. The incidence of cervical cancer among Indigenous women in Queensland is eight times the national average.[6]

1.13 Concern was expressed on the appropriateness of mainstream print based education material for the Indigenous population and women from other cultural backgrounds. Other issues raised include access to health services, language barriers, access to interpreter services and the impact of certain cultural beliefs and moral values on communication, education, awareness and participation in prevention programs.

1.14 The issues for women from other cultural backgrounds were highlighted during the Roundtable discussion by Ms Rosalind Robertson, a senior psychologist at the Royal Hospital for Women, who read an excerpt from an article titled 'Cervical Cancer Educational Pamphlets: Do They Miss the Mark for Mexican Immigrant Women's Needs?

> The interviewer says:
>
> Can you tell me why they do a Pap?
>
> The participant says:
>
> Well, I want them to check me because I'm scared of having cancer.
>
> The interviewer asks:
>
> What type of cancer are they looking for?

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[4] *Committee Hansard* 03.03.06, p.3 (Gynaecological Cancer Centre).

[5] *Committee Hansard* 03.03.06, p.7 (Gynaecological Cancer Society).

[6] *Response 2*, p.1 (Professor Hacker).

> The participant replies:
>
> Well, I think, cancer anywhere—wherever it's 'born'. It could be in the uterus, or like one of my husband's relatives that died of pancreatic cancer.[7]

1.15 The article concludes that the contents of cervical cancer educational pamphlets do not meet the needs of local Mexican immigrant women. Ms Robertson provided additional comment that 'there are cultural sensitivities and there is a lack of understanding about anatomy, and I think probably a lower socioeconomic group brings in a lower literacy level'.[8]

1.16 Discussion on the use and availability of interpreter services identified limited knowledge of the services offered by different organisations providing either a National or State-based service. Ms Margaret Heffernan suggested:

> Perhaps there is an opportunity here to do an audit on the current government funded resources like that, particularly for remote and regional centres. We are simply not disseminating the information out to those communities.[9]

Increased research funding to increase awareness and prevention of all gynaecological cancers to the same level of cervical cancer

1.17 Raising the awareness of gynaecological health issues is essential for women to be able to recognise the early signs of health issues and feel confident to visit their GPs to seek information, diagnoses and appropriate treatment. Gynaecological health is often not discussed, even by women who are close friends, due to the embarrassment, levels of ignorance or feelings of awkwardness. Words such as vagina, vulva, uterus and clitoris are not spoken about which leaves women with serious gynaecological health issues feeling isolated and alone.

1.18 A personal account of the experience a young mother who has Stage 4 vaginal cancer highlights the need for open and confident discussion on gynaecological health issues:

> I want more women to come forward with their opinions and to take a stand against the general consensus that we cannot or should not discuss our sexual health or genitalia with the same acceptance that men can and do.[10]

1.19 The Gynaecological Awareness Information Network (GAIN) is a community-based organisation of dedicated women who have endured the trauma of

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[7] Hunter JL. 'Cervical Cancer Educational Pamphlets: Do They Miss the Mark for Mexican Immigrant Women's Needs? *Cancer Control – Cancer, Culture and Literacy Supplement.* November 2005:42-50.

[8] *Committee Hansard* 03.03.06, p.16 (Ms Robertson).

[9] *Committee Hansard* 03.03.06, p.17 (Ms Heffernan).

[10] Second Reading Speech 30.11.05 (Senator Allison).

being diagnosed and treated for gynaecological conditions. GAIN aims to foster community awareness of women's gynaecological issues and provide information to empower individuals to develop responsibility towards gynaecological health. GAIN has initiated many unfunded activities raising the awareness of gynaecological health issues. Ms Kath Mazzella, founder of GAIN, provided the following examples of the initiatives:

> GAIN is having a Vulva Awareness Day on 1 April to coincide with the one held by women in America and England who have had vulval cancer or the same vulval issues. By doing this I think we can help the next lot of women who come through, so that the stigma is not there as much.[11]
>
> GAIN has established a National Gynaecological Awareness Day, and we are working towards an international gynae day as well. This a fantastic way to bring all these issues together—and the women's voices—and then we can perhaps deal with them. We can encourage Aboriginal women's groups to celebrate in the way they want to celebrate, but they also learn on the same day. I thought I would comment on that to perhaps try to see how we can get some funding to back the day so that we can educate the public.[12]

1.20 Regarding the funding for cervical cancer, the Commonwealth extended the existing Cervical Screening Incentives for General Practitioners initiative with continued funding of $31.6 million in 2005-06. This initiative provides incentive payments to encourage GPs to adopt a systematic approach to regularly screen all women patients between the ages of 20 and 69 years and in particular women at high risk, such as those in rural and remote areas, Indigenous women and women from culturally and linguistically diverse backgrounds.[13]

1.21 In 2001, the Commonwealth funded the establishment of the Ovarian Cancer Program to improve the health outcomes for women with ovarian cancer. The many initiatives under this Program are managed by the National Breast Cancer Centre (NBCC) and the publication *Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer* was released in 2004 and has been widely distributed.

1.22 Professor Hacker commented on the clinical guidelines for ovarian cancer:

> We tackled ovarian cancer because that was what the program was set up to do. There is no reason why the other cancers endometrial cancer, vulval cancer and cervical cancer could not be tackled in a similar way.[14]

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[11] *Committee Hansard* 03.03.06 p,32 (GAIN).

[12] *Committee Hansard* 03.03.06 p,29 (GAIN).

[13] http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm [accessed 16.03.06]

[14] *Committee Hansard* 03.03.06, p.19 (Professor Hacker).

1.23 The National Ovarian Cancer Network and Professor Hacker acknowledged the initiatives under the Ovarian Cancer Program but reiterated the disparity of funding allocations and the need for funding for all gynaecological cancers:

> Although the National Breast Cancer Centre develops various resources on ovarian cancer, compared to other cancers, especially breast and cervix, gynaecological cancers receive substantially less funds for research (both clinical and basic scientific research).[15]
>
> This has been good to the extent that we have had at least an awareness of ovarian cancer, but in fact all of the gynaecological cancers are very distressing for women. The psychosexual consequences, the fertility consequences, the menopausal consequences - all of these things are much more distressing than getting bowel cancer or pancreatic cancer, so I think that we really do need a gynaecological cancer centre to address all of these issues, in the same way that this has been able to quite effectively address ovarian cancer.[16]

Increase education of gynaecological cancer symptoms with GPs and primary care workers to ensure timely diagnosis and treatment

1.24 The referral pathway for women after detection of gynaecological cancer symptoms primarily begins with the GP. A GP must be able to recognise the symptoms of gynaecological cancers and refer the patient to the appropriate facilities and specialist practitioners. The National Ovarian Cancer Network states that only 50 per cent of women diagnosed with ovarian cancer are treated by gynaecological oncologists.[17] This evidence indicates that the referral pathway is ineffective in meeting the needs of women with gynaecological cancer.

1.25 GPs have the ability to access different forms of educational resources to learn more about gynaecological health and cancers. Some of these include posters, step-by-step checklists, Continuing Medical Education (CME) courses and various Internet based programs. Although these avenues to learning more about gynaecological cancers exist, evidence suggests that the overall level of GP's awareness and knowledge on these issues remains limited.

1.26 The Gynaecological Cancer Society stated:

> We need to train and retrain our GPs. They see gynaecological cancer so rarely that they can be excused for missing it, and they do. The ones who need the retraining are the ones who do not come to CME courses. The ones who do come probably do not need it. So, again, that is fairly simple: make it mandatory.[18]

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[15] *Response 4*, p.1 (National Ovarian Cancer Network).

[16] *Committee Hansard* 03.03.06, p.31 (Professor Hacker).

[17] *Committee Hansard* 03.03.06, p.25 (National Ovarian Cancer Network).

[18] *Committee Hansard* 03.03.06, p.24 (Gynaecological Cancer Society).

1.27 Ms Heffernan, when speaking about GP education, suggested:

> With respect to education and awareness, we have put the spotlight on GPs. I would love to see some legislation brought in where, as part of their annual professional development, some of their points have to be in a reproductive cancer, whether it is gynaecological or prostate, because we are developing the resources but the message we are hearing from all over is that they are not sufficiently aware of it.[19]
>
> …the recent material developed out of the National Breast Cancer Centre on ovarian cancer, they have done a very simplified poster checklist for GPs. It is about seven steps – 'If a woman presents with this, do this, then do that, then do that, then do that.' You could almost put it on the back of the toilet door. It is a fantastic resource. I would like to know how many GPs have read that, taken note of it and apply it. That is just for ovarian cancer. I think there is scope for development of a similar resource for the whole range of gynaecological cancers on a very easy, step by step checklist.[20]

Recognise the need for, and fund accordingly, psychosocial and psychosexual care for patients and families affected by gynaecological cancers

1.28 The diagnosis of gynaecological cancer is a very psychologically distressing experience for women. Treatment will likely affect a woman's sexuality, body image and/or reproductive capability. The psychosocial needs are significant, often long term and unfortunately frequently go undetected and unmet.

1.29 The *Clinical practice guidelines for the psychosocial care of adults with cancer* indicate that:

> Up to 66% of people with cancer experience long term psychological distress: up to 30% experience clinically significant anxiety problems and prevalence rates for depression range from 20%-35%. Many people report inadequate information to guide decision-making, and others are disadvantaged because of a lack of knowledge about practical support, even when such services are available.[21]

1.30 The National Health and Medical Research Centre (NHMRC) have developed clinical practice guidelines to assist health professionals who treat cancer patients with psychosocial care needs. The Guidelines have proved helpful and are aimed particularly at GPs, cancer specialists such as radiation and medical oncologists, surgeons, nurses, social workers, psychologists, psychiatrists, physiotherapists and occupational therapists.

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[19] *Committee Hansard* 03.03.06, p.44 (Ms Heffernan).

[20] *Committee Hansard* 03.03.06, p.28 (Ms Heffernan).

[21] http://www.nhmrc.gov.au/publications/_files/cp90.pdf p.12 [Accessed: 16.03.06]

1.31 Often women's psychosocial needs are met by services provided by self-help and support groups. The ability of women to access psychosocial services while receiving treatment in private hospitals is very limited and for women who live in remote areas psychosocial services are practically non-existent. The Gynaecological Cancer Society stated:

> The fact is that 50 per cent of women who are treated for gynaecological cancer are treated in private hospitals so, whilst it is true to say that most of the large public treatment centres have social workers and access to clinical psychologists and psychiatrists, that is not so in the private sector. You are looking at fully 50 per cent of the women who are treated for gynaecological cancer not having direct access to social workers or psychs. We really need to address that.[22]

1.32 Margaret Heffernan suggested an alternative to on-site practitioners:

> It is not practical at the moment to place a specialist counsellor in every centre or hospital, regional or rural, because there is simply not the trained number of people and a lot of them do not like to work out in the bush. However, we can set up information help lines like this as the first port of call, and then the person taking the call can either refer them on or manage it there. But again this requires funding for the dissemination of the information and for the knowledge that that service exists as the first point.[23]

Increased funding for research and prevention of STIs and their links with gynaecological cancers and infertility, especially human papilloma virus vaccine funding and Chlamydia prevention

1.33 STIs can be linked to acute illness, infertility, long term disability and death leading to severe medical and psychological consequences. It is now known that cervical cancer is caused by persistent infection with human papilloma virus (HPV). Two HPV vaccines, that specifically target HPV16 and 18 which are responsible for 70 per cent of cervical cancers, are being developed and are in the investigational phase.

1.34 The HPV vaccine, when approved for release, will be beneficial in the prevention of cervical cancer in Indigenous and multi-cultural communities where women are very resistant to Pap smear screening[24]. The availability of the vaccine in Australia will raise issues of affordability, potential for Commonwealth subsidies, and access pathways including the National Immunisation Program and education and awareness programs.

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[22] *Committee Hansard* 03.03.06, p.36 (Gynaecological Cancer Society).

[23] *Committee Hansard* 03.03.06, p.39 (Ms Heffernan).

[24] *Committee Hansard* 03.03.06, p.10 (Ms Heffernan).

1.35 Chlamydia is the most common treatable bacterial STI and can cause serious health problems such as ectopic pregnancy, infertility and pelvic disorders, if untreated.[25] In 2005, the Commonwealth provided $12.5 million over four years for increased awareness, improved surveillance and a pilot testing program for Chlamydia.

1.36 Ms Heffernan commented on current sex education programs:

> There is a need to look at our current education processes and programs that we are delivering and also to do an audit amongst secondary schools around Australia to find out how many of the students themselves are using barrier protection. We need to know how effective the educations staff think their programs are and whether we need to be changing the message.[26]

Conclusion

1.37 Gynaecological health issues not only affect the woman diagnosed but also have major implications for her family, her spouse, her community and society as a whole. The cost of medical treatment and the residual affect of psychosocial and psychosexual issues are immense. This petition has highlighted a number of issues surrounding gynaecological health that require further consideration and investigation. The Committee is hopeful that with further investigation into existing medical advances and resources and programs in operation, a coordinated effort towards prevention, effective diagnosis, treatment and education can be achieved for gynaecological health issues.

Recommendation

1.38 The Committee has considered the matter and recommends that consideration be given to the Senate conducting a full enquiry into the gynaecological health issues facing women as raised in the petition and explored at the Roundtable.

Senator Claire Moore
Chair

March 2006

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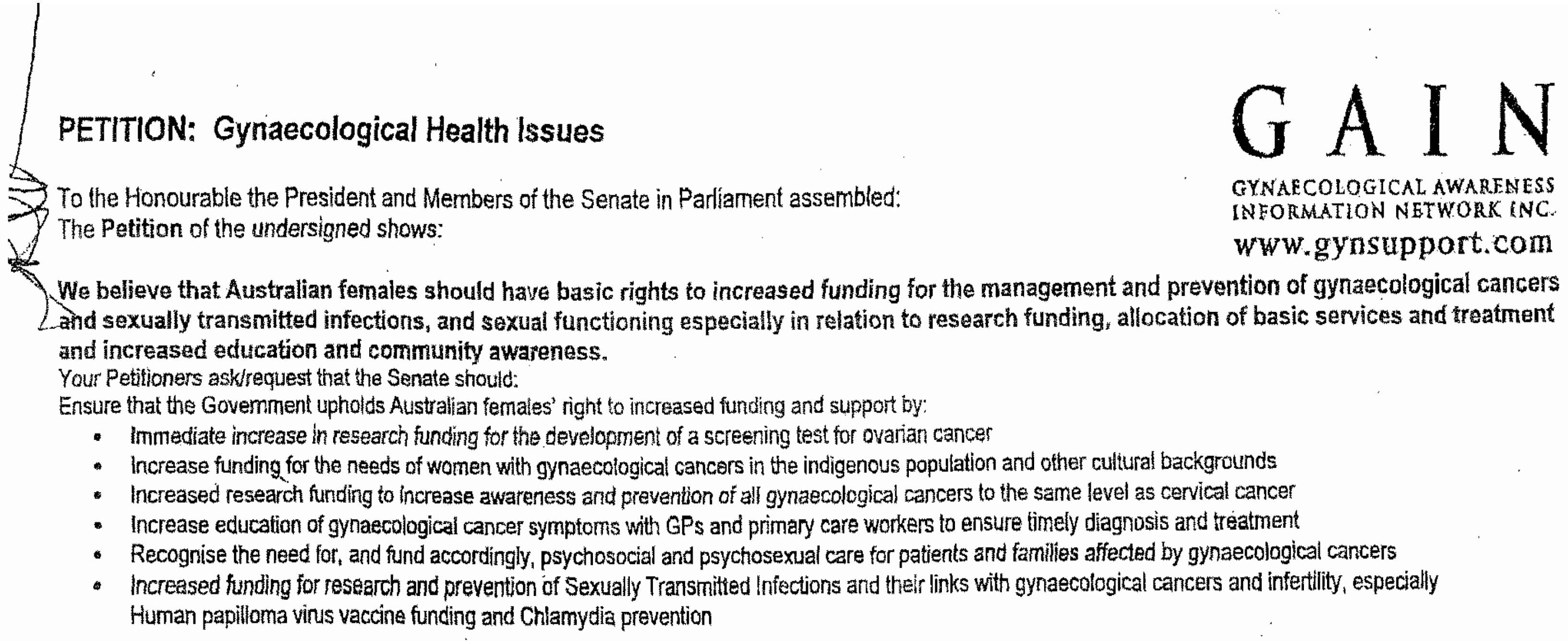
[25] Response3, p.12 & p.4 (Ms Heffernan).

[26] *Committee Hansard* 03.03.06, p.41 (Ms Heffernan)

APPENDIX 1

PETITION



GAIN
GYNAECOLOGICAL AWARENESS
INFORMATION NETWORK INC.
www.gynsupport.com

PETITION: *Gynaecological Health Issues*

To the Honourable the President and Members of the Senate in Parliament assembled:
The **Petition** of the *undersigned* shows:

We believe that Australian females should have basic *rights to increased funding* for the management and prevention of gynaecological cancers and sexually transmitted infections, and sexual functioning especially in relation to research funding, allocation of basic services and treatment and increased education and community awareness.

Your Petitioners ask/request that the Senate should:
Ensure that the Government upholds Australian females' right to increased funding and support by:

- Immediate *increase in research funding* for the development of a screening test for ovarian cancer
- Increase funding for the needs of women with gynaecological cancers in the indigenous population and other cultural backgrounds
- Increased research funding to increase awareness *and prevention of all gynaecological* cancers to the same level as cervical cancer
- Increase education of gynaecological cancer symptoms with GPs and primary care workers to ensure timely diagnosis and treatment
- Recognise the need for, and fund accordingly, psychosocial and psychosexual care for *patients and families affected* by gynaecological cancers
- *Increased funding* for research and prevention of Sexually Transmitted Infections and their links with gynaecological cancers and infertility, especially Human papilloma virus vaccine funding and Chlamydia prevention

APPENDIX 2

RESPONSES AND ROUNDTABLE

List of information received in response to petition

1 Robertson, Ms Rosalind (NSW)

Supplementary information

- Article *Cervical Cancer Educational Pamphlets: Do they Miss the Mark for Mexican Immigrant Women's Needs?*, by J L Hunter, Cancer Control 2005 provided at Roundtable 3.3.06

2 Hacker, Professor Neville (NSW)

3 Heffernan, Ms Margaret (VIC)

Supplementary information

- Statistics on cancer mortality by remoteness category provided at Roundtable 3.3.06

4 National Ovarian Cancer Network (OvCa Australia) (VIC)

5 Department of Health and Ageing (ACT)

6 Quinn, Professor Michael (VIC)

7 Gynaecological Cancer Society (QLD)

Information provided following the Roundtable

- **Ms Kath Mazzella** – DVD on information about GAIN Inc and *2005 State of the State of Gynecologic Cancers Third Annual Report to the Women of America* by Gynecologic Cancer Foundation
- **Ms Margaret Heffernan –** Additional information received 13.3.06
- **Department of Health and Ageing** – Additional information received 21.3.06
- **Gynaecological Cancer Society –** Supporting Partners Programme information pack received 24.3.06

Roundtable

Friday, 3 March 2006
Parliament House, Canberra

Committee Members in attendance

Senator Moore
Senator Adams
Senator Allison
Senator Ferris
Senator Humphries
Senator Polley
Senator Webber

Participants

National Ovarian Cancer Network (OvCa Australia)

Mr Simon Lee, Chair and Director

Gynaecological Cancer Society

Mr John Gower, Chief Executive Officer

Royal Hospital for Women

Professor Neville Hacker, Director, Gynaecological Cancer Centre

Ms Rosalind Robertson, Senior Psychologist, Gynaecological Cancer Centre

Ms Margaret Heffernan

Gynaecological Awareness Information Network (GAIN)

Ms Kath Mazzella, Founder

Australian Institute of Health and Welfare

Mr John Harding, Head, Health Registers and Cancer Monitoring Unit

Department of Health and Ageing

Ms Linda Powell, Assistant Secretary, Chronic Disease and Palliative Care Branch

Mr Ian Kemp, Director, Cancer Section