

**UNDER THE HEALTH AND DISABILITY
SERVICES ACT 1993**

**IN THE MATTER OF THE MINISTERIAL
INQUIRY INTO THE UNDER-REPORTING
OF CERVICAL SMEAR ABNORMALITIES**

BRIEF OF EVIDENCE OF ELIZABETH ANN MARSHALL

**WITNESS FOR THE
CANCER SOCIETY OF NEW ZEALAND, INC.**

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1. My full name is Elizabeth Ann Marshall, known as Betsy. I live in Auckland, where I have lived since moving to New Zealand from the United States in 1976. I have a social science background, with bachelor and masters of arts degrees from Wittenberg University and the University of Hawaii.
2. Since 1990 I have been employed as the Health Promotion Policy Adviser (formerly Health Education Officer) by the Wellington-based National Office of the Cancer Society of New Zealand, Inc, working from an office in Auckland. My key responsibilities include the development of policies on cancer screening; advocacy for effective national cervical and breast cancer screening programmes; advocacy for a national cancer control strategy for New Zealand; and the development of health information on cancer causes, prevention and early detection. In these roles I draw upon the advice and expertise of a wide range of specialists from outside the Society. Some of these specialists, like Dr. Brian Cox, serve in a voluntary capacity as members of the Society's National Health Promotion Committee.
3. During the past ten years I have been a member of a number of national groups advising on cervical, breast and colorectal screening. I am also a member of the National Cancer Control Steering Committee and played a major role in implementing the Committee's plans for a National Cancer Control Workshop in August 1999.
4. Prior to assuming my current national role, I was employed for fourteen years as a Health Education Officer by the Auckland Division of the Cancer Society.

The Cancer Society of New Zealand

5. The Cancer Society of New Zealand (CSNZ) is an independent, non-profit organisation, which receives no direct financial support from government. Funding comes mainly from donations and other fundraising activities. The Society has six regional divisions and a national office in Wellington.
6. The goal of the Cancer Society is to reduce the number of people who develop or die from cancer and ensure the best quality of life for people with cancer.
7. The Cancer Society acknowledges that the most common form of cervical cancer, squamous cell cancer, is largely preventable through effective cervical screening. Its information refers to the estimate that “if cervical screening is done effectively, it should be possible to reduce the number of women who develop cervical cancer by 70% and the number who die by 65%”. (EAM/CS/0001) The information also states that in order to be effective, screening must be provided in an organised way. It must also be oriented to the needs of the women using it.

CSNZ Role in the NCSP

8. As outlined in the Cancer Society’s National Strategic Plan for Health Promotion, the role of the Cancer Society with respect to cervical cancer is advocacy for an effective National Cervical Screening Programme (NCSP) which meets the World Health Organization requirements for effective screening.
9. As early as the 1960’s the Auckland Division of the Cancer Society supported a screening programme involving general practitioners in

the Thames region. Since that time the Cancer Society has helped to support cervical screening-related workshops and meetings, and it has produced several publications for general practitioners on cervical screening annexed as **EAM/CS/0002**.

10. Prior to the establishment of the NCSP, the Cancer Society produced and distributed leaflets and information sheets for women regarding cervical smear tests, smear test results and colposcopy. I annex examples of these as **EAM/CS/0003**.
11. During the early establishment of the NCSP, when responsibility for most health education materials was devolved to Area Health Boards, the Cancer Society became aware of the resulting inconsistency of information being produced. For this reason it produced a leaflet on cervical smear tests and the cervical screening register. I annex as **EAM/CS/0004** a copy of that leaflet and a report on its pre-testing prior to publication.
12. I annex as **EAM/CS/0005** a report on a post-test conducted among a small sample of women. The test compared the statement "...cancer of the cervix can be prevented" with the statement "...cancer of the cervix can *usually* be prevented". Based on the findings, the Cancer Society decided not to add "usually".
13. In 1985, 1990 and 1997 the Society provided financial support to three Department [Ministry] of Health /Cancer Society working groups to advise on routine recommendations for cervical screening.
14. In 1987 the Auckland Division of the Cancer Society was a party to the Cartwright Inquiry. One of its main concerns as a party was to address the teaching regarding cervical screening at the Postgraduate School of Obstetrics and Gynaecology and to present evidence to

support the establishment of a national screening programme in New Zealand.

15. Since the Cartwright Report recommended the establishment of a national screening programme, the Cancer Society has played an advocacy role during its early development and subsequent implementation phases, as illustrated by the letter to Dr Poutasi of 6 August 1996 produced by Ms Glackin as JMG/MOH/0091.
16. As indicated by the evidence of Janice Hobbs, support services staff of the Cancer Society act sometimes as advocates for patients.
17. During the past eleven years the Cancer Society has supported my membership of various national cervical screening advisory committees and my input into the development of health education materials produced by government agencies for the National Cervical Screening Programme. An example is the educational kit produced jointly by the Department of Health and the Cancer Society in 1990, referred to by Ms Glackin in her evidence.

My Involvement in Cervical Screening

18. My involvement in cervical screening began in 1983 when I initiated and co-ordinated a research project on factors affecting the response of women to cervical screening undertaken by Victoria Grace. I annex as **EAM/CS/0006** an article by Ms Grace reporting on the findings of the research. The survey found that screening was predominantly doctor-initiated and appeared to be offered to women who were middle-class, Pakeha or younger (under the age of 45) more often than to women who were working-class, Maori or older. Based on the results, the Society piloted a scheme to increase the number of women actively offered screening by their general practitioners. I annex as **EAM/CS/0007** copies of information

materials, including a description of the scheme, offered on a national basis to general practitioners in 1989.

19. In 1984 I was involved in a symposium in Dunedin at which Dr Jocelyn Chamberlain, a well-known English epidemiologist, identified the need for a population-based cervical screening programme in New Zealand.
20. As described in a Cancer Society newsletter attached as **EAM/CS/0008**, Dr Chamberlain presented a comparative analysis of data from Nordic countries, demonstrating the differences in cancer incidence rates between those countries with organised screening and those countries without.
21. Concerned about the need for uniform advice for doctors and women on the advised frequency of smears, I helped organise the working group supported by the Cancer Society and the Department of Health chaired by Professor David Skegg.
22. The report of this working group, known since as the “Skegg recommendations”, was published in August 1985 and was produced by Dr Boyd as GRB/MOH/0007. These recommendations have since formed the basis of cervical screening policy in New Zealand.
23. The Department and the Cancer Society jointly called a meeting in November 1985 to discuss the implementation of the “Skegg recommendations”. The meeting recommended that “the aim be to design a national cervical screening programme within 3-4 years”. The proceedings of the meeting were published in a report, (produced by Dr Boyd as GRB/MOH/0008) which was circulated for comment in 1986.

24. Responses to the report, which I attach as **EAM/CS/0009**, reflected a diversity of views. Those from the Postgraduate School of Obstetrics and Gynaecology at National Women's Hospital, for example, questioned the value of mass screening to the individual average woman. Laboratory representatives highlighted the need for quality control, with one recommending that the Health Department fund only TELARC assessed labs which, for efficiency, could be in four main centres.
25. The Department of Health did not confirm the "Skegg recommendations" as a basis of policy on cervical screening until January 1987, as documented in the letter I attach as **EAM/CS/0010**.
26. In 1986 I became a member of a Department of Health Cervical Screening Working Party, chaired by Dr Boyd, which met over the next two years to consider submissions to the meeting report and to make further recommendations. As indicated in my report to the Cancer Society, which I attach as **EAM/CS/0011**, meetings focused on specific issues and sought the views of invited participants and groups.
27. The Department of Health subsequently produced a report, which I attach as **EAM/CS/0012**. I participated in many drafts and redrafts of this report, which I understood to be a report of the Working Party. In his evidence, Dr Boyd (para 44) refers to a report under the same title as the background paper for the meeting, which took place immediately after the Cartwright Report. He produces a report of that same title as **GRB/MOH/0010**. There are differences between the text of the report which Dr Boyd produces and the draft, which I produce.

28. In the report, which I annex as EAM/CS/0012, the Department indicates that it did not advocate a nationwide screening programme at the time.
29. The Ministry of Women's Affairs disagreed with the Department of Health's position, and their statement of support for an organised programme was inserted. I produce a copy of the letter from the Ministry of Women's Affairs as **EAM/CS/0013**.
30. In 1987/88 I assisted counsel representing the Auckland Division of the Cancer Society at the Cartwright Committee of Inquiry. I attended throughout the hearings.
31. Since 1989 I have served on the following advisory committees on cervical screening:
- Ministerial Review Committee on Implementation of a National Cervical Screening Programme (1989)
 - Auckland Area Health Board Cervical Screening Advisory Group (1990-1995)
 - National Cervical Screening Programme Expert Group (December 1989-February 1991)
 - National Cervical Screening Programme Advisory Committee (CSAC) on Monitoring and Evaluation (1991-1994) – Chairperson
 - Cancer Society/Department of Health Cervical Screening Working Group (1991)
 - National Cervical Screening Programme Policy Advisory Group (1994-1996)
 - Ministry of Health Cervical Screening Advisory Committee (May 1995- June 1996)
32. I ceased to be a member of any Ministry of Health advisory committee at June 1996, when the term of that CSAC expired.

Although there was a new committee, which did not meet until June 1997, I was not invited to be a member. By that time I was serving on the advisory group developing the evaluation plan for the programme. I recall being told by the National Co-ordinator that I would not be invited to be a member of the new committee. The reason given was that my membership of the evaluation advisory group was considered a potential conflict of interest.

33. Currently I am a member of the Health Funding Authority Advisory Group for Population Based Screening Programmes, for which I served as acting chair during the first five months of this year.
34. In 1997 I was contracted to write a history of the National Cervical Screening Programme as part of the 1997 draft evaluation plan developed by Drs Brian Cox and Ann Richardson. The draft plan was produced by Ms Glackin as JMG/MOH/0047.
35. My involvement in most of the committees referred to above corresponds with that of Dr Brian Cox, whose evidence I have read. I will not cover the same material but will refer to my own experiences, with particular emphasis on my participation in the Expert Group, of which Dr Cox was not a member.
36. In my experience, the implementation of the NCSP has been compromised by the absence of a fully resourced, national coordination unit with the appropriate range of expertise, working within a stable environment. This absence undermined the capacity of the national advisory committees of which I was a member to operate effectively.
37. In highlighting some of these issues as they relate to the committees of which I was a member, I do not wish to appear critical of the

national co-ordination staff. In my experience all the national co-ordination staff have worked tirelessly for the programme. In addressing certain shortcomings, I also do not wish to detract from the significant achievements of the NCSP, which has been New Zealand's first national cancer screening programme.

38. In my view the NCSP would not have survived without the sustained commitment of many people over an extended period of time, including those with whom I have served on various advisory committees.

39. The specific issues on which I shall give evidence include:

- The vulnerability of NCSP to political change and instability.
- The effect of devolution/decentralisation within the health system on the NCSP.
- Ambivalence of the Department of Health towards implementation of the Cartwright Report with particular reference to the NCSP.
- Inadequacy of information and data in critical areas such as budget and screening coverage.
- Inadequacy of staffing within the Department of Health in terms of levels and expertise.
- Communication difficulties between advisory committees and the Department of Health.
- Lack of information regarding staffing responsibilities within the Cervical Screening Implementation Unit.
- Initial implementation of the NCSP before full development of policy.

Ministerial Review Committee

40. On 5 August 1989 I attended a workshop called "A Day of Reckoning" convened by the Auckland Women's Health Council.

Participants of the workshop included consumers and representatives of the Ministry of Women's Affairs and The Health Alternatives for Women (THAW). Helen Clark, then Minister of Health, attended part of the plenary session.

41. On 11 August 1989 I recorded in a letter to Ms Clark the recommendations of that workshop. I annex this letter and Ms Clark's reply as **EAM/CS/0014**. These recommendations reflected the concern of those attending that the recommendations of the Cartwright report on cervical screening were not being properly implemented.
42. Dr Alan Gray, the Medical Director of the Cancer Society shared these concerns at the time. He wrote to Ms Clark on 18 August 1989, and I annex a copy of his letter as **EAM/CS/0015**.
43. In response to these and other concerns expressed by other parties, the Minister appointed the 1989 Review Committee.
44. It has always been my impression that the Government at highest levels was committed at the outset to the establishment of a screening programme as recommended by Judge Cartwright. This is reflected in the letter to Dr Gray from Ms Clark, that I annex as **EAM/CS/0016**. This letter superseded a letter sent to Dr Gray by Dr George Salmond, the Director General of Health, which I attach as **EAM/CS/0017**. In his letter, Dr Salmond invited the Cancer Society to nominate a representative to a team to review the implementation of the National Cervical Screening Programme. He anticipated that meetings would be held every 4-6 months for at least the next 18 months. In her letter, Ms Clark said that this proposed timetable was not satisfactory to her and that she had decided to replace the envisaged review with an

immediate Ministerial review into the programme. She said that Heather Simpson of her office would chair the review.

45. Notwithstanding the Government's commitment, by the time the Ministerial Review Committee was appointed, many decisions about the programme had already been made at Departmental level. These were often in the absence of policy and/or inconsistent with the recommendations of the Cartwright Report. Examples included the "opt-on" register and the absence of a system for recording histology information.
46. Also by the time of the Review Committee, the Department had designed the programme to fit the newly adopted decentralised health system of fourteen area health boards, with fourteen separate registers.
47. The report of the Review Committee has been produced by Ms Glackin as JMG/MOH/0001.
48. In its report, the Review Committee expressed concern that Area Health Boards seemed to have been working without clear guidelines as to the objectives of the NCSP and without a policy framework to structure their regional programmes. It stated on page 14 that "there was an urgent need to develop policy for this programme and to put in place strong national leadership to give some direction to the boards programmes".
49. The Review Committee recommended the formation of an Expert Group. It suggested that the role of that Group should be to advise the Minister on policy issues, and the Department of Health's role should be to ensure that the policy was implemented.

50. The Review Committee also recommended the formation of a small working group to recommend policy guidelines for education and publicity activities. This group comprised Dr Brian Cox, Dr Gillian Durham, two staff members within Health Education Services of the Department of Health and myself. I attach as **EAM/CS/0018** the recommendations of this group regarding the epidemiology of cervical cancer and priority groups for cervical screening. The group passed their recommendations on to the Expert Group for use in developing policy for the programme.

The Expert Group

51. Following the Review Committee's recommendations, Helen Clark appointed the Expert Group to advise on policy and oversee the implementation of the NCSP. I note Ms Glackin's statement that no agendas or minutes of the Group have been located on Department files. I have what I believe to be a near-complete set of minutes. These have been available for inspection by all parties at the offices of the Auckland Division of the Cancer Society since before the commencement of these hearings. I attach as **EAM/CS/0019** selected sets of minutes to which I shall refer.
52. The work of the Expert Group was undertaken at meetings of the whole Group, at meetings of sub-committees and by individuals. I was a member of the sub-committees on Education, Communication and Acceptability and on Register and Evaluation. Other groups included Training and Monitoring of Smear-takers and Issues affecting Maori and Pacific Island Women. Recommendations of these sub-committees, which met regularly until the policy document was drafted, were incorporated into the Policy Statement of the National Cervical Screening Programme Expert Group produced by Ms Glackin as JMG/MOH/0005.

Expertise and Performance of the Expert Group

53. I have seen the memorandum of Sandra Davies to the Minister of Health of January 1991 produced by Ms Glackin as JMG/MOH/105.
54. I note several issues regarding the expertise and performance of the Expert Group raised by Ms Davies in this memo.
55. Ms Davies' views do not coincide with my personal recollections.

56. I am disturbed by the statement of Ms Davies that the Group was comprised of members who were “not ‘experts’ in their own, or related areas”. On the contrary, they brought a wide range of expertise and experience consistent with what both Judge Cartwright and the Ministerial Review Committee had recommended.
57. Mrs Koopman-Boyden, currently a professor and Dean of the Faculty of Arts and Social Sciences at the University of Waikato, was the chair of the Group. At that time she brought to the Group twenty years experience in academic institutions, with a strong background in research-based policy development.
58. Membership of the Group included an epidemiologist, pathologist, gynaecologist, general practitioner, a senior medical officer of the Family Planning Association, a senior nursing officer of the New Zealand Nurses Association, a senior staff member of the Ministry of Women’s Affairs, five consumer representatives and myself.
59. The consumer representatives were individuals who could advise in particular on acceptability to consumer groups, and we knew that acceptability of the programme to women was a key priority to its success. They included two Maori, one Pacific Islands, a representative from the Health Alternatives for Women and Sandra Coney. All had considerable experience in women’s health and were well respected by the groups they represented. Most of these women devoted considerable time outside meetings, in the main at their own expense, engendering support and trust among women for the programme.
60. Though the membership was large, in my experience Mrs Peggy Koopman-Boyden chaired the meetings with considerable skill and

expertise. On assuming the chair three months after the Group had started meeting (Heather Simpson from the Minister of Health's office chaired the initial two meetings), she quickly identified problems and facilitated their solution. I annex as **EAM/CS/0020** her memo of 16 May 1990, which I consider accurately represents the experiences of the Group and the issues that it faced at this time.

61. Some of the issues identified in this memo included the following:

- Problems associated with the Group being formed midway through the NCSP being established.
- Absence of programme policy.
- Absence of information necessary for policy development.
- Unavailability of budget information.
- Difficulty of working with the Department of Health due to lack of clarity regarding the relationship between the two bodies.
- Difficulty in communicating with the Department, in part due to Department representatives not always being present at meetings.

62. I also note that the memo from Ms Davies asserts that the Group was unable to work as a group, often unable to reach a consensus decision, with the result that from one meeting to the next, decisions made were debated, and often altered.

63. The Expert Group had eleven meetings over a fourteen-month period, and I was present at all but two of these. Although we often had full and frank discussion about a wide range of complex and difficult issues, I do not recall ever not having reached a consensus.

64. From the time that Mrs. Koopman-Boyden assumed the chair on 29 March 1990 the Group recommended that the Department undertake a number of projects critical to inform the development of policy. Examples included literature reviews, a national survey on

incidence of cervical screening and a review of the programme by an overseas expert, Dr Judith Straton. I annex as **EAM/CS/0021** and **EAM/CS/0022** respectively, two of my reports to the National Education Committee of the Cancer Society dated 4 October 1990 and 6 March 1991. These memos summarise the work of the Expert Group.

65. The Group's major project was the policy statement produced by Ms Glackin as JMG/MOH/0005. I note that the completion of this document is evidence that the Group was operating at a very high level of competence with full consensus. I refer further to this document later in my brief.

Relationship of Expert Group with the Department of Health

66. In her memo, Ms Davies refers to the Expert Group "having reservations about its relationship with the Department of Health". In my view a number of factors contributed to such reservations.
67. Without question, I recall the tension between the Expert Group and the Department of Health. A contributing factor to this may have been the wide range of complex technical and ethical issues, which had to be addressed by the Group. Perhaps unlike other Department advisory groups, the Expert Group was responsible for advising on the development of a complex programme encompassing all aspects of the screening pathway. Deliberations required a level of detail which may have been unprecedented in such advisory groups.

Inadequate Staffing Levels and Expertise within the Implementation Unit

68. The tasks expected of the Group, all whom were in full-time employment, required maximum support from the Department of Health. In my view the Department was unable to provide such support, in part because of the inadequate number and lack of continuity of staff working in the Cervical Screening Unit, as well as the limited range of expertise.
69. I believe that the Expert Group was also frustrated by the lack of staff to undertake essential work, such as developing the policy statement. At its meeting of 29 March 1990 (EAM/CS/0019, page 5), the Group recommended that a policy analyst or someone employed on contract develop the policy statement to accompany the National Guidelines for Cervical Screening Services. Although several people from outside the Department subsequently were employed, two members of the Expert Group, Sandra Coney and Robin McKinley, undertook a substantial part of the task.
70. In her review of the NCSP, which took place in June 1990 and was produced in a report annexed by Ms Glackin as JMG/MOH/0004, Dr Straton (page 56) refers to the number of changes that had taken place in personnel in the Cervical Screening Unit. She states that this led to a lack of continuity, and considerably reduced the effectiveness of the unit because of low morale and a loss of “institutional memory”. She also stated that the “situation is exacerbated by the lack of staff with a medical or nursing background”.
71. In her memo to the Expert Group of 22 May 1990, which I attach as **EAM/CS/0023**, Sandra Davies reported that the Women, Child and Adolescent Health Policy Section was “40% under staff establishment”. At unit manager level (including the National Co-ordinator) the Section was “66% under staff establishment”. She

acknowledged that, as a result, “the department preparation on Expert Group is holding brief only”.

72. In its letter to the Minister of Health of March 1990 the Expert Group expressed concern about the lack of medical/technical expertise in the Unit with the departure of Dr Gillian Durham and the discontinuation of her position within the Unit. I attach this letter as **EAM/CS/0024**. The Medical Director of the Cancer Society expressed similar concerns in his letter dated 30 March 1990, annexed as **EAM/CS/0025**. Although the Minister of Health indicated in her letter of 14 May 1990, annexed as **EAM/CS/0026**, that the Department would be investigating ways to remedy this situation, to my knowledge no suitable arrangement was made at that time or during subsequent terms of advisory committees of which I was a member.
73. As stated in a letter from Gillian Durham to the Auckland Area Health Board attached as **EAM/CS/0027**, the Department of Health also was undergoing restructuring in 1990, with the “new” department coming into being on 1 February. At that time all staff in the Cartwright Projects area, other than Dr Durham, were new and the Department was moving premises.
74. As acknowledged by the Expert Group chair in her letter to the Minister of Health dated 23 November 1990 (annexed as **EAM/CS/0028**), “until mid-1990 there was no support for the Expert Group from the Department of Health, and little action on the part of the Department itself”. However, in terms of the NCSP staff and the Expert Group the problems had been largely resolved in the latter part of 1990.

Communication between Expert Group and Department of Health

75. I believe that another factor contributing to the uneasy relationship between the Expert Group and the Department of Health was the limited access of the Group to staff in the Implementation Unit, other than management staff. In a letter dated 26 April 1990, annexed as **EAM/CS/0029**, I refer to a phone call I received from a senior advisory officer who I did not know was part of the unit. She explained that she was attending a women's health conference in the United States at her own expense and wished to know where she could go there to learn more about cervical screening. She expressed concern about the staff's relationship to the Expert Group and her desire to have more direct communication with us.

Lack of Data

76. In some cases the data essential to inform the development of policy was unavailable from the Department. As a result, the Group was unable to make firm recommendations until research it identified was undertaken. It is possible that someone like Ms Davies who did not have a research-based policy background would not have fully understood these matters.
77. After her first meeting, Mrs Koopman-Boyden wrote to the Minister of Health expressing the Group's concern about the urgent need for up-to-date statistical information on cancer incidence in New Zealand (**EAM/CS/0030**). The letter recommended as a matter of urgency that the Cancer Registry be resourced with equipment, staff and the legislative framework to provide such information.

Department of Health Ambivalence towards the NCSP

78. In my view, one of the key factors contributing to the tension between the Expert Group and the Department of Health to which I referred earlier was the Group's perception that the Department was not committed to a national programme. I recall that it was for this reason that Sandra Coney tabled a report on "The case for a National Cervical Screening Programme" at the meeting of 29 May 1990. I attach this report as **EAM/CS/0031**.
79. Throughout the period from the commencement of the Cartwright Inquiry up to at least 1991, both the proceedings and the report of the Inquiry were the subject of sustained attack by members of the medical profession. Examples included an article by Dr Erich Geiringer in the *Listener* of November 1988 entitled "Trial in Error"; an article by Dr Graeme Overton in the *Dominion Sunday Times* of March 1989 entitled "Cartwright Report Based on a Scam"; and an article in *Metro* magazine July 1990 entitled "Second Thoughts on the Unfortunate Experiment". Against this background it must have been difficult for any but the most expertly informed personnel to sustain a commitment to the implementation of the Cartwright Report.
80. The Expert Group's scepticism about the Department's support is evidenced by a cartoon, which was circulating among us in May 1990, which I annex as **EAM/CS/0032**. This scepticism may have been well founded; it transpired that the following year the Department of Health reduced the Expert Group's seventy-page policy statement to a ten-page document (produced by Ms Glackin as JMG/MOH/0015).
81. On 2 August 1990 the Expert Group wrote to the Minister of Health, expressing concerns about the commitment of Government to the NCSP, the budget for the programme, the limitations of the register

and the continuing communication difficulties with the Department of Health. The letter, which I attach as **EAM/CS/0033**, referred to reservations being expressed within the Department of Health about the need for a nationally co-ordinated programme.

82. The minutes of the 13 September 1990 meeting (EAM/CS/0019, page 11) record that the chair had received a reply from the Minister, confirming the Government's commitment to the programme. According to these minutes, Heather Simpson from the office of the Minister of Health, also attended the meeting.
83. I also refer to my report to the Cancer Society's National Education Committee on 4 October 1990 (EAM/CS/0021). In this I referred to the Expert Group's awareness of opposition to the programme, which was based on the adherence by some to the principle of devolution of all health services to Area Health Boards.
84. On 19 October 1990 I wrote a confidential memo to Dr Bridget Robinson, Chair of the Society's National Education Committee, and Dr Peter Dady, Medical Director, which I annex as **EAM/CS/0034**. In this I refer to the lack of support of senior level staff to a nationally co-ordinated cervical screening programme based on the belief that Area Health Boards should be left to develop their own programmes. The memo also refers to the Director General of Health's delay in signing a contract for the purchase of Area Health Board computers (which I describe as a delaying tactic until the election), despite instructions from the Minister of Health on two occasions.
85. In the minutes of the Expert Group meeting of 1 November 1990 (EAM/CS/0019, page 19) the chair thanked the cervical screening programme staff for their assistance in arguing the case for the

Director General's signing the register contract, which had been signed the night before the election.

86. As indicated in her press release of 18 October 1990, produced by Ms Glackin as JMG/MOH/0006, the Minister of Health, Helen Clark, endorsed the need for a nationally co-ordinated programme.
87. On 15 November Mrs. Koopman-Boyden wrote to the new Minister of Health, Mr. Simon Upton, to provide a synopsis of the situation to date with the NCSP and stressing the need for the full implementation of a nationally co-ordinated programme. I annex her letter as **EAM/CS/0035**.

Vulnerability of NCSP to Political Change

88. In the memo of 4 October 1990 annexed as EAM/CS/0021, I referred to the Expert Group's concern about the likely future of the programme under a changed government. On or about 16 November 1990, the new Minister of Finance, Ruth Richardson, announced that all extra spending commitments made by the outgoing Labour government during the election campaign, including \$4.5 million for the NCSP, had been suspended pending review by the Cabinet. I attach a memo I wrote to colleagues in the Cancer Society, which included the Minister's press statement, as **EAM/CS/0036**.
89. At a meeting of the Expert Group on 4 December 1990 (EAM/CS/0019, page 28), the National Co-ordinator reported that the Department was facing "huge problems" following this announcement that programme funding had been frozen. The Expert Group also discussed the ongoing uncertainty regarding the NCSP and concern that the new Associate Minister of Health responsible for the programme, Katherine O'Regan, had raised "doubtful questions"

about the register. It was agreed that the Government needed to be persuaded on what the essential components of a national programme were.

90. On 13 December a delegation from the Expert Group, including Mrs Koopman-Boyden, Dr Ruth Bonita and Dr Clinton Teague, met with the new Associate Minister of Health, Katherine O'Regan. According to the minutes of the 1 February 1991 meeting of the Expert Group (EAM/CS/0019, page 34), discussion had not focussed on the reasons for having a national programme but on what the obstacles were in achieving this goal. The meeting noted this as a positive step.
91. On 14 December 1990 the chair, together with George Salmond and Ian Johns from the Department of Health, met with Katherine O'Regan. A summary of the meeting is provided in a memo from Mrs. Koopman-Boyden dated 18 December 1990 (EAM/CS/0037) and in the minutes of the 1 February meeting (EAM/CS/0019, page 34).
92. At the 14 December meeting the Associate Minister gave assurances that the budget issues for the programme would be "sorted out" and would not be a problem. She also endorsed key policy recommendations put forward by the Expert Group, instructing the Department to implement these.
93. These events demonstrate the way in which the Expert Group, and, no doubt other parties committed to the NCSP, continually were having to fight for the survival of the programme.
94. According to the above memo, there was also some discussion at the meeting regarding responsibility for the national register. In response

to the Director General's opinion that the register should be contracted out, e.g. to an Area Health Board, Mrs. Koopman-Boyden said "it was important to have the Department in an overseeing role over all the area health boards". She notes, however, that a "watchful eye will have to be kept here". (EAM/CS/0037)

95. According to the memo, the Chair of the Expert Group also questioned Dr Salmond and Mr Johns regarding who in the unit would be undertaking all of the work relating to programme implementation, including meetings with doctors, etc. In response to their view that this was the co-ordinator's responsibility, she commented that she did not see this as possible without contracting someone at a reasonably senior level to assist. In her view the lack of staff on the ground had been responsible for problems in programme implementation.

The Cervical Screening Advisory Committee (1991-1994)

96. As the chair of the CSAC which met from May 1991 until October 1994, I confirm that the terms of reference of the Committee are those included in Appendices 1 and 2 of the Committee's final report produced by Ms Glackin as JMG/MOH/35.

Staffing Levels and Expertise during CSAC's Term

97. In his brief of evidence Dr Cox refers in paragraphs 91, 96, 120, 129, 133, 142, 164, 166, 177, 179 and 187 to the concerns and advice of the Cervical Screening Advisory Committee (1991-1994) regarding staffing and resource issues relating to the NCSP co-ordination unit. I wish to cite briefly some additional references and summary information. Most of the minutes to which I refer have been produced by Dr Cox as BC/CS/0004.

98. During the 1991-1994 period there were two national co-ordinators. There were also two five-month periods of time when the co-ordinator's position was vacant (July 1992 to February 1993 and September 1994 to January 1995).
99. Minutes of the CSAC meeting of 15 June 1994, annexed as **EAM/CS/0038**, record on pages 3 and 4 the concern of the Committee that when the position of Maori Co-ordinator was established, one of two analyst positions was disestablished. The minutes also note that the Maori Co-ordinator had no operational budget.
100. The position of register co-ordinator, which had been recommended by Dr Straton in 1990 and endorsed by the CSAC at the 13 September 1991 meeting (BC/CS/0004, page 22), had not been established during the Committee's term. Instead, the work was undertaken on contract, resulting in a high use of resources and the loss of opportunity to build up in-house expertise.
101. In its final report, produced by Ms Glackin as JMG/MOH/35, CSAC refers on page 4 to the impact of insufficient staff and resources on the unit's ability to directly monitor the fourteen local registers, resulting in variations of procedures and data coding between areas.
102. As documented on pages 68 and 69 of the history of the NCSP contained within the Monitoring and Evaluation Plan produced by Ms Glackin as JG/MOH/0047, staff changes and resignations resulted in a two-year delay in the revision of the NCSP policy, which began in early 1994. The policy was not published until 1996.

103. By the end of the term of CSAC in 1994, none of the original NCSP staff were in office. The Committee's final report states that this had serious implications for a programme with a high degree of operational functions for which specific expertise is required on a day-to-day basis. In the Committee's view, this delayed the amalgamation of the fourteen separate registers into one national register and the correlation of cytology and histology results. (JMG/MOH/0035, page 5)
104. The final report of CSAC (page 13) also refers to the difficulty in recruiting and retaining permanent staff with the appropriate expertise (e.g., in the fields of public health and epidemiology) as a barrier to programme monitoring and evaluation. It highlighted the need for in-house personnel for routine monitoring to compile performance measures, identify when they are unsatisfactory and alert the person with overall responsibility for appropriate action. The report also noted that the availability of expertise predominantly through advisory groups rather than through salaried staff did not adequately fulfil this need.
105. On 21 December 1994 I received a letter from the Associate Minister of Health, responding to the recommendations in the CSAC final report. These included the need for good operational leadership with a public health perspective on a full-time basis and paid staff with expertise from several disciplines, including medicine, epidemiology, statistics, computing and cytology.
106. In her letter produced by Ms Glackin as JMG/MOH/0036, the Associate Minister listed the staff at that time. These included two national co-ordinators, an analyst and assistant analyst, a register co-ordinator, a programmer and a help desk person. She also stated that

the unit had formal access to a medical advisor and a part time word processor/support position.

Vulnerability of the NCSP during Health System Restructuring

107. Substantial changes to the health system were announced by the Government shortly after the first meeting of the CSAC in 1991. As a result, the Committee became involved in advocacy for an NCSP which could meet the WHO requirements for effective screening within the reformed system.
108. In its final report the Committee outlined in Appendix 3 (JMG/MOH/0035, pages 23-26) its submissions and correspondence relating to the NCSP within the reformed health structure. Some of this correspondence is produced as JMG/MOH/0088.
109. In his brief of evidence, Dr Cox also makes reference in paragraphs 73, 86, 94, 96, 97, 99, 101, 104, 107, 111, 118, 120 and 130 to Committee discussions and documents related to the continuation of the NCSP within changes to the health system.
110. Like the events arising during the term of the Expert Group, these subsequent events further demonstrated the way in which those of us committed to the NCSP were constantly fighting for its survival.

The Cervical Screening Advisory Committee (1995-1996)

111. In his brief of evidence (paragraphs 188-213), Dr Cox cites some of the issues addressed by the next CSAC at its meetings in May 1995, August 1995 and February 1996. I attach as **EAM/CS/0039** minutes of the final meeting, which took place immediately following Dr Cox's resignation from the Committee.

112. As noted on pages 2, 3 and 5 of these minutes, the Committee discussed the Ministry of Health's memorandum to the Minister of Health regarding the review of accountabilities of the NCSP. This memorandum was produced by Ms Glackin as JMG/MOH/0040. As indicated in the minutes, the CSAC stressed the need for one national programme with strong national operational leadership, rather than four programmes run by four RHAs. The Committee acknowledged that the NCSP did not fit in the reformed health sector, and that this was not "the first attempt to make it fit". The minutes note that the Committee continued to discuss the review after the Ministry of Health officers left the meeting, before members met with the Associate Minister of Health, Katherine O'Regan. I recall that at the meeting with the Associate Minister, the Committee expressed its grave concerns about the proposed changes.

113. These discussions again demonstrate the way in which advisory committees continued to argue for the survival of a national programme. Over and over, during the years when advisory committees should have been focused on the effective implementation and operation of the NCSP, we were unable even to rely on its continued existence.

My Involvement in Issues Concerning Patient 1 and the Gisborne Situation

114. I recall receiving a phone call from Janice Hobbs of the Gisborne/East Coast Centre of the Cancer Society in 1997 regarding Patient 1. Although I made notes of our conversation, and subsequent conversations with her and with Di Best, the National Co-ordinator of the NCSP, I no longer have these.

115. I recall Ms Hobbs explaining to me that R, the mother of Patient 1, had contacted her. Ms Hobbs said that the cervical smear tests of Patient 1, who had been treated for cervical cancer, had been misread. She said that the Medical Tribunal had considered the case and that Patient 1 would be making a public statement about her case and the Tribunal's findings.
116. Ms Hobbs was aware that such publicity probably would result in other women being concerned about their smear test results and contacting her for advice. She asked my advice as to how to respond to such calls, based on national policy. I recall suggesting to Janice that she contact the local cervical screening manager, and I offered to contact Di Best, the National Co-ordinator.
117. I recall phoning Di Best and relaying the information Ms Hobbs had given to me, indicating that the woman concerned had come from Gisborne. I recall that our conversation focussed on how Ms Hobbs and the Ministry of Health could respond to women's concerns about the accuracy of their smear tests, should the case be publicised. I also recall asking Ms Best whether the NCSP had a protocol in place for investigating the cases of women with mis-read smears who were enrolled in the programme. I recall that our conversation focussed on the appropriate response to any media publicity relating specifically to Patient 1, rather than on the responsibility of the programme relating to specific cases of mis-reading.
118. It is my recollection that Ms Best agreed to consult others in the Ministry, including corporate communications and possibly Dr Gillian Durham, about the matter. Although I recall having a second phone conversation with Ms Best soon thereafter, I do not recall any further communication about the matter once I learned

from Ms Hobbs that Patient 1 had decided not to issue a press statement.

119. In late March 1999, soon after an article was published in the NZ Herald on 20 March regarding the rulings of a High Court case regarding Patient 1, Ms Hobbs phoned me. She clarified that the case involved the woman about whom we had spoken in 1997. She said there was a possibility of other women in Gisborne who had developed invasive cervical cancer whose smears possibly had been misread. She said that the mother of Patient 1 had told her that Dr George Hitchcock had offered to re-read slides, and she asked my opinion on whether women should contact him.
120. I phoned the Health Funding Authority and arranged to meet with members of the public health team responsible for the NCSP to discuss the matter. The meeting, which took place on 30 March 1999 (just prior to Easter), was attended by Bette Kill, HFA Manager of Public Health, Julia Peters, Jane McEntee and myself.
121. At the 30 March meeting I indicated that, according to Ms Hobbs, other women in Gisborne possibly were affected by mis-read smears. As a result, the Cancer Society was recommending that the HFA undertake an external review of the laboratory concerned. Ms Kill indicated that because personal health services were responsible for laboratory contracts, they would need to address any "micro issues" regarding laboratory performance. According to my diary notes, I stressed that women had been assured through the NCSP resources, particularly when the programme was being established, that the register would help to ensure quality and audit. For this reason a review of the lab concerned was essential.

122. Between 30 March and 9 April, when I again met with the HFA staff, I had a number of phone discussions with Ms Hobbs and HFA public health staff. I recall telling Janice on several occasions that the HFA required more concrete evidence concerning the possibility of other women being affected by misreading. On 13 April I advised her by fax to advise anyone with concerns to request that they or their doctors contact Dr Peters.
123. On 9 April 1999 I met again with the HFA public health staff. At that meeting I was informed that the HFA would be undertaking a project to address concerns about the Gisborne laboratory and the pathologist concerned and that this project would be the responsibility of Personal Health Services, with input from members of the public health team. I attach as **EAM/CS/0040** a draft letter, which I wrote following the meeting to confirm my understanding of the HFA proposal. I sent this draft to Ms Kill, to ensure it reflected accurately the discussions at the meeting. When Ms Kill came to see me several days later, she said she was not keen for me to send the letter at that time. I believe this was because the personal health services of the HFA were still in the process of defining the scope of the project and considering the possibility of bringing in overseas expertise.
124. On 28 April 1999 the media reported statements made in Parliament by the Alliance health spokeswoman, Phillida Bunkle, that an unknown number of women may be at risk from having their smears read by an unnamed North Island pathologist. Following this and subsequent publicity, I became actively involved in discussions with the HFA, Cancer Society expert advisors and staff and others regarding how to address adequately the Gisborne “situation” and the increasing concerns of women. During the next month I kept a log of action detailing these activities.

125. In April and May 1999 there was growing concern among some Cancer Society staff that the HFA was not acting swiftly enough in providing a definitive response to the Gisborne situation.
126. Being involved in numerous discussions with the HFA during this period, I believe that an important factor contributing to the length of time required for the HFA to respond was the split in responsibilities for the NCSP between the public and personal health operating groups within the HFA. It was my impression from discussions with the public health team at the outset that until this crisis, there had been limited communication between the two groups.
127. Dr Peters has referred to concern expressed by other external stakeholders regarding the divisions of roles and responsibilities for the NCSP in para 165 of her brief of evidence.
128. Earlier this year the HFA decided to transfer responsibility for laboratory services, along with the National Cervical Screening Register and colposcopy services, to the Public Health Operating Group. In its letter of 6 March 2000, which I attach as **EAM/CS/0041**, the HFA Public Health Screening Advisory Group applauded this transfer as a major step towards meeting the World Health Organization requirement for one office having responsibility for the programme.
129. In my view, another reason for the delay was the absence of a standard protocol for responding to such concerns. I note that Dr McGoogan has produced as *EM/CA/0002 Guidelines for Managing Incidents in the Cervical Screening Programme*, which provides guidance for such a response.

The National Cervical Screening Programme and a National Cancer Control Agency

130. The HFA document *Framework for public health screening programmes*, produced by Dr Peters as JMP/HFA/0016, page 3, indicates that the breast and cervical screening programmes should be considered as components of a national cancer control strategy.
131. Dr Peters also produced an internal HFA draft paper on strategic options for screening programmes within current changes to health system as JMP/HFA/0031. The paper states that one of the principles for planning is sustainability over the long term in a changing environment. It also identifies as one of the strategic options, the establishment of a separate entity responsible for national co-ordination and funding for both programmes.
132. In his brief (para 31), Dr Cox cites the advice in the booklet *Cervical Cancer Screening Programmes: Managerial Guidelines* that if cancer control has been designated to a special agency, the designated official responsible for screening should be within that agency.
133. I concur with the views expressed by Dr Cox in his brief of evidence (para 254 and 255) that a Cancer Control Agency should be established to have responsibility for cancer control in New Zealand.
134. I also concur with his view stated in paragraph 257 that the central offices for the NCSP and the breast screening programme, the databases of these programmes and the Cancer Registry should be placed in this agency.

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Elizabeth Ann Marshall

Exhibits Produced by Elizabeth Ann Marshall

Ref No.	Exhibit
1	Selected Cancer Society of New Zealand information sheets on cervical screening (2000).
2	Selected Cancer Society of New Zealand publications on cervical screening for general practitioners (1987 – 1999).
3	Cancer Society of New Zealand leaflet <i>The Cervical Smear Test</i> and fact sheets <i>Cervical Smear Test Results</i> and <i>Colposcopy and Biopsy</i> (1989).
4	Cancer Society of New Zealand leaflet <i>Facts on Cervical Smear Tests and the Cervical Screening Register</i> (1992) and <i>Communication Pre-test Prepared for the Cancer Society of New Zealand Incorporated</i> (April 1991).
5.	Report of <i>Testing of Statement in Cancer Society Cervical Screening Leaflet</i> (June 1992).
6.	Grace, M. Factors affecting the response of women to cervical screening. <i>NZ Family Physician</i> 1995; 12: 139-142.
7.	Cancer Society of New Zealand description of general practitioner package on cervical screening and the leaflet <i>Two questions that could save your life</i> (1989).
8.	Cancer Society of New Zealand. Need for Effective Cervical Screening Programme in New Zealand. In <i>Cancer News</i> (September, 1984).
9.	Letter from Floss Caughey, including a summary of submissions to the <i>Report on Screening for Cervical Cancer</i> , to Betsy Marshall (31 October 1986).
10.	Letter from RB Boyd to Professor D C G Skegg (12 January 1987).
11.	Report on Department of Health Cervical Screening Working Party by Betsy Marshall to the Cancer Society of New Zealand (undated).

12. Department of Health. *Towards a More Effective Cervical Screening Service for Women in New Zealand* (August 1998).
13. Letter from Celia Lampe to Dr Bob Boyd (11 February 1988).
14. Letter to the Hon Helen Clark from Betsy Marshall (11 August 1989).
15. Letter to Ms Helen Clark from Alan Gray (18 August 1989).
16. Letter to Dr Alan Gray from Helen Clark (1 September 1989).
17. Letter from George Salmond to Dr Alan Gray (31 August 1989).
18. Memorandum to Education, Communication and Acceptability Sub-Committee of the Expert Group from Betsy Marshall (26 January 1990).
19. Selected minutes of meetings of the National Cervical Screening Programme Expert Group (March 1990 – 1 February 1991).
20. Memo to Members of the Expert Group from Peggy Koopman-Boyden (16 May 1990).
21. Report to the National Education Committee of the Cancer Society of New Zealand on the National Cervical Screening Programme Expert Group (4 October 1990).
22. Final Report to the National Education Committee of the Cancer Society of New Zealand on the National Cervical Screening Programme Expert Group (6 March 1991).
23. Memorandum to Expert Group Members from Sandra J Davies (22 May 1990).
24. Letter to Helen Clark from Peggy Koopman-Boyden (5 April 1990).
25. Letter to Ms Helen Clark from A J Gray (30 March 1990).
26. Letter to Dr A J Gray from Helen Clark (14 May 1990).
27. Letter to the Chief Health Officer, Auckland Area Health Board, from Gillian Durham (21 February 1990).

28. Letter to Helen Clark from Peggy G Koopman-Boyden (23 November 1990).
29. Letter to Robin McKinlay from Betsy Marshall (26 April 1990).
30. Letter to Helen Clark from Peggy Koopman-Boyden (5 April 1990).
31. Coney, S. *The case for a National Cervical Screening Programme. A Report to the Expert Group* (29 May 1990).
32. Cartoon (24 May 1990).
33. Letter to Helen Clark from Peggy Koopman-Boyden (2 August 1990).
34. Memorandum to Bridget Robinson and Peter Dady from Betsy Marshall (10 October 1990).
35. Letter to Mr Simon Upton from Peggy G Koopman-Boyden (13 November 1990).
36. Memo to Helen Glasgow and Peter Dady from Betsy Marshall (16 November 1990).
37. Memo to Ruth Bonita from Peggy Koopman-Boyden (18 December 1990).
38. Minutes of the Meeting of the Cervical Screening Advisory Committee (15 June 1994).
39. Minutes of the Meeting of the Cervical Screening Advisory Committee (12 June 1996).
40. Draft letter to Bette Kill from Betsy Marshall (April 1999).
41. Letter to Dr Don Matheson from Betsy Marshall (6 March 2000).