# SENATE INQUIRY

# GYNAECOLOGICAL CANCER

**SUBMISSION BY**

**(Mrs) LISLE FRANCES FORTESCUE**

## THIS IS MY STORY – I AM AN OVARIAN CANCER SURVIVOR.

**In March 1998 I was diagnosed with OVARIAN CANCER.**
**What was my response – ANGER?**
**Not that I had ovarian cancer, but rather I knew nothing about it. I had never heard of ovarian cancer. I now know why, because for generations of women, ovarian cancer, and in fact all gynaecological cancers were referred to as WOMEN'S PROBLEMS DOWN THERE.**

**What an indictment on society that in today's era of so called knowledge that every female is not aware that lurking down there may be a killer working in the shadows.**

**I am sufficiently conceited to believe because of my background that if I didn't know about ovarian cancer, how many other women were in the same position.**

**My health has always been a priority. I am of a generation when we grew up with all types of deadly diseases such as scarlet fever, rheumatic fever, both of which I suffered, and the dreaded polio. Thanks to modern science today's children are relatively free of such deadly outcomes, and so they grow to adulthood unaware of health dangers lurking in the background.**

**In my business activities I was regularly reading magazines of all types, Australian and International, fashion and anything to do with fashion, and other general magazines. Never at any stage did I read or hear of ovarian cancer before my diagnosis.**

**A recent event that took place in your Senate Chamber caused me great sadness, and reminded me of how much has to be done in creating awareness.**

Cast your minds back to the RU486 debate. On the very day that Senator Nettle wore into the Chamber a yellow t-shirt shouting the message "Mr Abbott keep your rosaries off our ovaries", I was asked to take the place to speak at a function on ovarian cancer because the named speaker, Kathleen Thornton, had been readmitted to hospital. Kathleen, a 32 year old barrister, with a brilliant career ahead of her, died a few weeks later.

On seeing Senator Nettle wearing such a t-shirt, it was obvious that she did not know anything about ovarian cancer, and that this t-shirt, sponsored by the YWCA, was most offensive to all women suffering and fighting ovarian cancer and their families, not forgetting those families who have lost love ones because of ovarian cancer.

In fact, I want Tony Abbott to have his rosaries on female ovaries, and that as a result of this Senate Inquiry, realistic funding will be provided.

## WHAT WERE MY SYMPTOMS?

Regular gynaecological checkups have always been slotted into my calendar. This is where ovarian cancer is so silent. I was diagnosed in March 1998. In the previous October 1997 I had undergone my regular pelvic check-up and Pap smear. No problem.

Late in February 1998, I was aware that I was being woken from sleep at night to visit the toilet more frequently than usual. On one occasion, on getting back into bed, my left hand fell on my left side, and there was a hard mass. It was only lying down that this mass was evident. Next morning a visit to my female GP, who fortunately immediately detected a problem. Dr Kahlil organised an ultrasound and an appointment with Dr Victor O'Toole, an obstetrician and gynaecologist, that very afternoon.

This was when I had my first CA125 blood test. It was 38 – normal 35. Dr O'Toole was already in touch with Professor Hacker, and they both hoped that it was not ovarian cancer. The CA125 blood test whilst helpful following ovarian cancer can be misleading as a diagnostic tool pre diagnosis.

A full hysterectomy a few days later confirmed that it was in fact ovarian cancer, and I was conscious of a sudden silence from the nursing staff. Please note that often women may believe they have had a full hysterectomy, but find to their peril some years later, they still have their ovaries.

In a conversation with Dr O'Toole, I requested the best professional care possible even if it meant going to New York or London. I will never forget Dr O'Toole's reply. "The very best is right here in Sydney with Professor Neville Hacker.

## MY FIRST APPOINTMENT WITH PROFESSOR HACKER – MARCH 1998

Women who undergo a hysterectomy may believe they are entitled to a period for recovery, but not in my case.

I left the Strathfield Private Hospital on the Monday, a week after the operation, and reported to Professor Hacker at the Gynaecological Cancer Centre at the Royal Hospital for Women at Randwick the following Thursday.

From the moment my husband and I alighted from the lift on level 2, we realized this was something special, and at no time since has my view altered that this is a remarkable centre of excellence, the like of which we must be proud of and support in its efforts to help females of all ages through this difficult time whether it be ovarian cancer, or any other type of gynaecological cancer.

Professor Hacker informed me I had Stage II Clear Cell Ovarian Cancer.
I asked what are my chances.     His reply!

40% SURVIVAL AT 5 YEARS.
Can you imagine any woman receiving this statistic?

Compare this with breast cancer, which is now 87% and rising. I applaud what has been achieved with breast cancer, but it is imperative that the accent diverts to ovarian cancer and other gynaecological cancers which are so personal and embarrassing for every female.

Professor Hacker, in his quiet, expert and comforting manner, explained my situation and his recommendation for treatment. He introduced me to the Sister in Charge of Chemotherapy, who explained the type and nature of the chemotherapy with which I was to be treated. The first treatment would take place the following Monday. Professor Hacker then contacted Professor Friedlander who would supervise my chemotherapy.
Professor Hacker explained the various consultants within the centre, including Ros Robertson, a psychologist, whose input and help within this unit is so invaluable to patients and their families.

As my husband and I returned to the car park, I stated "It will be business as usual". If my survival statistic was 40% at 5 years, it would require all my energy and optimism to keep on top. I told everyone that I had ovarian cancer. Many females are unable to even talk about it to anyone, such is their distress. Fortunately our business activities were conducted from home. Perhaps I could say this was a very productive period for me because

**instead of being out and about fulfilling diary commitments including business trips to New York and London, etc., I was able to commit myself to "thinking" and "planning" for the future. It was a short distance from the computer to the bed.**

## CHEMOTHERAPY

**Everyone knows about chemotherapy but until you undergo the experience, it is impossible to fully comprehend its implications. The Centre had provided me with details of possible problems, and that if at any time, 24 hours – I had any problem to contact them. I used this service on several occasions, and at no time was I ever put "on hold" – answers were always provided.**

**Contemplate for one moment losing one's hair.**

**Whilst in the chemotherapy room, I observed young females with beautiful long hair – their crowning glory, face this horror. I recall on my final visit, a most distressed woman being introduced to the chemotherapy room. She was probably in her mid thirties and had from memory several children. She had beautiful long fair hair. If you don't take steps to cut the hair short immediately, a female faces the prospect of waking in the morning and seeing handfuls of hair on her pillow. (I had short hair but took the precaution of wearing disposable caps to bed so that each morning, I removed the cap and threw it away without looking.) During the day if you happen to touch your hair, the slightest movement, and you will have a handful.**

**Once all your hair has gone, and everyone knows the look, you look at yourself in the mirror and realise this is something real and happening to me.**

**I tried to look on the bright side because all hair goes, so at least I didn't have to wax my legs!**

**Many patients suffer effects of extreme nausea from chemotherapy.**
**The word "constipation" takes on new meaning sometimes resulting in patients being admitted to hospital.**
**If you happen to eat certain foods, mouth ulcers will occur.**

## SECOND LOOK OPERATION

**Following four chemotherapy treatments, Professor Hacker explained that in July I would undergo a further operation with this strange name "second look". I asked how serious compared with the hysterectomy. His response was more serious because it was his task to examine thoroughly the pelvic area to ensure there was no sign of cancer. I now have an impressive scar.**

**Whilst I have never worn a bikini, imagine for a young female how devastating this is.**
**The operation took place on the Monday. The following Friday evening Professor Hacker paid me a visit to inform me that the tests had revealed I was now in remission. However, I was to have two further chemotherapy treatments.**

**On the following Monday, the Centre held a staff meeting when patients and their treatment were discussed, and I knew by the response from this meeting as everyone involved came into my room, how rare such good news is. It made me feel very humble and thankful.**

## IN REMISSION

**Professor Hacker explained to me that every three months I would undergo a CA125 blood test. This is when this blood test is invaluable in supervising the outcome. At five years, the three months turned into six months.**

**Having passed five years, I am now what is called a "survivor", but do not think for one moment that ovarian cancer is ever far from my thoughts. Every six months when I visit my GP for the CA125 blood test, I face ovarian cancer again. Am I still in remission?**

## GYNAECOLOGICAL CANCER CENTRE – ROYAL HOSPITAL FOR WOMEN.

**Because of my business experience, I believe I can comment on this Centre. Never in my experience, and bear in mind I am now 72 years of age, with over 40 years playing a prominent part in my particular expertise, have I experienced such excellence. I may be wrong, but I understand that it is one of the few Australian gynaecological centres caring for females from diagnosis, through treatment and unfortunately in too many cases death. Even with breast cancer, there is no such centre. You will note that I use the word "females" because to say women would indicate older females. Professor Hacker has cared for teenagers aged 13.**

**Professor Neville Hacker is the head of this fine team. He has spent his life taking care of women with such problems. Can any of us imagine a job where explaining death every day is part of the job specification? What amazed me was that so many of the staff at the Centre were originally at Paddington before the new hospital was built.**

## MY PART IN CREATING AWARENESS.

**Following my remission I made a promise to myself that if Professor Hacker ever asked me to support the Centre, vocally, I would do so. To talk about**

**such experiences is always difficult, because they come into the category of things we prefer to forget. To forget in my case would be to forget the thousands of Australian females who will fall victim to this silent killer.**

## AWARENESS BY GPs

**Since remission, I have heard many, many stories of how women feel let down by their GP which results in late diagnosis of ovarian cancer. Imagine for a moment a visit you have made to your GP. You have vague symptoms which could mean anything, and we expect a GP to pin point exactly what is wrong.**
**With many health problems, the GP conducts a blood test which on analysis can result in an outcome.**

**BUT THERE IS NO TEST THAT ALLOWS EARLY DIAGNOSIS FOR OVARIAN CANCER**

**AND THIS IS THE PROBLEM**

**UNTIL SUCH A BLOOD TEST IS DEVELOPED FOR OVARIAN CANCER, WOMEN WILL CONTINUE TO DIE BECAUSE THEY ARE DIAGNOSED AT A LATE STAGE WHEN THE CANCER HAS GONE BEYOND THE OVARIES.**

## GO FUND www.gofund.org.au

**Go Fund stands for Gynaecological Oncology.**

**When Professor Hacker returned to Australia in 1986 after being Director at the Gynaecological Cancer Centre at ULCA, the Go Fund was established to raise funds to establish a small research laboratory at the old Royal Women's Hospital at Paddington.**

**Its aims were:**
**RESEARCH**
**TREATMENT**
**AWARENESS**
**PREVENTION OF GYNAECOLOGICAL CANCER.**

**Since it was established the Go Fund has had many prominent Australians on its Board, some of whom have lost wives and daughters to ovarian cancer.**

**There is now a collaboration between the Gynaecological Cancer Centre at the Royal Women's Hospital at Randwick and the Garvan Institute of Medical Research.**

In 2005, the Go Fund produced a video/DVD as an aid to create awareness and raise funds. This tells the story of Georgia, a 13 year old teenager, trying to cope with puberty but having another problem added to her life, Justine, a 30 year old eloquent, highly intelligent female – now dead, and me, Lisle Fortescue. It also illustrates how the Eckowitz family coped with ovarian cancer and the impact on their lives. Professor Hacker outlines the problems of diagnosing ovarian cancer, and Dr Philippa O'Brien of the Garvan Institute explains her work. This is as simple an explanation as is possible to see, and makes one wonder why we have tolerated such a situation of ignorance for so long of this major problem. It tells a powerful story.

## COLLABORATION BETWEEN GYNAECOLOGICAL CANCER CENTRE AT ROYAL WOMEN'S HOSPITAL, RANDWICK & GARVAN INSTITUTE OF MEDICAL RESEARCH.

It is this collaboration which must be provided with far greater funding than it is now receiving.

If you are looking at a business proposition, you look at who is running it. What is the potential for a successful outcome?

Australia has a history of outstanding success in scientific research, and because of Professor Hacker's expertise, I believe that success here has far more potential than anywhere else in the world. Perhaps others are working on this project, but it would be impossible to find greater dedication, experience and understanding of the task than under Professor Hacker's guidance. Not only is Professor Hacker working locally at Randwick, but his expertise is sort throughout the world. In my experience, when seeing Professor Hacker, the consultation has sometimes been interrupted by other medical people, perhaps in Sydney, Dubbo, Fiji, the Netherlands, Lebanon, of elsewhere calling for advice. Medical people worldwide regularly visit his centre to observe how it is conducted. It is in fact a place of learning for the world.

Professor Hacker has always stated that it is "THE NUMBER OF HANDS ON THE JOB" which is vital for the quickest resolution of the problem. It is not just a matter of one brilliant scientist, but rather the tedious but exacting work day after day by many researchers.

Hands on the job require real investment by Government, because it is impossible for the Go Fund through its fund raising to raise sufficient funds. For example the Go Fund held its major fund raising event, a cocktail party in March, attended by 450 people. It raised $410,000.

**I do not wish to decry any effort to raise funds whether large or small, but we will all be dead before this blood test is discovered at this rate, and future generations will still be wondering what we were doing to solve the problem.**

**Political parties of all persuasion are now realizing that more must be done. Cancer has even been an unwelcomed visitor to some members of the Australian Senate.**

**Having been provided with information regarding NHMRC funding, on reading this, despite the goodwill, one is struck by the unfocused nature of the funding, a few dollars here and a few dollars there indicating lack of proper evaluation into what is really required. The easy way out in other words.**

**THE NO. 1 ISSUE IS RESEARCH RESULTING IN A BLOOD TEST**

**TO ALLOW POPULATION SCREENING FOR OVARIAN CANCER.**

**Easier said than done, but Government must demonstrate emphatically its understanding of the problem by providing funds to the right people to take a further step forward.**

## CONCLUSION

**Listening to the 2006 Federal Government Budget speech delivered by the Treasurer, my spirits rose when he mentioned the words "Garvan Institute of Medical Research".**
**I hope I am not disappointed.**

**In this submission I have covered certain aspects of ovarian cancer from a personal point of view. I also feel very strongly that funding for research addressing gynaecological cancer should be directed at the collaboration of the Gynaecological Cancer Centre at the NSW Royal Hospital for Women at Randwick, and the Garvan Institute of Medical Research, for reasons stated. It is my firm belief that their success will answer many of the other points raised in the Terms of Reference of this Inquiry.**

**This Senate Inquiry provides the opportunity to overcome generations of ignorance of gynaecological problems. My concentration has been on ovarian cancer, because I am a survivor.**

**Never forget**

**AN AUSTRALIAN WOMAN DIES EVERY 10 HOURS FROM OVARIAN CANCER**

**THIS STATISTIC HAS NOT ALTERED SINCE I WAS DIAGNOSED IN 1998**

**and it is just not good enough in 2006.**

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**June 6, 2006**