SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY INTO GYNAECOLOGICAL HEALTH IN AUSTRALIA

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

REPORT SUBMISSION
16TH JUNE 2006

Executive Summary:

GAIN Inc is an independent, not for profit community organisation established to generate awareness and disseminate information of the myriad of gynaecological conditions that affect women in community every day. We are a consumer's group and work with the health and medical fraternity, women's organisations (health and non health), government and general public. Our main aim is to move gynaecological health up the agenda and to empower women to take more control of their gynaecological health. More than any other organisation, GAIN understands the impact on women, their partners, childrens and families, as to the devastating effects of debilitating gynaecological conditions – we work with women who have suffered a condition (both pre and post diagnosis) and their families. We provide support by way of putting people in contact with others who have experienced similar conditions and act as a conduit to other support organisations (such as the Cancer Council, Endometriosis Support and Infertility support).

GAIN is a volunteer organisation based in Perth, Western Australia, established by one women who endured the trauma of vulval cancer and felt the effects of the lack of information and resources available to her. GAIN attempts to deal with the ripple effect of gynaecological conditions and the psychosocial effects on our community – these two issues are often overlooked in the diagnosis, treatment and research of gynaecological conditions.

The original petition to the Senate that preceded this Inquiry was organised and authored by Victoria's Margaret Heffernan and Alexa Rosengarten. The petition was organised in conjunction with GAIN's *National Gynaecological Awareness Day* 2005. GAIN is especially pleased to see the results of this petition and thanks the Community Affairs Committee for initiating this inquiry. GAIN also thanks Margaret Heffernan and Alexa Rosengarten for their work and effort in implementing and following through the petition.

GAIN notes that the original petition focused on gynaecological '*health*' and the Senate Community Affairs Reference Committee's Inquiry also uses this term however, the Terms of Reference have been developed with the narrower focus of gynaecological *cancer*. Given the number of women (and their families) affected by a range of gynaecological health issues including endometriosis, polycystic ovaries syndrome and vulval vestibulitis, it is felt that the Inquiry would benefit a larger percentage of the community if the Inquiry were expanded to reflect the wider spectrum of gynaecological health issues.

This submission has been collated from GAIN committee and general members comments. We have also received support from:

- WEL (Women's Electoral Lobby) WA (see Appendix 'A')
- BPW Business and Professional Women WA (see Appendix 'B')
- Australian Federation of University Women WA Inc. – (see Appendix 'C')

The submission has also been endorsed by:

- Ms Noeline Hartley OAM, health educator , Western Australia
- Ms Hope Alexander, Masters / Public Health candidate (Edith Cowan University).

> *"I know that it (HPV) is very common condition, it is still stereotypically made to be a 'bad' condition, as it's of course it has to be, treated as a sexually transmitted disease. So you are judged as being promiscuous"* – Email to GAIN

ABBREVIATIONS:

HPV	Human Papilloma Virus
NGO	Non Government Organisation
NFP	Not for Profit
GP	General Practitioners
CIN	Cervical intra-epithelial neoplasia

Response to Specific Questions:

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

GAIN (and we suspect the general public) is largely unaware of the level of federal government funding available for research addressing gynaecological cancers. Indeed, this information is difficult to source. Given the lack of publicly available research findings (particularly those cancers other than cervical), this would lead us to believe that either:

a) The level of funding is not adequate
b) Research findings are not readily accessible

GAIN has often had problems sourcing up to date and verifiable research data. GAIN also believes that while mortality and incident rates of gynaecological cancers are recorded, the pre cancerous condition of HPV (and CIN 1, 2 and 3) is not recorded in the same way. We believe this is a big issue in Australia, as the pre-cancerous and cancer incident rates are not truly reflective.

There are two significant current issues that needs funding consideration:

1. The new HPV vaccine (as developed by Professor Ian Frazer, Australian of the Year) that prevents the receipt of the virus, which leads to cervical cancer. While the medical research has been completed, there is an urgent need to get government approvals for this vaccine through and the vaccine on the market. In addition, funds need to be provided for vaccination of every primary aged schoolgirl as part of a school implemented program (similar to the Rubella inoculations program). GAIN understands the initial and on-going cost of this will be enormous however, the future savings in health care, lives and emotional trauma will far outweigh the program cost. The vaccine has the potential to eradicate cervical cancer and steps must be taken now, to fund its implementation.

2. The need to find a suitable screening program for ovarian cancer – currently this is a major problem for Australian women, as it is largely undiagnosed until it is too late. An adequate and reliable screening tool has yet to be found and while awareness campaigns have been implemented widely in Australia, as the symptoms are so close to more common and less problematic heath problems (such as bloating and abdominal pain) many women still go undiagnosed until it is too late. Most ovarian cancer cases end in mortality, with 85% of women with ovarian cancer dead within five years[1]. A trial for a new screening program is being conducted by the Ovarian Cancer Institute and urgently needs funding.

Overriding both of these issues, is the need for funding of awareness campaigns. It is one thing to conduct the research however, if the public is not aware of the conditions and consequences, the research results fall on deaf ears. Financing most awareness campaigns becomes the responsibility of NGOs (like OvCa and Cancer Council) and small NFPs such as GAIN. The federal government needs to either adequately

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[1] Source: OvCa website: http://www.ovca.com.au/

resource these organisation to carry out their campaigns and activities and / or, embark on a full-scale public awareness campaign on issues such as HPV and Ovarian cancer.

"Most women don't even know why they go for pap smears" – GAIN Member (via email)

Many women are unaware that pap screening only detects cervical cancer – it does not detect vulval, uterine and ovarian cancers. As such, many women have their routine pap smears every 2 years assuming that is all they need to do. We need a comprehensive, government initiated and supported gynaecological health awareness campaign. This campaign should be delivered through schools, universities, TAFE colleges, workplaces, multicultural and indigenous networks, women networks and through the mass media. In addition, doctors and medical practitioners must also be educated to check for other signs of ovarian cancer when patients present with 'everyday' symptoms such as bloating, pelvic or abdominal pain and gastrointestinal conditions. This education should be a key outcome / KPI to de delivered via federal government funding through the Divisions of GPs.

"More focus needs to be put onto ruling cancer out before anything else. Too many women are mis-diagnosed with a gynaecological complaint and brushed aside and by the time cancer diagnosed it is too late" – GAIN Member (via email).

Awareness of HPV is of critical importance. Most women have no idea what HPV is and are oblivious to the fact that it can lead to cervical and vulval cancer. Research undertaken by GlaxoSmithKline in 2005 showed that while the majority of Australian women are aware of Cervical Cancer (98%), almost two thirds (60%) have never heard of HPV. Further, over 75% of Australian women are unaware of the link between HPV and cervical cancer. This is a extremely worrying, given that HPV is sexually transmitted and that over 70% of Australian women are likely to be infected with HPV at least once in their lives[2].

"I think the biggest issue for me was the lack of education. They don't know that HPV causes cervical cancer or that most sexually active people are likely to have been exposed to the virus. I have a friend that had some early stage cervical cancer removed with laser treatment and she had no idea that HPV was the culprit" - GAIN Member (via email).

Often, when detected via pap screening, HPV is called "the warts virus" by doctors and gynaecologists. Many women would have no idea that the "warts virus" is actually HPV and can lead to vulval and cervical cancer. This is totally wrong and needs to be addressed within the medical fraternity. Education of doctor / patient communication should be delivered through the (already well funded) Divisions of GPs, as a key outcome in the lead up to the roll out of the HPV vaccine.

A coordinated approach is required:

There are too many disparate medical, research, consumer, NGO and pharmaceutical companies and organisations all working on HPV in some way and there is a great lack of a co-ordinated approach. GAIN Inc has been encouraging a coordinated approach within Western Australia and is working with the Cancer Council WA on a HPV Network, which has brought together a number of stakeholder groups to look at generating HPV awareness in the lead up to the release of the vaccine. It is critical that all states implement and similar approach, as well as on a national basis. The federal government, together with the states, could lead this type of approach.

A concern with this Term of Reference is its narrow focus and the implication that gynaecological cancers are the primary gynaecological health issue facing women today. The word 'cancer' is emotionally charged and engenders fear in the public (and rightly so), however the Inquiry should be mindful that there are many non-cancerous gynaecological conditions/issues that warrant research and that these should not be viewed as less important simply because they aren't life-threatening. Many gynaecological health issues have been identified as potential precursors to gynaecological cancers and/or infertility and, in the spirit of preventative medicine, warrant further research. It is only by undertaking a full analysis, acknowledging the interdependencies between certain issues/conditions and cancer, that a comprehensive research program can be established – one that has justified its priorities and is able to publicly reveal these in a transparent and accountable manner.

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[2] Source: Market research conducted by GlaxoSmithKline Australia, in 2005

Once the *range* of gynaecological health conditions/issues have been scoped, it is possible to then investigate the *level* to which each of these (cancer being one) requires research funding.

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

GAIN believes that it is important that appropriate key performance indicators be established to determine the efficiency, effectiveness and adequacy of the current programs and services in order to assess the success of current funding bids and determine whether a given program or initiative's outcomes have been attained. These indicators should be published and made readily available for public scrutiny.

This Term of Reference should direct the Inquiry to look at whether the screening programs and treatment services available are meeting their objectives and if not, whether this is simply due to a lack of resources (financial or otherwise) or some other cause (i.e. inappropriate scope, objectives, strategic planning, marketing etc). It should also request that a 'gap analysis' be conducted to establish whether screening programs are adequate (note that extending the scope of the Inquiry to include screening for non-cancerous conditions is a necessary challenge) and whether a full range of treatment services (that extend beyond physical care) are available. Once such analysis has been conducted, funding requirements may be addressed.

Having said this, GAIN does not believe that the services for detection of and support of women with gynaecological cancers is adequate. If they were, we would not have the numbers of deaths occurring and, in relation to ovarian cancer, there would not be an 85% mortality rate. An adequate screening tool for Ovarian cancers needs to be found urgently (see comments in (a) above).

However, the funding issue is not just about screening. It is very much about support, treatment and awareness. They all go hand in hand. Gynaecological cancers need to have the same awareness as Breast Cancer and there is movement in Australia for this to happen. Gynae cancers are very specific cancers that need tailored services and support – people can much more readily talk about bowel cancer than they can vulval or cervical cancer. For this reason, we need an Australian spotlight on gynaecological cancers as a group (not swallowed up in just cervical cancers which is the most treatable).

Support services for gynaecological cancers are very poor. This is demonstrated by the amount of women from around Australia that contact GAIN for support. Having said this, the Cancer Council does a very good job and in WA, the Cancer Council is working closely with GAIN to develop new services and as such, is about to launch an on-line support service for women with gynaecological cancers, in partnership with GAIN. This is very exciting and we hope that other states will follow this initiative.

However, the Cancer Council's brief is to cover all cancers, which is a huge and expensive undertaking. Due to the societal taboos surrounding gynaecology, these cancers need their own funding for support services. Many women find it very problematic to talk to anyone about a gynaecological cancer due to the shame and embarrassment (as well as cultural practices) that surround it. Some women are worried about the assumptions regarding their sexual practices that are often made when women talk about having a gynaecological condition. Many women suffer in silence and never tell anybody.

"I received a letter from my Father to inform me my Mother had Cancer. No details. One month later, she died… Years later, I found my mother's death certificate. It read -- Cancer on the vulva. My mother's closest sister knew nothing about my mother's cancer. They had never talked about it and I certainly could not talk to my Dad about it" – GAIN Member (via newsletter)

Unfortunately, many women ignore the symptoms (due to the embarrassment of having to discuss it with their GP), or, having talked to no-one about it, think the symptoms are "normal" are and therefore, never seek diagnosis. This can lead to on-going pain and discomfort and in many cases, death. Most women find emotional support in being able to talk to other women who have been through the same experience. This sharing is vital – both for sharing successful treatments and ways of living with their conditions, as well as understanding that others know what you are going through.

" I have felt a re-assurance knowing there are others to talk to. The loneliness of the condition disappears" – GAIN member (via newsletter)

10 years ago we couldn't talk about breast cancer in the way we can now. We need the same to happen for gynaecological cancers.

"The expense of treating it (CIN) was huge. There are costs over a 12 month period, as I have another colposcopy in July to ensure (sic) it hasn't returned or all the abnormal cells were removed and then follow up tests in December. I can only get a percentage back from Medicare for the specialists in house surgery expenses, but I couldn't claim any of those procedures from my health care as it was all in house, even though it was a surgical procedure. This is an issue as some procedures become so technologically advanced, you don't need to go into hospital, which is great. The first time I had CIN iii, in early 1999, I had day surgery and went under a general anaesthetic, my recent experience at the beginning of the year was in the specialist's in house surgery with a local anaesthetic. So the treatment has advanced, but the costs have also" – Email to GAIN

Many women who have contacted GAIN have expressed their concern that women cannot afford private health care often have to wait for referral treatments and care through the public system. This is of great concern, especially where late diagnosis occurs and time is of the essence. Increased specialist gynaecology services are required in the cities but more importantly, in the regions. In some cases, women wait months just to see a gynaecologist for a routine examination.

"I also had a problem with the issue of private versus public treatment. In my case, I had no choice but to go private as my cancer was too advanced to wait to get into see a public specialist at (the public hospital). Had I not gone straight to see (private specialist) and waited for an appointment at (public hospital), it's likely that my cancer would have progressed far enough that the hysterectomy would have been unavoidable. I also had a problem with paying $650 for a PET scan. No Medicare rebate. Although I could have waited 6-12months to go through the public system, but who knows what could have happened if I had waited for that. The cancer could have spread to my uterus, bladder, bowel and even my ovaries and I would be facing a death sentence and not just infertility" – GAIN Member (via email)

(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;

Screening can not be approached on a "one size fits all" scenario. Recent research shows that "Aboriginal and Torres Strait Islander women are up to four times more likely to die from cervical cancer than non-Indigenous women…This is because the number of Indigenous women having regular Pap tests is dangerously low"[3]. Once again, this is a national disgrace, given that cervical cancers are one of the treatable gynaecological cancers. The recent article appearing in Medical Journal Australia reported that indigenous women are 10 times more likely to die from cervical cancer due to inadequate screening services in remote areas. This must be addressed through different techniques developed especially for indigenous communities in both urban (but more importantly) remote areas, and culturally specific awareness campaigns. Additional and specific funding needs to be allocated to designing tailor made screening programs for indigenous communities and a coordinated approach to delivering these is required. This awareness and education needs to be dovetailed into other federal and state government programs for indigenous Australians.

Similar problems exist in multicultural communities. "Migrant women generally have low rates of pap smears, breast examinations and mammograms (especially women from Asia). This is likely to be due to a number of factors including poor health education and cultural modesty, as well as a lack of familiarity with preventive health and screening"[4]. This website goes on to say that "If they come from cultures where sexuality is not discussed, and where sexual enjoyment for women is regarded as a sign of "looseness", they are likely to be

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[3] Source: Pap Screen Victoria website http://www.papscreen.org/article.asp?ContentID=Indigenous_pap_tests

[4] Queensland Government A-Z Health Topics website: http://www.health.qld.gov.au/multicultural/cultdiv/womens_health.asp

at higher risk of poor sexual and reproductive health. Vietnamese women have a higher rate of mortality from cervical cancer than any other ethnic group, for example, while Turkish women have high fertility rates and high rates of unwanted pregnancies and sexually transmitted diseases".

> *" I was overwhelmed to find out that such an organization exist, I just find now and joined straight away… it has been a very stressful and tearful time for me and my daughter. Me and my daughter are both stressed and frustrated I ask as a support group do we meet with other member or can we talk with someone on the phone on time of distress or need advice is there a chat room?"* – Email to GAIN (multicultural community member)

One of the barriers to break down is that of the "taboo" subject of gynaecology and sexuality. This is an issue for all women, but particularly indigenous and many multicultural communities, where sexuality is not often discussed and women's business is exactly that. It is extremely difficult to get women to see male doctors for examinations when in their cultures, this is not allowed. Access to female doctors is critically important and culturally sensitive screening and examination methods must be implemented. This includes taking mobile services out to remote communities – perhaps into the homes of community members or, into indigenous cultural centres or meeting places. In regions where women's business / festivals are held, pap screening and education could take place. This would only be possible for open gatherings, by supporting female indigenous doctors and nurses to attend and / or by training indigenous law women from these cultures to conduct the examination. Of course, all of these strategies need to be developed in conjunction with the relevant indigenous communities.

For some migrant women, sex education is rare and therefore understanding of their anatomy and gynaecological health is very low. These are major barriers to screening and demonstrate that education and screening processes must go hand in hand. The types of education campaigns delivered to these communities need to be very different from those delivered through main stream school based programs and, specific funding must be applied to this.

Case Study

GAIN's Founder delivered a talk about gynaecological health at a NSW Aboriginal Women's Health Organisation in 2004. This was the first time a talk about gynaecological health had been scheduled. During the talk, it was revealed that one of their prominent community members had died from cancer "that started in the cervix". At the same meeting, one woman, aged 42, admitted she had never had a pap smear. After having her first pap smear, cancer was detected and she had to have a complete hysterectomy to remove it. Thankfully, she lived… As a result of the group's understanding that their member's death could have been prevented, they decided to establish an annual screening day in honour of their deceased community member.

Men have a role to play too!:

Education and awareness about gynaecological issues is not just for women. Men must also be educated – particularly those at pre-sexual ages - as many problems (particularly HPV) arise from sexual activity and no matter how educated a woman is, the responsibility is joint. This is also important in circumstances where a woman does develop a severe gynaecological condition, so that her partner can understand what she is going through (both physically and emotionally) and thus provide the necessary emotional support. Many males refuse to even discuss the matter with their partners, serving to further isolate a woman emotionally.

In many cases, male partners are also very affected by gynaecological conditions. It can affect a woman's sexual drive (and physical ability to participate), can cause depression, in some cases can be physically debilitating therefore increasing reliance on their partners for day to day activities and, can reduce the emotional support and nurturing that women provide for their partners and children. It can have devastating effects on whole families, which means men too need to have awareness, so they can develop understanding and cope with the unforseen side affects. Most medical practitioners and support services do not acknowledge this and there are very few support services available for partners and families.

Case Study

GAIN was recently contacted by a gentleman whose wife had died from vulval cancer some two years prior. He is traumatised by his wife's death – especially as neither of them heard of vulvar cancer before and the period between diagnosis and death was relatively short. Understandably, this gentleman is still trying to come to terms with the loss of his life partner, but also with the fact that in most circles vulval cancer "can not" be discussed. In addition, information about the cancer is very limited and he felt isolated and not did know where to turn.

Overall, existing screening services need to be assessed, not only to determine their capability to provide an essential level of physiological service, but also to meet the psycho-social and psycho-sexual needs of the women concerned, their families, and the community as a whole. Provision of physiologically focussed educational materials and services alone fails to address the need for, or provide the funding associated with, the emotional, mental and spiritual facets of health and healing (on both an individual and societal level).

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

"GPs need to be better informed in order to provide better information to their patients" – GAIN Member (via email)

GAIN has many, many stories from women who complain about misdiagnosis from their GPs. While we do not wish to cast any aspersions on the medial community, it is widely acknowledged that greater education in diagnosis and dealing with gynaecological conditions is required. Many women have complained that their GP has told them that some of their conditions are "all in their head", that more serious conditions are often diagnosed as "simply thrush" or, cancer is dismissed because of "their age".

"…I asked him(GP) a simple question while he was removing the lump, I asked is it a cyst and he said no its not a cyst. he added that he doesn't want to worry me and that everything (sic) is probably fine. I would of believed him had I not seen the look in his eyes" – Email to GAIN

GAIN acknowledges that there are many wonderful GPs and gynaecologists in Australia who are doing sterling work. And for every brickbat, we hear a bouquet. However, women are suffering and dying from misdiagnosis and we believe much of this can be prevented with improved GP awareness and education. Having said this, we understand that the problem is not just one way – many women are unable to describe their anatomy accurately (for example, we will say "there is a lump on my vagina instead of my vulva") or feel too embarrassed to broach the subject with their GP. Others will only give filtered symptoms or information for fear of being labelled "sexually promiscuous". These barriers must be broken down. To do this, more two-way communication is required between consumers and practitioners. This should be addressed both in medical training and, while GPS are out in the field, on an on-going basis. Again, this is a role that the Divisions of GPs and health consumer and support groups can play.

"As other sufferers have reported, doctors can be diligent and sympathetic, but are often unable to recognise the problem" – GAIN member (via newsletter)

Education of the medical community should not focus solely upon the provision of physiological information; rather it should foster an appreciation of people and communities as integrated physical, emotional, mental and spiritual entities. Medical practitioners should be exposed, and encouraged to promote, an appreciation of the psycho-social and psycho-sexual precursors to gynaecological conditions (of which cancer is but one) and be prepared to seek the advice, and recommend the services of, practitioners trained in the areas of counseling, change management and emotional support.

The risk factors associated with gynaecological conditions (cancerous and non-cancerous) are wide and varied and not all are attributable to physical causes alone. As health and disease should be viewed as an interplay between a range of factors, education of the medical community with regard to the nature and impact of these factors, is paramount.

"...It was a relief to be diagnosed months down the track after unintentional mismanagement by many doctors. Any topical treatment had only increased the pain. It took about a year for this pain to gradually improve with a regime of amitriptyline (an anti-depressant), supplements and general nurturing" – GAIN Member (via newsletter)

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

Cannot be stressed enough! We do not know enough about what differentiates us as women. Most girls are taught at high school about the menstrual cycle. STIs and contraception but little is taught about the actual risk factors of gynaecological conditions and cancers – i.e. what causes them, until it is too late. We need to be educating our teens before they become sexually active.

As noted above, this education must not be limited to the physiological aspects of health and disease; rather it must be integrated with the larger, more challenging issues of a psychological nature. It must also extend beyond the narrow realm of cancer education to education regarding the full range of gynaecological issues facing women in today's society. Education needs to focus on the holistic nature of risk factors, symptoms and treatment, in order that it is relevant to communities; accommodate the individual's preference for a range of treatment options (ranging from conventional to alternative); and be extended to include non-cancerous gynaecological conditions/issues.

"Prior to the seminar I had little knowledge about that area of my body and was ignorant of the significance of it. Your seminar has given me confidence in exploring this further and maybe it will help me embrace it rather than shunning it or pretending (sic) it doesn't exist" – Feedback from GAIN seminar

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

GAIN feels unable to comment on this, as we do not have enough knowledge on what representation currently exists. We are not aware of Cancer Australia (assuming it is different from the Cancer Council Australia?), which, in itself, would suggest that the representation is not adequate.

Summary

GAIN firmly believes that the biggest issue to overcome in regards to gynaecological conditions and cancers, is the stigma that is associated with it. In today's enlightened society where women are equal; sexual preferences are acknowledged; communication methods are in abundance and; almost any topic is discussed openly in the mass media, gynaecology is *still* a taboo subject. It seems incredulous in this day and age that both women and men feel that they can not openly discuss these issues without fear of being labeled as 'sexually promiscuous' (especially when many conditions are *not* at all related to sexual activity!), feeling guilt about their sexual habits or, being dismissed as being "women's business" and therefore, not for open discussion. This attitude must be broken down if we are even going to truly make change, save women's lives and shield our community from unnecessary emotional trauma. This needs a top down approach as well as a bottom up approach. In this light, GAIN is especially pleased to see that Professor Ian Frazer has been awarded 'Australian of the Year' for his work with gyaencological conditions. We see this as one of many critical steps in moving forward.

On behalf of our members, GAIN thanks the Senate Community Affairs Committee for the opportunity to respond to this Inquiry and looks forward to long overdue change in the era of gynaecological health.

"Because I was really unlucky and have had it (CIN) twice with only 2 sexual partners during that time (8 years), it did take me a little bit of time to not think I was being punished for having sex" –Email to GAIN

Should you require GAIN to make a personal representation to the committee, please contact our Chair, Natalie Jenkins on 0409 115 851 or natalie.jenkins@optusnet.com.au

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June 14, 2006

Ms Natalie Jenkins
GAIN
2 Delhi Place
WEST PERTH

Dear Natalie,

GAIN’s Submission To Senate Community Affairs Reference Committee Inquiry into Gynaecological Health in Australia

On behalf of Women’s Electoral Lobby (WA) Inc, I congratulate you and the GAIN Committee on your Report Submission, which WEL received today.

Having read the document, it is clear to us that it embraces an approach to women’s health and well being which all members of WEL would endorse. GAIN’s Submission is comprehensive, balanced, informed and authoritative.

GAIN has achieved a landmark in women’s health by galvanising the genuine support of ordinary Australian women so well that the Senate Community Affairs Reference Committee undertook its Inquiry on this vital, neglected area of specialisation.

WEL members in Western Australia can recall the first meeting with Kath Mazzella when she came to a WEL General Meeting seeking recognition for her goals to establish services and information about gynaecological health. At that meeting her aims were warmly received not least because we had lost an outstanding and much loved member to vulvar melanoma. WEL believes that for reasons stated in your submission there is a dire need to address the issue of gynaecological health in new ways which reflect the growing awareness of women, and indeed men, in the 21st century.

Yours sincerely,

Ruth Greble
WEL Office Bearer

APPENDIX ‘B’

To whom it may concern

Business and Professional Women of Western Australia are concern that Gynaecological cancer needs are under represented in the budget submission. We support the work of GAIN in their quest to improve information and support for women who have gynaecological issues.
Once again we are pleased to offer our support to the GAIN submission to the Gynaecological Cancer Enquiry on this important issue of budget allocation.

Yours sincerely

Michelle Miller

BPW State President

Western Australia

Australian Federation of University Women WA (Inc.)

Response to the Government inquiry into gynaecological health and cancer

Referring to the document dated 3rd March 2006 being the Hansard transcript of the Round Table discussion of the Community Affairs References Committee responding to the petition on gynaecological health issues.

Response to Professor Neville Hacker on p. 8 - Need for a screening test for ovarian cancer – still have 350 genes to check.
The screening test is needed for all women, not just those with a family history of cancer. However, it is only **detecting the disease after it has started.**

If one **attempts to prevent it in the first place** as occurs for vaccination procedures, one should then consider **diet**:
Response to Mr Lee on page 12 – he did not think the evidence for diet being a risk factor was good.
*** This ignores the evidence in a paper published in the British Journal of Cancer (2002), 86: 712-717. “Diet and ovarian cancer risk: a case-control study in China” by M. Zhang, ZY Yang, CW Binns and AH Lee”. Correspondence to Dr. AH Lee at Curtin University of Technology, WA - email Andy.Lee@curtin.edu.au.

254 patients with histologically confirmed epithelial ovary cancer were compared with 652 controls and a food questionnaire was used to measure the **habitual diet**.
The findings suggested that a diet rich in fresh vegetables and fruits but less animal fat, salted vegetables, fried, cured and smoked food, contribute to a lower risk of ovarian cancer.
Australian data of a similar kind **should be sought.**

Response to Ms Heffernan on page 49 – the Royal Australian College of General Practitioners could easily insist that a certain number of **CME points** had to be earned by education relating to gynaecological cancer. Already the Royal Colleges decide what portion of the annual requirement is earned from particular activities.

Response to Prof Hacker on p 31 where he mentions a **bi-annual vaginal ultrasound –** this should extend to all women – not just those with a family history of cancer.
There already exists a MBS number for Pelvis, Female, ultrasound scan of, by any or all, approaches where (a) the patient is not referred by a medical practitioner was 55733. In 2001, the AMA fee was $66. Perhaps something like this could be used as a screening number.