

ADDENDUM TO BRIEF OF RONALD WILLIAM JONES

1. Thank you for giving me the opportunity to express some personal views. It has been important that patients have appeared before this Inquiry, particularly those with cervical cancer. Equally, it is important that those who directly care for women with gynaecological cancer, such as Dr van der Mark and myself, have an opportunity to present our views. The majority of individuals appearing before this inquiry have never experienced direct contact with women with cervical cancer, and in this group I include Public Health professionals, MOH/HFA personnel and those working in or associated with laboratories. Those of us who deal with real women with cancer, understandably have different perspectives and a more emotional approach to the gross failure of the government sponsored screening programme in Gisborne. There is a world of difference between sitting behind a computer screen tinkering with cancer data or sitting on an ethics committee with a cup of tea, to actually facing a women with cancer. I have cared for women with gynaecological cancers in Auckland for almost 30 years and I am involved in both teaching and research in the field of gynaecological precancer and cancer. I have a sense of déjà vu as I sit here today. A number of us are for the second time in little over a decade involved in a major cervical cancer inquiry.

2. I would like to briefly set the scene with a number of quotations from august medical journals.
 - (i) British Medical Journal 1962 “ A population screening programme is capable of virtually eliminating invasive carcinoma of the cervix”.

- (ii) British Medical Journal 1963. “ Cancer of the cervix must now be regarded largely as a preventable disease”.
- (iii) FIGO 1964. “Cancer of the cervix is now regarded as a preventable disease.
- (iv) FPA Journal 1964. “Deaths from carcinoma of the cervix could be eliminated in this country (UK) before the end of the century”.
- (v) American Journal of Obstetrics and Gynaecology 1964. “We see the day ahead when there will be no more invasive carcinoma of the cervix”.
- (vi) British Medical journal 1965. “ Now the battle against uterine cancer has been won.”

3. I see my role today as an advocate for all New Zealand women, not simply those with whom I have been involved during this investigation in Gisborne. No women wants to get cancer of the cervix. However, it is a fact of life that the prophesies which I have just quoted, are wrong, and that in spite of the best organised cervical screening programmes, some women will develop cancer. I understand that even the best organised screening programmes only achieve an approximate 75% reduction in the incidence of cervical cancer.

I must make it very clear that I regard a well organised cervical screening programme as the cornerstone of any prevention programme. However, it must be understood that all health screening programmes are imperfect. As I will point out later, we must have a broad multifaceted public health programme aimed at improving women’s health generally and incorporating screening policies.

4. It must also be clearly understood that an abnormal cervical smear is simply a report written on a piece of paper. Unless a woman already has cancer, the report has no immediate significance. Of more concern, are those women with already established cervical cancer. Herein lies a paradox in women's health policy. Millions of dollars are spent on a national cervical screening programme, but we have only the crudest information on what is happening to women with cervical cancer – a disease that kills. Let me put things into perspective. The risk of a woman with the most advanced histologically proven precancer (CIN 3) progressing to invasive cancer after 1 year is approximately 2%. (This data comes from the “unfortunate experiment” at the National Women's Hospital). To put it another way, if the lesion is not treated for 10 years, the woman with established cervical cancer may be dead within a year. Surely it is therefore important that we have detailed local and national information on women with cervical, or for that matter any cancer?

Can anyone tell me if the results of cervical cancer treatment in Auckland and Christchurch are the same? A small difference in the median survival time in one centre may point to improved treatment in that centre – something which is important to the individual women.

I heard Dr Duncan talking last week about his ability to “tinker with data”. He is lucky, because he has data! The National Women's hospital is New Zealand's largest gynaecological cancer unit, but we do not have a single piece of clinical information relating to invasive gynaecological cancer on a computer. We have been asking for a data manager for well over a decade, but

we are told that resources are not available for such data collection or analysis. As the young generation would say, “lets get real”. We spend millions on refining a national screening programme, but we have no idea what has happened to women with established cancer – only if they are recorded as a “death” on the national cancer statistics. Surely this country should be spending more dollars on diseases that kill. One can predict that in addition to the cost of this Inquiry, the minister of Health will direct increased resources to the National Cervical Screening Programme. I would suggest the Minister stops for a moment and thinks about those women who already have cervical cancer and asks what she is doing to help them.

5. I am concerned that narrow focus on the terms of reference of the inquiry may lead to a report without the balance I as a clinician would like to see. A narrowly focussed report may suit those involved in the health bureaucracy but it will not serve the best interest of all New Zealand women. Reports such as the one which will emanate for this Inquiry will inevitably be interpreted in a very literal fashion by those involved in the health policy arena – spawning endless committees – each with its own recommendation. The danger is that a narrowly focused report will lead to an unbalanced approach to cancer prevention and management. Cancer prevention requires a broad front.
 - (i) Public health and sexual health policies (HPV).
 - (ii) There must be no barriers (cost, cultural, embarrassment etc.)
to women to present early with symptoms.
 - (iii) Doctors and smear takers must be able to elicit a proper history
and perform an adequate examination.

I would like to digress briefly and again examine our priorities and how we are going to get the best value from our health system. We have four departments of Obstetrics and Gynaecology in New Zealand. Three of the Chairs are currently vacant. I know that Wellington and Auckland have both been vacant for a considerable time and that there are no prospects for (high calibre) appointees in the foreseeable future. When I was young, these were sought after prestigious positions. We need to urgently address the reasons why academic women's health is in such a perilous condition. I would suggest that money spent on good teachers – individuals who can teach students how to inspect the cervix and take a good smear – would be an excellent investment in any cervical cancer prevention strategy. Is it too much to ask the community to fund a Chair into research into gynaecological cancer? This would be much cheaper than having another cancer fiasco in the future.

(iv) Cervical cytology, which is the cornerstone of a prevention programme.

(v) Management strategies for cervical cytology abnormalities:

Colposcopy – the tables attached to my Brief illustrate that colposcopy is an imperfect investigative tool.

Histopathology - while histopathology is the “gold standard”, it, too, has certain limitations.

Treatment- we know that in the ideal circumstances of treatment up to 3 women per 1000 will develop invasive cervix cancer during long-term follow-up.

- (vi) Prospective audit of the failures of those women who develop invasive cervical cancer.

I note others are now embracing the idea of prospective mandatory reporting and audit into all new cases of cervical cancer. (It is important to differentiate between a retrospective audit as proposed by Professor Skegg, and a prospective audit into newly diagnosed cases). Some of us have been promoting prospective audit for some time . The Working Party which addressed the question of “Management of Women with Abnormal Cervical Smears” (1998) recommended this approach. The details are set out in Section 10 of my brief. Following publication of this report about 2 years ago, I discussed the issue with Bette Kill and Dr Peters at the HFA. While both listened sympathetically, I left our meeting with the very clear impression that this was “too hard” and that nothing would happen. I was right. But this Inquiry came along and now the idea is now being promoted by others. It is amazing the effect that an Inquiry like this can have.

One of my major fears is that this Inquiry will lead to increased litigation, as it has elsewhere in the world. Few women will benefit financially from this approach. Unfortunately it will not improve their prospects of cure from the disease.

A process of perspective audit of all new cases of cervical cancer will involve changes to the present legislation and will involve legal protection for the

parties concerned. I would recommend an independent committee of two individuals, an experienced gynaecologist and an experienced cytopathologist with ability to co-opt.

6. Cancer research. When someone is told they have cancer, two immediate questions come to their mind – will I die and why me? The next response of most people is to ask what can be done to help and why don't we know more about their particular cancer.

New Zealand has an abysmal record in the study and research of gynaecological cancer, the most important studies being those which led to the first Cervical Cancer Inquiry.

I was extremely upset when I learned that the Gisborne Ethics Committee had hidden behind the cloak of privacy legislation in refusing Professor Skegg's research application. As I have already said, I have been caring for women with gynaecological cancer for nearly 30 years. I know that the women with cancer would have wanted, indeed expected, such research to go ahead with urgency. With time, I have become increasingly cynical and angry about those politically correct individuals who with no personal experience of such awful circumstances create and hide behind any unreasonable legislation in order to prevent further progress in the understanding of cancer.

The next challenge for the Gisborne Ethics Committee will be to decide whether the scientifically important data gained as a result of this unfortunate incident can be used to benefit both Gisborne and other New Zealand women in the future.

7. The development of the NCSP has unfortunately coincided with the politically driven changes which have reshaped our health services. (“Reform” is the wrong word because it might suggest improvement!) we need to ask whether the corporate approach has been conducive to the development of the NCSP? The Inquiry must examine in detail the role of the various National Co-ordinators. Why have we had five National Co-ordinators in 10 years? What were the backgrounds of the incumbents, were they suitable for the post, what did they achieve, why did they all stay such a relatively short time in the post etc? If the HFA places such importance of the NCSP, we must learn why the most recent appointee to the National Co-ordinator’s post is only part-time? It is in my view that the National Co-ordinator of a cervical screening programme must be a dedicated full-time employee.

I know I speak for many health professionals when I say that we are really concerned about the Ministry /HFA being able to carry out the tasks allotted to it. Have there been or are there people in the Ministry of Health / HFA with the knowledge, experience and skills necessary to make the policies or to develop, maintain and monitor NCSP? There is plenty of evidence at this stage to demonstrate the answer in NO. I have concerns about the “preferred Provider” process for HFA contracts relating to cervical screening. How much nepotism is involved in the appointment of those who formulate the HFA policy. There needs to be much more transparency and “names on documents”.

Aside for the issue relating to the NCSP which I have just presented, I have to say that the HFA team led by Tracy Mellor have in my opinion carried out a very difficult operation with great skill, attention to detail and with the best interests of the affected women at heart. Importantly, Tracy and her team have never shirked from a commendably open and honest approach to the multitude of issues.

Three Gisborne women- Goldie Proffit, Shona Teaho and Missie Winiata have done much to assist and facilitate the process of clinical re-evaluation in Gisborne.

8. I started by commenting on the fact that this is New Zealand's second major inquiry into cervical cancer and I would like to end by comparing these two tragedies. The responsibility for the events leading to the 1987/88 Cervical Cancer Inquiry lay entirely in the hands of the medical profession. No-one else could be blamed. Since that time two important events have taken place. Firstly, the development of a corporate health structure and, secondly, the development of the NCSP – initially with the Ministry of Health and latterly by the HFA. By and large medical professionals (certainly clinicians) have been excluded from the new health bureaucracy. The present disaster has followed these two latter events and represents a damning indictment of New Zealand's recent public health strategies. The primary responsibility for the systems failure which have led a group of Gisborne women to develop cervical cancer and in some cases die from it must in my opinion lie fairly and squarely with successive governments, Ministers of health and their departments. (See

the “Government Policy for National Cervical Screening” 1991 – which states “ monitor the quality of smears ”). Dr Bottrill’s alleged incompetence was only the most visible evidence of a failure of a much larger health medicine. The misplaced loyalty by some of Dr Bottrill’s pathology colleagues only serves to deflect the primary responsibility from those who were charged with the task of developing maintaining and monitoring the National Cervical Screening Programme.

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