AUCKLAND WOMEN'S HEALTH COUNCIL

Submission to the Gisborne Cervical Cancer Inquiry

The Auckland Women's Health Council (AWHC) is an umbrella organisation for individual women and women's groups in the Auckland region who have a commitment to women's health issues. The focus of the Council which was formed 12 years ago is broad and spans many issues that are of interest to women, particularly those that impact upon their health and the health of their families.

The Council has a special interest in matters resulting from the Cartwright Inquiry into the Treatment of Cervical Cancer at National Women's Hospital and has actively supported the establishment and ongoing development of the National Cervical Screening Programme as part of its commitment to women's health and to patient rights. As will be seen from the statements made in our submission the AWHC has been involved in a number of important ways with promoting the programme to women and lobbying for its survival in a health system that has undergone major restructuring and experienced considerable upheaval over the past 10 years.

In beginning our submission the AWHC would make a number of points regarding the Inquiry and the reason it was set up. The Council is very mindful of the needs of the Gisborne women who are the victims of this medical disaster and who are owed at the very least a special duty of care. Council members support their call for the Inquiry to be held in Gisborne rather than Auckland. They are after all the main players and witnesses in this Inquiry and they should be able to attend the hearings if they wish. Holding the Inquiry in Auckland will effectively deny them this right.

The AWHC strongly supports the right of the women in Gisborne to choose their own legal representation. It is unacceptable for the Maori women in Gisborne to not to have access to Maori legal representation paid for by the government. Once again these women are being denied choices in terms of getting their special needs met.

The Council also believes that the issue of compensation for all those whose lives have been placed at risk by this women's health catastrophe must be included in the Inquiry's terms of reference. It is unconscionable for the women to have to go through months of an Inquiry and then have to start all over again with another legal process in order to address the issue of their right to compensation.

History of AWHC's support for the NCSP

The AWHC has actively supported the establishment of the cervical screening programme since before its commencement in 1993. This was part of the Council's determination to see all of the recommendations in the Cartwright Report implemented. As part of a network of women's health councils and women's health groups, the AWHC

has promoted the programme and encouraged women throughout the country to have regular cervical smears and to opt to go on the Cervical Screening Register.

The Council subsequently put a considerable amount of time and effort into supporting the change to make the Register an opt-off register instead of an opt-on register as Council members were aware that many women were not being told about the existence of the register and the many advantages of being included on it. The successful outcome of our lobbying efforts meant that many more women were then included on the register who would otherwise not have been. This helped the NCSP to meet its enrollment targets.

The Inquiry's Terms of Reference
The AWHC's submission will now focus on the eight terms of reference that the Inquiry has been charged with addressing.

Term of Reference 1
To determine whether there has been an unacceptable level of under-reporting in consequence of mis-reading and/or mis-reporting of abnormalities in cervical smears in the Gisborne region.

Based on the media reports on the level of under-reporting of abnormalities in cervical smears the AWHC urges the Inquiry team to recommend that all the work of this laboratory be urgently reviewed.

Term of Reference 2
If you determine that there has been an unacceptable level of under-reporting, to identify the factors that are likely to have led to that under-reporting.

The AWHC submits that the NCSP has made considerable progress in meeting the objectives that were set when the programme was established. It has also survived the constant restructuring within the health system over the past 8 years remarkably well. However, there has been a price to the years of constant change.

Lack of central office and screening co-ordinator
Because the NCSP did not fit with the health reforms the programme was split between a number of departments within the Ministry of Health and the Health Funding Authority. . This occurred despite the fact that the World Health Organisation identified "a central office or individual responsible for planning, co-ordinating, monitoring and evaluating the programme" as being a key organisational requirement for a successful screening programme. (1)

The AWHC believes that the failure to establish and maintain a central office has been one of the factors that have led to the lack of knowledge in the RHA/HFA and in the Ministry of Health about what was going on in Gisborne and the fact that so many

abnormal smears were being under-reported. There was no-one with the appropriate authority and responsibility checking to see that standards were being maintained, monitoring all aspects of the programme and taking the necessary action when problems were identified.

No evaluation or regular audit of the screening programme

Another factor has been the lack of a full evaluation and review of the NCSP which may well have identified such problems before women's lives were lost and others had their lives seriously compromised. Despite repeated calls from women's health groups, health professionals and health agencies for a full evaluation of the NCSP no evaluation of the screening programme has been undertaken. Associate Health Minister Katherine O'Regan issued a statement on 30 June 1996 stating that there would be review of the NCSP in 1997 as set down in 1993 when the programme was launched. (See Appendix 1)

There can be no doubt that had the NCSP been undergoing regular audits as it should have been, the problem which has been identified in Gisborne would have been detected much earlier. Other problems may also have been revealed.

Substandard laboratories

Another factor involves the lack of accreditation of Dr Bottrill's laboratory. In 1994 the government's accrediting agency, Telarc, inspected the laboratory and found that it did not meet the required safety standards. One of the problems that was identified was that Dr Bottrill was reading just 20 slides a day when it was considered necessary that at least twice that many should be read to meet the required standards.

Another factor was that Dr Bottrill had no peer review system in place, a process whereby the slides he had examined and judged to be normal were rapidly rescreened by another technician.

The fact that this laboratory continued to screen slides as part of the cervical screening programme despite its failure to meet the required safety standards is unbelievable, totally unacceptable and reprehensible. The AWHC demands to know how the Regional Health Authority was able to continue paying out for what had been identified by its own accrediting agency as a grossly substandard service.

Māori

Pathologists with no training in cytology

It has subsequently been revealed that Dr Bottrill had no formal training in cytology. The system whereby all pathologists already in practice can be admitted to the Royal Australasian College of Pathologists without having to pass the entrance exam has resulted in large numbers of pathologists practising cytopathology with no qualifications by examinations and this has undoubtedly been a contributing factor in the unacceptable level of under-reporting of abnormalities in cervical smears.

The AWHC believes that there is a need to undertake an urgent review of the formal qualifications of all practising pathologists who are part of the NCSP in New Zealand.

Term of Reference 3
If you determine that there has been an unacceptable level of under-reporting, to satisfy yourselves whether or not this was an isolated case rather than evidence of a systemic issue for the National Cervical Screening Programme.

The AWHC is of the opinion that the unacceptable level of under-reporting of abnormal smear results that has already been reported by the Sonic Healthcare laboratory is unlikely to be an isolated case. Our opinion is based on many of the factors referred to already in our response to Term of Reference 2. For example, the system of pathologists being "grandfathered" into cytopathology is very likely to have caused problems elsewhere in New Zealand and to be a systemic issue for the NCSP.

As there has been no review or audit of the NCSP, there is no way of ascertaining whether what happened in Gisborne is an isolated event. It is now vital that this Inquiry determines what the true situation is in order to provide reassurance that all aspects of the cervical screening programme are meeting the required standards.

The Council submits that common sense suggests this is likely to be a systemic issue for the NCSP due to the fact that there are other rural areas throughout the country in which pathologists are or have been isolated and their work was not checked, or the laboratories concerned were not monitored and any deficiencies followed up. There has also been the previous experience of the pathologist from Good Health Wanganui who misdiagnosed more than 50 cancer patients. Dr James Burkinshaw was responsible for misdiagnoses that resulted in some patients having unnecessary surgery including six women who had unnecessary mastectomies, while others who had been told their tumours were benign were later told they had cancer. This was another case of a lone pathologist whose work was not checked until it was too late.

The AWHC believes that a <u>full</u> evaluation is needed to enable problems such as this to be identified and dealt with as soon as possible. How many tragedies will it take before appropriate systems are put in place that ensure standards are being met at all times?

Term of Reference 4
To identify changes already made to legislation, to laboratory or other processes or to professional practices to address the risks of under-reporting of abnormalities in cervical smears.

The AWHC is aware that all community pathology laboratories are now internationally accredited and that the Royal Australasian College of Pathologists has instituted a compulsory continuous professional development programme. These two measures will help to ensure that problems already identified with respect to pathologists with no

training in cytology or working in isolation, and laboratories which have not been accredited are a thing of the past.

Term of Reference 5
To identify other changes agreed to be implemented, either by the Government or by professional organisations, that will further address any risks of under-reporting of abnormalities in cervical smears.

In response to a letter from the AWHC dated 30 September 1999 then Minister of Health Wyatt Creech stated on 1 November that the screening programme is currently being evaluated by both the Ministry of Health and the Health Funding Authority:
"The Ministry's evaluation will be undertaken by an independent team and will assess the appropriateness of follow-up and treatment for women with abnormal smears. The team will also audit the screening histories and treatment of women who have invasive cervical cancer…
The Health Funding Authority is reviewing operational aspects of the programme and has identified areas that need strengthening and improving." (Appendix 2)

However, the AWHC believes that these reviews fall far short of the full evaluation outlined in a document produced by the University of Otago for the Ministry of Health dated 30 April 1998 and entitled "*Evaluation Plan For the NCSP*." In response to one of the AWHC's letters the then Minister of Health Wyatt Creech referred to this document as a draft.

However, the copy of the document that the Council has in its possession does not include the word draft on the title page.

The AWHC submits that a full evaluation of the programme must be undertaken and that the reviews currently being undertaken are not enough. There may be other problems with the NCSP which are contributing to under-reporting of abnormal smears which have yet to be identified.

The AWHC has also been involved in making submission on the Health Funding Authority's draft documents "Policy and Quality Standards for the National Cervical Screening Programme" and "Evaluation and Monitoring Plan for National Cervical Screening Programme." The Council understands that there will be a second round of wider public consultation on these two documents over the next few months. It has not been lost on Council members that had such standards been put in place at the outset then the horrifying events at Gisborne would not have occurred.

Term of Reference 6
To consider all relevant proposals that could ameliorate any risks of under-reporting of abnormalities in cervical smears and identify whether these are covered by 4, or 5 above and whether further changes are needed.

The AWHC argues that there is an urgent need to reinstate central co-ordination of the NCSP. The Council's evidence of the need for this is based upon both the Cartwright Report and the requirements identified by the WHO.

The AWHC begins by referring back to the Cartwright Report. At the bottom of page 201 of this report in the chapter on cervical screening Judge Silvia Cartwright wrote:
"The Ministry of Women's Affairs, in its consultation with New Zealand women, has identified a population-based cervical screening programme as one of the most pressing women's health issues. The Ministry recommends establishing a '**national, centrally co-ordinated** screening programme which is based on the needs of women [and which] must be acceptable, culturally appropriate, and affordable.'"

On page 205 of the same report Judge Cartwright wrote:
"The introduction of a **centrally-organised** but regionally-based cervical screening programme will need **strong leadership** to develop and maintain it. In most parts of the world a director is appointed to co-ordinate and provide the leadership for what in New Zealand will be an innovative programme. I believe that this is essential to the success of any such programme."

And on page 207:
…"there are several factors which lead me to favour a programme that is centrally organised" …

The AWHC maintains that the screening programme has become fragmented and that this is partially responsible for the situation that developed in Gisborne.

The AWHC also submits that **all** of the World Health Organisation's key organisational requirements for a successful screening programme must be implemented immediately. These include:

- A central office or individual responsible for planning, co-ordinating, monitoring and evaluating the programme
- an agreed policy and set of objectives for the programme against which to measure the programme
- computer-based information systems
- extensive continuing coverage of the eligible population
- quality control of both smeartaking and smear reading
- measures to ensure that women with abnormal smears are followed up and treated.

The NCSP is a public health activity and as such it requires the establishment and continued maintenance of high quality services. In the case of the NCSP these services include the recruitment of women, smeartaking, laboratories, and follow-up care for women found to have abnormalities.

The AWHC would also emphasise that regular scheduled evaluations of the NCSP must be undertaken to ensure that the programme is meeting the required standards and to

reduce the risk of under-reporting and of any other problems with smeartaking and smear reading.

The Council would also refer to section 3.6 of the Ministry of Health's 1996 policy document. (1)

The list of MOH responsibilities on page 26 includes the item *"monitor and evaluate the NCSP*."

The list of RHA responsibilities on page 27 includes the *item "monitoring and evaluation of the NCSP in each RHA region*." The fact that we are making submissions and appearing before this Inquiry is evidence that these agencies have not fulfilled their responsibilities.

The AWHC submits that this must now change. There must be regular evaluations of the screening programme. A number of women's health groups including the AWHC have been writing letters to the Minister of Health and the Ministry of Health for several years requesting an full evaluation of the screening programme, and arguing for the need for regular monitoring. Copies of the letters the Council wrote last year and the responses we have received are included in Appendix 2.

Reinstatement of the expert group

The Council recommends that the expert advisory group to the Minister of Health "representative of a wide range of women health consumers and appropriate health professionals" be re-established. This group was set up in wake of the Cartwright Inquiry and was one of Judge Cartwright's recommendations. (2) The Council argues that an expert group is needed to ensure that all aspects of the programme are adequately resourced and monitored, to enable women health consumers to have a voice and in this way be accountable to New Zealand women and the general public, and to provide some stability to, and a form of continuity and ongoing support for the programme.

Protection needed for the NCSP

The AWHC notes with considerable concern the many changes which the NCSP has undergone over the past 6-7 years as a result of the health reforms and the constant restructuring of New Zealand's health agencies. The Council believes that this Inquiry must make strong recommendations to the government that there is an urgent need to establish a central programme that will be free from instability and an environment of constant change. A centralised national structure must be established which will be safe from any further "health reforms."

Term of Reference 7

To comment on any other issue the Inquiry Team believes to be of particular relevance.

Compensation for the women
The AWHC requests that the Inquiry Team deals with the question of compensation for the Gisborne women. The system has let these women down badly and it is unacceptable for the Inquiry not to deal with this issue and make some recommendations to the government about compensation. It is unacceptable morally, financially, psychologically and emotionally for the women of Gisborne to be put through a full Inquiry and then once it is over to have to start all over again with another legal process in order to obtain compensation.

Although compensation for those affected by the events leading up to this Inquiry have not been included in any of the terms of reference, the AWHC urges the Inquiry to address the need for compensation for the women under Term of Reference 7.

Term of Reference 8
To make recommendations, consistent with section 4(a) of the Health and Disability Services Act 1993, as to any future action the Government or its agencies should consider taking.

The AWHC suggests that "in order to secure for the people of New Zealand the best health" the recommendations the Council has made throughout our submission need to be adopted. These include:

- Acknowledging that the health reforms have not been in the best interests of the NCSP and the programme needs to be established in line with WHO recommendations and kept free from any further restructuring and instability.
- Regular audits and reviews of the NCSP as described in the document "Evaluation Plan For the NCSP."
- A requirement that all aspects of the NCSP meet the appropriate standards and that services which do not meet the required standards are immediately excluded from the programme until they do measure up.
- Re-instatement of the NCSP expert group with emphasis on consumer representation and participation.

In conclusion the AWHC would add that as previously indicated the Council would like to appear before the Inquiry to speak in support of our submission. We wish to do this as late as possible in the proceedings so that we may add further points as we feel necessary.

Lynda Williams

On behalf of the Auckland Women's Health Council