COMMONWEALTH OF AUSTRALIA

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Gynaecological cancer in Australia

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SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Wednesday, 16 August 2006

Members: Senator Moore *(Chair)*, Senator Humphries *(Deputy Chair)*, Senators Adams, Allison, Carol Brown and Polley

Participating members: Senators Abetz, Barnett, Bartlett, Bernardi, Mark Bishop, Bob Brown, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Fielding, Forshaw, Hurley, Joyce, Kirk, Lightfoot, Ludwig, Lundy, Marshall, Mason, McGauran, Milne, Murray, Nettle, O'Brien, Parry, Payne, Siewert, Stephens, Stott Despoja, Watson, Webber, Wortley and Wong

Senators in attendance: Senators Adams, Allison, Ferris, Humphries and Moore

Terms of reference for the inquiry:

To inquire into and report on:

Gynaecological cancer in Australia, and in particular the:

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

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

c. capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;

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

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

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

WITNESSES

Committee met at 9.00 am.

TRIMBLE, Dr Edward Lloyd, Head, Gynecologic Cancer Therapeutics, National Cancer Institute, National Institutes of Health, Department of Health and Human Services, United States of America

Evidence was taken via teleconference—

CHAIR (Senator Moore)—Good morning, Dr Trimble. This is a hearing of the Senate Community Affairs References Committee. You have received information about our parliamentary process regarding the protection of witnesses and all those kinds of things. If you have any questions about that, please let us know. You have provided us with a copy of your opening statement. Would you like to make a comment? Then we will go to questions.

Dr Trimble—On behalf of Dr John Neiderhuber, the Acting Director of the United States National Cancer Institute, we would like to thank you for the opportunity to testify at this hearing on gynaecologic cancer. For personal as well as professional reasons, I am encouraged by the keen interest your committee has shown in improving outcomes for women with gynaecologic cancer in Australia. I chose the speciality of gynaecology, inspired in large part by my mother, Dr Frances Trimble, who was a 1942 medical graduate of Sydney University. She trained in gynaecology at Prince Alfred Hospital, King George V and the Royal Hospital for Women in Sydney. Her younger sister, Mrs Constance Smith, who worked as a physiotherapist in New South Wales for many years, died of ovarian cancer in 1996, at age 76.

I do not need to remind you about the global burden of gynaecologic cancer. In many countries the leading causes of cancer deaths among women are breast and cervical cancer. Major progress has been made in the developing world in the fields of breast and cervical cancer prevention, screening and treatment, but we have many miles to go before we can relieve women worldwide of the burden caused by these and other malignancies, such as cancers of the ovary and uterus.

In 1937 a dedicated group of cancer advocates, led by Mrs Mary Lasker, generated the momentum that would help start the United States National Cancer Institute. These advocates persuaded the United States Congress and President Franklin Roosevelt of the importance of cancer research, including both basic and clinical studies. Today, the United States National Cancer Institute sponsors research on prevention, screening, treatment, symptom management and survivorship. Our budget in 2005 was $US4.7 billion. The NCIUS leads the United States National Cancer Program, which includes cancer control efforts across a variety of federal programs, close partnership with patient advocacy groups, and public-private partnerships with the biotechnology and pharmaceutical industry. Our research is conducted by doctors, nurses and patients as well as scientists from around the world.

Talented Australian scientists have been among the most competitive in the world in securing funding for cutting edge cancer research from the National Cancer Institute. Australian doctors and scientists have been in the forefront of the fight against gynaecologic cancer. Professor Ian Frazer, of the Centre for Immunology and Cancer Research at the University of Queensland, the 2006 Australian of the Year, has achieved worldwide renown for his work on the human papilloma virus vaccine. Professor Neville Hacker, of the Royal Hospital for Women and the

University of New South Wales, was one of the founders and the fifth president of the leading international professional society in this field, the International Gynecologic Cancer Society. He has served as a frequent consultant to the World Health Organisation due to his expertise in the treatment of gynaecologic cancer.

The current President of the International Gynaecologic Cancer Society, and also associated with the Royal Hospital for Women and the University of New South Wales, Professor Michael Friedlander, is respected around the globe for his expertise in ovarian cancer biology and treatment. Professor David Bowtell of the Peter MacCallum Cancer Centre won a million-dollar grant from our Department of Defense to establish a landmark cohort study and tumour bank for women with ovarian cancer.

In the United States, government agencies, such as the National Cancer Institute, other parts of the National Institutes of Health, the Department of Defense and the Department of Veterans Affairs sponsor and conduct clinical trials. The NCI, working with the cancer research and advocacy communities, has set up multidisciplinary clinical trials cooperative groups to conduct these definitive trials. Our oldest cooperative group is now 50 years old. These groups bring together patients, nurses, doctors and scientists from university teaching hospitals, cancer centres, children's hospitals, community hospitals, veterans' hospitals and military hospitals. Our backing for these groups, which now totals $150 million each year, includes support for the research infrastructure, such as central offices for data management, statistical analysis, trial design, audits and quality assurance and regular meetings to review ongoing research and plans for the future as well as financial support for the participating institutions.

This latter support partially covers the cost of paperwork for local institutional review boards in addition to the time required from nurses, doctors, and data managers. We have been delighted to have the help of Australian investigators with many of our trials, particularly in paediatric cancer as well as in gynaecologic and gastrointestinal cancer. Our current phase 3 trial evaluating a novel approach to chemo-radiation for the treatment of women with advanced cervical cancer is based on innovative work done by Dr Danny Rischin through the Peter MacCallum Cancer Centre and the Trans-Tasman Radiation Oncology Group. The most recently completed NCI sponsored phase 3 trial for women with advanced ovarian cancer, GOG 182, was designed with the help of Professor Michael Friedlander. Australian sites were among the most active in accruing patients to this study, which is the largest treatment trial ever conducted for women with ovarian cancer. We know, however, that collaboration between United States and Australian investigators in cancer clinical trials has been hindered by difficulties in obtaining ongoing financial support for clinical trials infrastructure.

Over the past five years, the National Cancer Institute has provided extensive technical assistance to the All Ireland Cancer Consortium and to the government of the United Kingdom as they have established their own networks for cancer clinical trials. We are currently in discussions with the French National Cancer Institute and the Italian National Institute of Health as to how we can best help them strengthen their networks for cancer clinical trials. We would be pleased to explore opportunities for similar collaboration between the United States National Cancer Institute and our Australian counterparts. We look forward to working with you to reduce the burden of gynaecologic cancer around the world. I have been asked to clarify that our budget in 2005 was $4.7 billion. Thank you for inviting the National Cancer Institute to testify at these important hearings. I will be happy to answer any questions you might have.

CHAIR—Thank you. We will now move to questions.

Senator HUMPHRIES—I have a personal question to start with. When did your mother finish practising at King George V Hospital in Sydney?

Dr Trimble—I think she did three years of residency and then locums during the war. She emigrated to the United States in 1946.

Senator HUMPHRIES—I was born at that hospital. I just wondered if she was around when I was born, but obviously not.

CHAIR—That's in the *Hansard* now.

Senator HUMPHRIES—The budget for the NCI, $4.7 billion, is an extraordinary amount of money. I assume that budget is in part directed towards work on the HPV vaccine. In the United States, what stage has the development of a vaccine reached and what prospect is there for it being rolled out across the US population?

Dr Trimble—The Food and Drug Administration approved the Merck vaccine Gardasil in May. Subsequently, our Centers for Disease Control and Prevention have made recommendations for the inclusion of the Gardasil vaccine in our standard vaccination program. This means that automatic financial coverage for the vaccine is available for 40 per cent of the population—essentially the poorest members of our population. It is anticipated that our third-party payers, the insurance companies, will also pay for the vaccine. We were developing an extensive educational campaign in conjunction with the professional society to try to encourage parents to have their daughters vaccinated.

Senator HUMPHRIES—What will be the targeted age range for that vaccine?

Dr Trimble—The recommendation is to vaccinate girls at ages 10 to 13, but there is also provision for catch-up vaccination through to the age of 21.

Senator HUMPHRIES—Given the size of the budget for research in the US, what would you say is the state of research? Is there any estimate of how close researchers might be to significant breakthroughs on any of the major gynaecological cancers?

Dr Trimble—Obviously, we are all very excited by the development of the human papilloma virus vaccine, which was based in large part on the work done by both Dr Frazer in Brisbane as well as doctors Doug Lowy and John Schiller at the NCI. We are particularly excited because this is work to which we contribute a lot. We are very excited about that. We also have exciting work going on in the use of proteomics as a screen for ovarian cancer. We are supporting some large screening trials for ovarian cancer based on older technology. We are hoping that, as proteomics move ahead, we will be able to open larger screening trials for ovarian cancer. We are a little further behind on endometrial cancer. Our portfolio of basic research is not as big as we would like it to be. We are sponsoring a State of the Science trial in concert with the United Kingdom National Cancer Research Institute in November, in large part to see how we can push the field for endometrial cancer.

Senator HUMPHRIES—Thank you very much.

Senator FERRIS—Would you be able to give us a breakdown of the $4.7 billion research budget? I am interest to know how much of that budget is spent on gynaecological cancer research.

Dr Trimble—I can get that to you by email. I do not have those figures off the top of my head.

Senator FERRIS—That is fine.

Dr Trimble—As I recall, about $100 million is for ovarian cancer, perhaps $90 million is for cervical cancer and about $40 million is for endometrial cancer. We will email you the exact figures.

Senator FERRIS—Thank you. Does your organisation have any material on public education campaigns for those forms of cancer? In Australia it is well understood that women need to be aware of the need for pap smears, but one of the difficulties that have come out in evidence concerning ovarian cancer is the need for women to be aware of some symptoms which are vague and often ill-defined, which often means that ovarian cancer is not discovered until much later in the process. What are you doing about a public education campaign?

Dr Trimble—One of our sister agencies, the Centers for Disease Control and Prevention, has a public education campaign targeting ovarian cancer and the vague symptoms that you have mentioned. They have worked with the society of oncologists and several of the ovarian cancer advocacy groups in helping to identify these symptoms and to develop a broad based educational campaign.

Senator FERRIS—Where is the Centers for Disease Control and Prevention located?

Dr Trimble—It is in Atlanta, Georgia.

Senator FERRIS—A member of our committee has a rural background, and I know that she will want to ask you about patient assisted transport. But I will begin that theme by asking: what arrangements are made for women in remote areas of the United States to be treated for diseases such as gynaecological cancers? Do you have a system where those women have to come into a centre, or do you have some of your people going out to those rural areas on a regular basis? How is that done?

Dr Trimble—We rely on both approaches, but we know that this is an area where we need to do more. We recently hosted a summit meeting on cancer health disparity. It became clear at that meeting that much more needs to be done for rural cancer patients. As you mentioned, often the treatment facilities are in the large cities, so to get the best radiation therapy or surgery, one needs to go to the big city. This is a problem for patients living in rural areas, particularly if they need to make multiple trips. So we have efforts, working with our advocacy groups, to set up temporary residences for people so that they can live for a month or six weeks next to the treatment facility. We also work with a variety of advocacy groups, including the American

Cancer Society, to help with transportation. But we know this remains a major issue in ensuring that rural patients get state-of-the-art care.

Senator ADAMS—Is there any sort of scheme available to rural patients to help them with fuel for their car, flights or accommodation? Is any funding available to these people from the government?

Dr Trimble—Not so much from the government. We do have a limited set of money for patients who are treated at the National Cancer Institute clinical centre. If patients are accepted on protocol at this research hospital in Bethesda then we do pay for transportation, wherever they live. But for patients who are treated outside the National Cancer Institute clinical centre there are unfortunately limited funds available. It varies from state to state and from county to county. Some localities have set up excellent programs using their own tax dollars as well as support from the advocacy community, such as the American Cancer Society, to find help with transportation as well as housing. But it is a major challenge in many areas of the United States.

Senator ADAMS—Do you have many patients who suffer from lymphoedema of the lower limbs or body from gynaecological cancer in the United States?

Dr Trimble—We do. The major cancer in which we see lymphoedema is vulvar cancer. Fortunately, vulvar cancer is becoming rarer, so the number of cancers is small and the number of women who experience lymphoedema is correspondingly small. Nonetheless, it is a very bothersome issue. We are running a clinical trial to see if we can modify surgical technique to improve lymphoedema. We are also seeking to learn from our colleagues with expertise in the treatment of breast cancer by checking some recommendations they have to reduce lymphoedema.

Senator ADAMS—Are there any public health services that do the treatment for lymphoedema?

Dr Trimble—As I recall, most of our insurance carriers, including Medicare, will pay for some services related to the treatment of lymphoedema. The challenge is to make sure people are compliant with those treatments and to come up with better treatments. We do not have a treatment today that is 100 per cent effective in preventing lymphoedema or in curing people of it once it develops.

Senator ADAMS—I ask that question because of the time it takes to provide physiotherapy for lymphoedema treatment. It is a problem in our smaller towns for patients to access the number of treatments they need in the time the physiotherapist is available. A physio can probably do four ordinary physio sessions in the time it takes to do one session for a lymphoedema patient. That is a big problem for us here. Is that happening over there?

Dr Trimble—I do not know what the restrictions are. We have a variety of healthcare plans and they all have different rules, which is very confusing for the patients and the doctors. The other issue we have to a greater extent than you do is that 40 million Americans have no health insurance whatsoever. So the greatest challenge we have is making sure they get appropriate cancer care.

Senator ALLISON—You said in your opening statement that US and Australian investigators in cancer clinical trials have been hindered by difficulties in obtaining ongoing financial support for clinical trials infrastructure. Could you expand on that? Is the problem mostly in Australia, or is the US not lifting its weight? How much money is required, in your view, and how much infrastructure are we talking about?

Dr Trimble—The United States has been supporting infrastructure for clinical trials for the past 50 years. We budget approximately $US150 million each year to help support that infrastructure. That is not as much as we would like to give. We know that many of the institutions that participate in our clinical trials have to contribute their own money to supplement the money we give them so that they can conduct that research. We pay on average a per capita payment of $US2,000 for each patient approved for clinical trials. At the current time the pharmaceutical industry pays closer to $US5,000 to $US6,000, which we think is closer to the true cost at the institutional level. We are very grateful to the institutions and the doctors in the United States and elsewhere who participate in our trials, because we know the money we are able to give them is not enough.

On the issue of collaboration between Australia and the United States, we have seen strong support from the paediatric oncology community in Australia, which has been able to raise charitable funds to help support the infrastructure for clinical trials. It has been harder for the oncologists in Australia to raise money from charity to support adult clinical trials. Only within the last two years has support come both from the federal government in Canberra. As well, I know the New South Wales Cancer Institute has earmarked money to help support some of the Australian groups that happen to be headquartered in New South Wales.

Senator ALLISON—Central to our inquiry has been the question of why gynaecological cancer has received far less attention publicly and research dollars than, say breast cancer, where we have a very good record of improvement to recovery. Is it also the case in the United States and do you have a specific body that advocates for gynaecological cancer? People tell us we need to not just tack gynaecological cancer onto our breast cancer council, but to have a gynaecological cancer centre in Australia which would bring together research, advocacy and awareness and so on. How does it work for you?

Dr Trimble—We have found that an approach focused on gynaecologic cancers has been an effective one. In practice in the United States, breast cancer is generally managed by a different group of individuals—whether radiation oncologists, medical oncologists, surgical oncologists—than gynaecologic cancer. In addition, the advocacy groups have largely been separate. So through the National Cancer Program and through the activities that we do at NCI and at our sister agency, the Centers for Disease Control and Prevention, we have more focus on individual cancer sites such as ovarian cancer, cervical cancer, or breast cancer. Where we have tended to lump things together it has been under the heading of ‘gynaecologic cancer’, which has been largely separate from breast cancer.

Senator ALLISON—And you advocate that approach? Would you encourage us to go down that path too?

Dr Trimble—I don’t feel comfortable giving you strong advice on what to do because you know your situation in Australia better than I. I did look at the ovarian cancer centre website that

you have set up. It is a part of the Breast Cancer Centre website. There did not seem to be any links to any other gynaecologic cancers. So I certainly think it would be reasonable for you all to consider the possibility of a gynaecologic cancer research centre that would focus on the major gynaecologic cancers.

Senator ALLISON—Thank you very much.

CHAIR—Do you have any comments to make about workforce issues? It has come up quite consistently in the evidence before us that there is a desperate need to have appropriately trained and dedicated people across a range of medical expertise working together in these areas. We have had evidence—I have forgotten the name—from another doctor from the US who talked about concerns with the number of medical oncologists coming through, particularly in gynaecological areas plus in radiology and physiotherapy, the whole gambit. Would you care to make any comments about the workforce?

Dr Trimble—Certainly, we have learned the importance of having individuals who screen and treat women for gynaecologic cancer trained in the specific requirements that are appropriate for these cancers. We know that patients do better if they are treated by individuals, whether those people are medical oncologists, surgical oncologists, gynaecological oncologists, radiation oncologists, nursing oncologists or social workers who have day-to-day experience with gynaecologic cancer. Their outcomes are better, whether it is in terms of overall survival or quality of life. So the challenge comes for two areas—first in making sure that you have the appropriately trained individuals, as well as ensuring that as many patients as possible get to those individuals.

CHAIR—We have also heard evidence about the need for appropriate social supports for people going through the process, and one of the areas where there has been a great lack of research is looking at those psychosocial elements. In the range of trials that you oversee through your organisation, have any trials been done on those kind of things—the personal, sociological support for people?

Dr Trimble—Very much so. We have a strong research focus on the psychosocial aspects of cancer treatment and cancer survivorship. We look at these issues in terms of the prevention of ovarian cancer, in terms of screening for cervical cancer during treatment and after treatment, and end-of-life care. We think this is a critical area of research.

CHAIR—Is there something on a website we could look at on that element? We have been given significant evidence about the clinical trials on drug therapies, surgical therapies and those things but we are a little light on when it comes to clinical trial information about the psychosocial aspects. Can you refer us to something we can mention?

Dr Trimble—We will email you that link. We do have several websites focused on both research and patient education on this topic.

CHAIR—That would be useful. Is there anything that you would like to add?

Dr Trimble—No, I am delighted that you are having this hearing and I look forward to hearing your recommendations.

CHAIR—Thank you very much, and thank you for your time.

Committee adjourned at 9.31 am