15 June 2006

Mr E Humphery
Secretary
COMMUNITY AFFAIRS REFERENCES COMMITTEE
PARLIAMENT HOUSE
CANBERRA ACT 2600

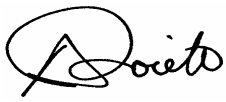
Dear Mr. Humphery
I attach the submission from the Hunter New England Centre for Gynaecological Cancer (HNECGC) to the Senate Inquiry into Gynaecological Health in Australia.

HNECGC is located at the John Hunter Hospital in Newcastle, NSW. Our views and recommendations regarding the needs of women with gynaecological cancer and their health care professionals are made in the attached submission.

I would like to thank you and the Commonwealth Government for the opportunity to provide you with our views.

We look forward to a productive outcome and hopefully major advances in the care of women with gynaecological cancer.

Yours sincerely



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SENATE INQUIRY INTO GYNAECOLOGICAL CANCER SERVICES

HUNTER NEW ENGLAND CENTRE FOR GYNAECOLOGICAL CANCER

Conjoint Associate Professor Anthony PROIETTO
Director

June 2006

Summary

In its submission to the Senate Inquiry into Gynaecological Health in Australia, the Hunter New England Centre for Gynaecological Cancer (HNECGC) makes the following recommendations :

A National Gynaecological Cancer Centre

1. that the Commonwealth Government establish a National Centre for Gynaecological Cancer to co-ordinate all aspects of gynaecological cancer care, education and research.

Funding for Treatment Services and Health Support Programs of the HNECGC

2. that the Commonwealth Government provide funding so that the number of specialist medical practitioners (gynaecological oncologists, radiation oncologists, and medical oncologists) employed by the Hunter New England Area Health Service's gynaecological cancer centre can be increased to meet the clinical needs of its population.

3. that the Commonwealth Government provide funding so that the amount of theatre time available to the specialist medical practitioners (gynaecological oncologists, radiation oncologists, and medical oncologists) of the Hunter New England Area Health Service's gynaecological cancer centre can be increased.

4. that the Commonwealth Government provide funding so that the number of staff of the more remote community hospitals can be increased and trained to allow post-treatment follow-up of the patient in a hospital or centre closer to their home.

Medical Community's Educational Needs

5. that the Commonwealth Government provide funding so that the number, frequency, reach and location of the education programs run by the HNECGC for generalist medical practitioners and other health staff can be increased.

Community's Educational Needs

6. that the Commonwealth Government provide funding so that the number, frequency, reach and location of the education programs run by the HNECGC for the general community can be increased.

About the Hunter New England Centre for Gynaecological Cancer

The Hunter New England Centre for Gynaecological Cancer (HNECGC) is the only major gynaecological oncology centre between Sydney and Brisbane, located at John Hunter Hospital (JHH) in NSW. In reality, it serves a vast geographical area, from the Central Coast of NSW to the NSW border and out as far as western NSW.

The HNECGC was established in 1991. In 1994 the Centre was accredited as a MRANZCOG training centre of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists. In 1999 it was accredited as a training site for subspecialty training (CGO) in gynaecological oncology. In 2002, as part of the NSW Government's review of services (The Greater Metropolitan Clinical Taskforce, GMCT), the HNECGC became one of the four gynaecological oncology networks in NSW.

The Centre consists of one 0.4 EFT Staff Specialist Gynaecological Oncologist, one VMO Gynaecological Oncologist, one full-time Clinical Nurse Consultant, one 0.5 Cancer Nurse Coordinator, one full time Social Worker, a 0.5 EFT Psychologist and twelve dedicated gynaecological oncology beds. In addition, the Centre works with two Medical Oncologists and two Radiation Oncologists who are on a separate campus. The Centre also has access to Pathologists and Palliative Care Specialists. A full-time data manager is also part of the team.

The HNECGC is responsible for :

- the provision of a co-ordinated and comprehensive service to women with gynaecological cancer from initial diagnosis and assessment to specialised therapeutic services, social support and palliative care;
- the development of protocols for the management of patients with the various gynaecological cancers, in consultation with the Departments of Medical Oncology and Radiation Oncology;
- statistical collection and analysis, and clinical research;
- delivering education programs to the medical and allied health community;
- delivering education programs to the general community;
- teaching undergraduate and postgraduate medical and paramedical staff.

Gynaecological Cancer in NSW

The term *gynaecological cancer* refers to cancers of the ovaries, fallopian tubes, uterus, cervix, vagina and vulva. These cancers represent almost 10% of all cancers in women.

Among the gynaecological cancers, cancer of the uterine body has become the most frequent. According to the Cancer Institute of NSW (*Cancer in New South Wales Incidence and Mortality 2003*; May 2005), 558 women were newly diagnosed with uterine cancer in NSW in 2003. This represents 3.8% of all female cancers. Ninety-five women died of uterine cancer, representing 1.7% of all female cancer deaths. The Cancer Institute states that 1 woman in 74 will develop cancer of the uterus by the age of 75 years.

In NSW in 2003, 363 women were newly diagnosed with ovarian cancer (*Cancer in New South Wales Incidence and Mortality 2003*; May 2005). Ovarian cancer represents 2.5% of all cancers in women. It accounts for 3.8% of female cancer deaths, or 214 women. One woman in every 121 will develop this cancer before the age of 75 years.

Cancer of the cervix was diagnosed in 243 women in NSW in 2003 (*Cancer in New South Wales Incidence and Mortality 2003*; May 2005), 75 women died of this disease. One woman in every 186 will develop cervical cancer by the age of 75 years. However, incidence rates for cervical cancer are decreasing over time. The Cancer Institute of NSW notes that the age standardized incidence rate fell by 46% and the aged-standardized mortality rate fell by 52% in the ten years from 1994. This fall can be mainly attributed to the pap smear screening program.
The most effective treatment for women with gynaecological cancers must involve a co-ordinated team approach which includes the general practitioner, gynaecologist, gynaecological oncologist, pathologist, medical and radiation oncologists, nursing staff, social workers, counsellors and community services. Treatment is usually complex and lengthy, and best given in specialist gynaecological cancer centres.

Gynaecological Cancer and the HNECGC

The HNECGC has, for several years now, been staffed by a part-time Staff Specialist and a VMO. In 2004, the Centre treated 1288 women, of whom 201 were new patients. Details are given in Table 1 and Figure 1. In addition to these, a number of public patients are seen in the private rooms because they do not wish to wait several weeks to be seen in the public clinic. These patients are then booked for surgery at JHH.

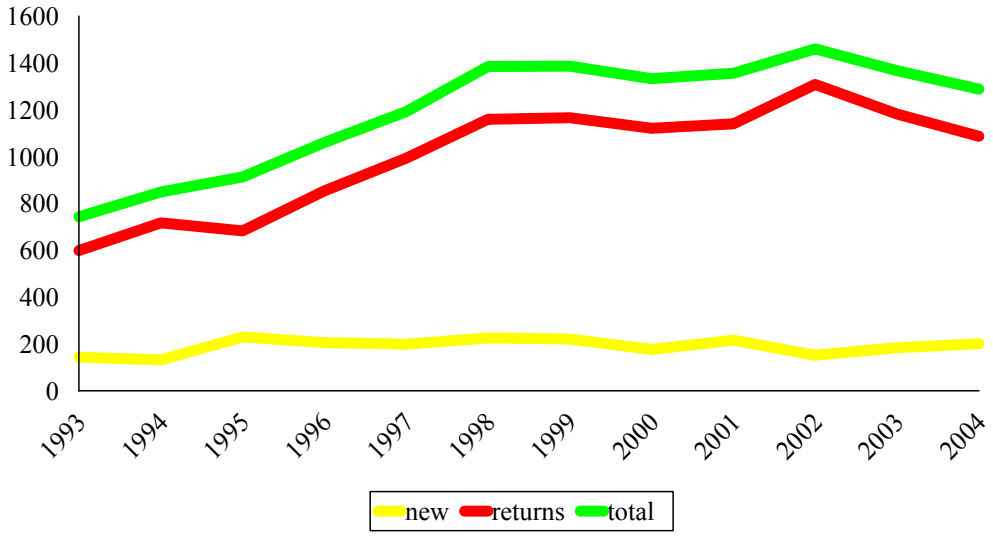
As can be seen from Table 1, the total number of women treated has increased from 743 in 1993 to 1288 in 2004, an increase of 545 patients or 75%. The number of new patients has increased by 40% from 144 in 1993 to 201 in 2004.

The waiting time for a new patient to be seen in clinic by a Gynaecological Oncologist at the HNECGC is currently is about two weeks.

Table 1 : Number of New, Return and Total Patients at HNECGC, 1993 - 2004

	New	Returns	Total
1993	144	599	743
1994	132	717	849
1995	230	683	913
1996	206	854	1060
1997	199	993	1192
1998	226	1159	1385
1999	221	1166	1386
2000	177	1121	1333
2001	216	1140	1356
2002	152	1308	1460
2003	184	1182	1367
2004	201	1087	1288

Figure 1 : Number of New, Return and Total Patients at HNECGC, 1993 - 2004



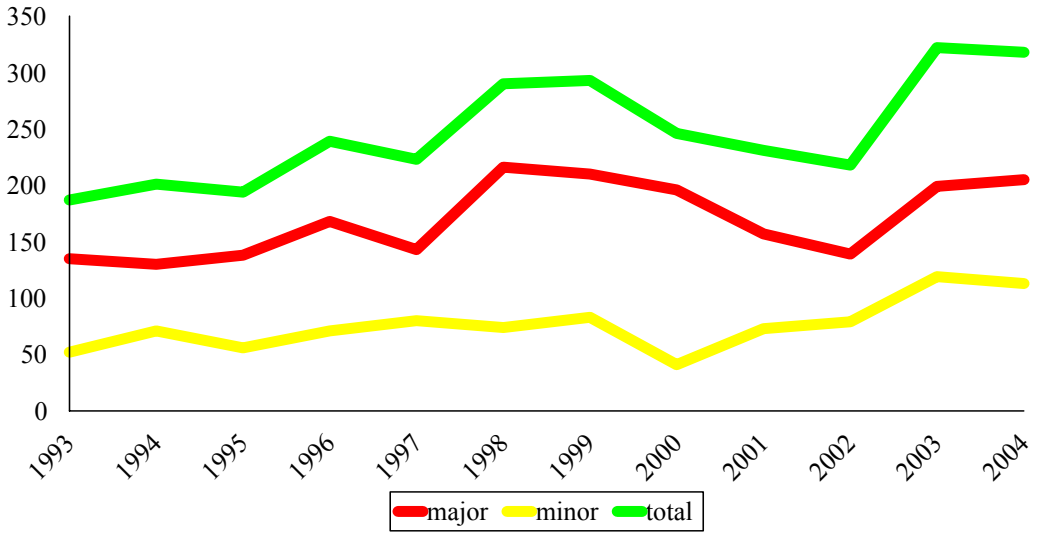
The Centre performed 318 operations in 2004, of which 205 were major operations. The number of surgical procedures has increased from 187 in 1993 to 318 in 2004, an increase of 70 %. The number of major procedures has increased by 52% over this period. See Table 2 and Figure 2.

Patients currently wait up to ten weeks for a gynaecological cancer operation in the Hunter New England Area Health Service. This is substantially more than the waiting time in the cancer centres in the Sydney Metropolitan area.

Table 2 : Number of Major, Minor and Total Operations at HNECGC, 1993 - 2004

	Major	Minor	Total
1993	135	52	187
1994	130	71	201
1995	138	56	194
1996	168	71	239
1997	143	80	223
1998	216	74	290
1999	210	83	293
2000	196	41	246
2001	157	73	231
2002	139	79	218
2003	199	119	322
2004	205	113	318

Figure 2 : Number of Major, Minor and Total Operations at HNECGC, 1993 - 2004



Comment and Recommendations

In this submission it will be argued that the workload of the HNECGC is excessive, the waiting time for gynaecological cancer operations is totally unacceptable (and indeed, detrimental to the health and prognosis of the patient), and that the service provided to the more remote parts of the Region and state is suboptimal. It will be further argued that the gynaecological oncology service provided to the Australian community and the community of NSW is fragmented and under-funded and that the Commonwealth Government needs to consider making an immediate and substantial increase to the funding provided to this area and to the establishment of a nation-wide umbrella organization.

The incidence of gynaecological cancers will increase over the next several years. Such an increase in the incidence of gynaecological cancer will bring with it emotional and psychological distress to the women and their families. It will also have major funding implications for the government. However, it will be argued, that the morbidity and mortality associated with gynaecological cancer can be reduced with an increase in funding.

A National Gynaecological Cancer Centre (NGCC)

The HNECGC is one of the four major gynaecological cancer centres in NSW. These centres work more or less independently and there is no national body to act as a resource and coordinating centre for gynaecological cancer. Resources vary between each of the four NSW centres and between the states. Although every attempt is made, it is very difficult to pool knowledge, resources and data, resulting in inefficiency, waste and duplication.

The establishment of a national dedicated body will minimise duplication, provide strategic direction and leadership, develop and standardise protocols and guidelines, co-ordinate research and education programs, serve as a focus for women diagnosed with cancer, and act as a resource for the medical and allied health professionals involved in their care. It will ensure the most effective use of limited resources.

It is recommended that the Commonwealth Government establish a National Centre for Gynaecological Cancer to co-ordinate all aspects of gynaecological cancer care, education and research.

Funding for Treatment Services and Health Support Programs of the HNECGC

According the Hunter New England NSW Health website, "the people we serve number more than 836,211 and live in an area of about 132,845 square kilometres". The HNECGC also treats a substantial number of patients from the outside the Region's boundaries (including, the Central Coast, mid-North Coast, and Northern NSW). The population serviced by the Centre is, therefore substantially greater than the 836,000 people residing within the boundaries of the Region.

The Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZCOG) states that one Gynaecological Oncologist is needed per 400 000 population. The HNECGC should, therefore, have at least two Gynaecological Oncologists in order to adequately service the needs of the community. Currently, it has an 0.4 EFT Staff Specialist and a VMO.

The Hunter New England NSW Health website also notes that "overall, on both [Socio-Economic] indices, Hunter New England had values that were somewhat lower than the mean for NSW as a whole, and also lower than Sydney-based area health services." Thus, the people serviced by the HNECGC are less likely to be in a position to attend private medical specialists and be treated in private hospitals.

The waiting times for surgery for the patients of the HNECGC are far higher than those for the Sydney-based cancer centres. The long waiting times are a combination of a shortage of gynaecological oncologists in the Region and lack of operating theatre time. At the beginning of December 2005, when the waiting time for cancer surgery was at 10 weeks for patients of the HNECGC, the gynaecological cancer centres based in Sydney were contacted to ascertain their waiting times. Their responses were, "never more than two weeks", "normally 2 – 3 weeks", "maybe 2 – 3 weeks", and "usually 1 – 3 weeks". Thus, women with gynaecological cancer who happen to live in the area serviced by the HNECGC are expected to wait more than three times as long as those women who happen to live in Sydney.

Currently, waiting times for radiation therapy in the Hunter New England Area Health Service are so long that patients cannot be accepted for treatment in the Region and are being referred to Sydney and the Central Coast. Women with gynaecological cancers who live in this Area and need radiation treatment are required to travel hundreds of kilometres to receive that treatment. These women not only have a life-threatening illness, they also have to leave their support networks behind and travel to an unfamiliar location to receive major treatment.

Similarly, there is a waiting time of up to six weeks for women with gynaecological cancer to be seen by a medical oncologist in the Hunter New England Area Health Service. There is a further delay before treatment can actually be commenced.

Expediency of treatment is vital if women with gynaecological cancer are to have a high chance of cure. A delay in treatment will almost always result in a poorer prognosis for the women involved. In this Region, women have to wait about two weeks to be seen in clinic, then up to 10 weeks for an operation, then up to 6 weeks for a chemotherapy consult, let alone chemotherapy treatment. They can't even get radiation treatment in the Region because the waiting time is so long. These delays can decrease the cure rate for some women with gynaecological cancer.

High quality clinical services giving women the best chance of cure should be provided to all women regardless of their place of residence. It requires adequate funding and resources. The centres based in Sydney are far better staffed than those in regional areas and waiting times for consultations and treatment are shorter. It is critical that resources are made available to allow women from regional and remote areas to equitably access services that residents of major population centres are more readily able to use. This will require not only additional specialist medical staff and other health professionals, but also increased access to operating theatres, and improvements in travel and accommodation assistance to allow patients from the remote parts of the Region to travel to the HNECGC for diagnosis and treatment. The Government also needs to invest in the number and training of staffing of the

smaller local hospitals and health centres so that as much of the after care and monitoring as possible can be done in the patient's own environment.

It is recommended that the Commonwealth Government provide funding so that the number of specialist medical practitioners (gynaecological oncologists, radiation oncologists, and medical oncologists) employed by the Hunter New England Area Health Service's gynaecological cancer centre can be increased to meet the clinical needs of its population.

It is recommended that the Commonwealth Government provide funding so that the amount of operating theatre time available to the specialist medical staff of the Hunter New England Area Health Service's gynaecological cancer centre can be increased.

It is further recommended that the Commonwealth Government provide funding so that the number of staff of the more remote community hospitals can be increased and trained to allow post-treatment follow-up of the patient in a hospital or centre closer to their home.

Medical Community's Educational Needs

In order to provide the patient with the best chance of cure, it is imperative that the medical practitioner who first comes into contact with women with gynaecological cancer has sufficient up-to-date knowledge of the disease, has access to a referral system which will maximise the health outcome for the patient, has access to educational material for himself / herself and the patient, and has the support (s)he needs to continue to care for that patient over the many years she will have the disease.

Symptoms of gynaecological cancer can be very vague and difficult to diagnose. Moreover, generalist medical practitioners will see women with gynaecological cancers relatively infrequently. Limited exposure to the disease combined with its vague, difficult to diagnose symptoms can make it very difficult for generalist medical practitioners to accurately assess the patient.

The HNECGC runs education programs for medical practitioners. The Hunter Postgraduate Medical Institute (HPMI) also runs seminars to update Gynaecologists, General Practitioners, and Obstetric and Gynaecological Registrars in the care and treatment of women with gynaecological cancer. The objectives of our programs are to equip clinicians with the information necessary to make appropriate referrals, undertake the necessary investigations to assist with the diagnosis of a gynaecological cancer and, provide care for women with the sequelae of treatment.

Women with gynaecological cancer benefit because their local medical team can provide them with up-to-date information on their illness (which will go some way to reducing the anxiety they feel), and make expeditious and appropriate referrals for them.

The programs run by both the HNECGC and the HPMI are always extremely well attended and very successful. However, due to the limited resources (both financial and human) they are usually run in Newcastle and on only a few occasions, making it very difficult for medical practitioners and other health professionals from the more remote parts of the Region to attend.

The education programs of the HNECGC need to be run in a number of the Region's major centres so that all medical and health professionals have the opportunity to attend. They also need to be run far more frequently than is currently possible.

It is recommended that the Commonwealth Government provide funding so that the number, frequency, reach and location of the education programs run by the HNECGC for generalist medical practitioners and other health staff can be increased.

Community's Educational Needs

The education of the community is vital if we are to ensure early diagnosis and treatment of gynaecological cancer and thus increase the cure rate and prognosis for our patients.

The HNECGC does involve itself in a number of education forums aimed at members of the public. The staff have appeared on television programs, given radio interviews, and presented talks. The Centre also has developed a number of information packages and makes extensive use of the materials produced by other organizations, such as the Cancer Council of NSW as well as those of the other states. However, our resources are extremely limited and our major priority must be the treatment of the women referred to us.

The Commonwealth Government needs to provide funding so that the education programs aimed at the general community can be better co-ordinated and have a higher audience reach.

It is recommended that the Commonwealth Government provide funding so that the number, frequency, reach and location of the education programs run by the HNECGC for the general community can be increased.