

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

**IN THE MATTER OF**      The Ministerial Inquiry into the  
under-reporting of cervical  
smear abnormalities

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**EVIDENCE OF ANDREA MILITIA WINMILL (Patient 12)**

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I, ANDREA MALITIA WINMILL of Gisborne say:

### **Introduction**

1. I was born on 22 October 1972. I am 27 years of age. My husband John and I have been together for seven years. We were married on 18 October 1997. We have no children, but for about eight months before my illness, we were trying to have a child. I work as an administrator.

### **Health History**

2. I have had regular smears since I was sixteen years of age. It was advertised, "*never fear have a smear*". I believe that these words were chosen in an effort to coax women like me to have a smear. Therefore, I saw it as being important for my own health and peace of mind to have regular smears. I always believed that the smear results were accurate. No one informed me that smear results were not always accurate.
3. I opted to go on to the national cervical screening register in about 1993. I was about 20 years of age at the time and one of the nurses at the WELL Women's Clinic suggested that I register. The reason I was given was that this would keep a record of my smears that I could have access to.

## Recent Treatment

4. I visited my GP, Dr Cloete for a smear on 22 June 1999. This was because of the publicity about free smears being given in Gisborne. Dr Cloete telephoned me ten days later and told me that I needed to have a colposcopy, as my smear results were CIN III. I knew that this meant that there was something wrong because I was so used to being told that my results were clear. Dr Cloete kept apologising and saying sorry to me. This caused me to be a bit concerned but I still did not think that it was anything serious.
5. When I questioned Dr Cloete further, she told me that it was a very high-grade abnormality and at the stage before it progressed to cancer. She said that she would refer me for a check up to Dr Van De Mark, a gynecologist at Gisborne Hospital.
6. I finally had an appointment with Dr Van De Mark at Gisborne Hospital on 17 August 1999. At that appointment, I had a colposcopy.
7. I do not remember much of my discussion with Dr Van De Mark that day, because I think I was in shock. I thought that Dr Van De Mark would tell me that that there was nothing to be concerned about and everything would be okay. I do recall that Dr Van De Mark told me she could see a lesion but that she did not think it looked very big. She took samples and arranged an appointment to give me my results.

8. On 15 September 1999, I attended a further appointment with Dr Van De Mark to get my results. Dr Van De Mark told me that the colposcopy confirmed I had a CIN III. I told her I was sick to death of doctors and that I wanted to look into the option of alternative medicine rather than a biopsy. Dr Van De Mark tried to talk me out of considering alternative medicine. She gave me the worst case scenario such as full-blown cancer, which she said would result in a hysterectomy and/or chemotherapy. Dr Van De Mark said she would give me three months to think about my options.
9. Still in denial, I left Dr Van De Mark's office feeling confused, angry, upset and let down. I could not understand how I could have a high-grade abnormality if every smear up until that point in time had been clear. I was a stickler for having smears done and I thought I had had about half a dozen smears taken in the previous eight years. I was to find out later that I in fact had had eight smears in the previous nine years.
10. On 2 November 1999, I went to my next appointment with Dr Van De Mark. I realised then that the best option for me was to have the biopsy. Dr Van De Mark examined me and told me that my lesion was no worse. She did not carry out the planned colposcopy as I was going ahead with the biopsy. I was told I would get an appointment in the mail. I was under the impression that if I had the biopsy everything would be fine.

11. About a week later, on 11 November 1999, I went to see Dr Cloete. She informed me that a smear read by Dr Bottrill on 18 June 1992 had been misread and that it was reread in Australia as high grade. Dr Cloete told me to lodge a medical misadventure claim through ACC. This was all unfamiliar to me, as I did not know what medical misadventure meant or what it was all about. My claim to ACC was accepted on 30 March 2000.
  
12. I felt very shocked and devastated that I was one of the affected women. I had thought that it was possible, but wanted hard evidence before I would believe that was the case. Dr Cloete provided that evidence.
  
13. On 9 December 1999, I had a biopsy at Gisborne Hospital. Both John and I felt elated that I had had the biopsy as we thought that this meant that we could put this matter behind us and carry on. I was not concerned about the results as in my mind I was satisfied that the biopsy had removed all the abnormal cells.

14. I then received a telephone call at work from Dr Van De Mark. She told me she was very concerned with my results and that my condition was more advanced and I actually had cancer of the cervix. She told me that the cancer was 5mm deep into my tissue and that the crucial stage was 3mm deep. She explained that once it gets deeper it starts to affect the blood vessels, which feed the lymph nodes. Hearing this did not register, as all I heard was the word cancer. Dr Van De Mark said that her main aim was to get me into the clinic to see the visiting cancer specialist Dr Ron Jones.
  
15. That day was a blur for me. I had just turned 27 and I was told I had cancer. That same day I telephoned a close friend, as I did not know how I was going to tell my husband John, I had cervical cancer. How do you tell your husband and the father of your future children that you have cancer of the cervix? Not only would there be no children but also there were doubts as to whether I would still have my health and even my life. In one afternoon, our lives as we knew them had been shattered.
  
16. I finally found the courage to tell John. He was speechless. I just cried and cried. John found it very hard as he had lost a very close cousin to cervical cancer eight years previously and was again faced with the prospect that he may lose me.

17. On the evening of 16 December 1999, Dr Van De Mark telephoned me at home and apologised for telling me my results over the telephone. John and I arranged to meet her on the evening of 17 December 1999 so that we could talk with her and she answer what questions she could for us.
18. At that meeting, I asked Dr Van De Mark to arrange to have the three smears taken after my misread, re read. These smears were originally read in January 1994, June 1996, and October 1997. I later found out that there was another smear taken in May 1993.
19. On 22 December 1999, John and I saw Dr Ron Jones at Gisborne Hospital. Still in denial, I expected him to tell me that there was a miracle cure and that everything would be fine. This was not the case. Dr Jones was blunt and to the point. He said they were going to get my tissue re-examined by another panel of experts, but really, he saw no other alternative for me but to have a radical hysterectomy. It was then that I realised there was nothing else we could do. I still could not believe that after having regular smears the outcome was that I was to be robbed of my right to have children, and in the worst case scenario even my life.

20. On 11 January 2000, I had another appointment with Dr Van De Mark. I had heard nothing from the hospital about my operation so I questioned Dr Van De Mark as to when my operation would be. It had been almost three weeks since I received my results and I was very anxious to push to get my operation done. Dr Van De Mark told me that she would find out the date of the operation and tell me.
21. Since finding out the results of the biopsy, I read a lot about cancer. I knew that once the cancer had progressed into the lymph nodes it could spread through the rest of my body. It was extremely hard knowing this foreign “thing” was growing inside me and nothing was being done. I don’t know what was worse the eight years of not knowing that there was something wrong and then suddenly finding out that the diagnosis had come too late, or the three weeks of knowing what I had and what was to come.
22. As I was becoming very worried that I did not have a date for the operation and I wanted to know the results of the smear rereads, I telephoned Dr Van De Mark again on 13 January 2000. Dr Van De Mark said that she had contacted National Woman’s Hospital in Auckland but still had not had a reply from the hospital. I found it very frustrating that I had to chase the doctors to get an operation and deal with the fact that I had been diagnosed with cancer. I felt I had to push as I wanted and needed answers and matters were just not happening fast enough.

23. After further calls to Gisborne Hospital with still no operation date, I was ready to give up. I felt that the public health system was letting me down again. I telephoned the office of the local MP, Janet Mackey who referred me to Nancy Sibley, the patient advocate at Gisborne Hospital. After a few telephone calls Nancy Sibley found out that somehow I had been dropped off the operating register at the National Women's Hospital. It was amazing. Nancy Sibley got more answers and action in one afternoon than I had had in a month. I now firmly believe the saying, it is not what you know it is whom you know.
24. On 24 January 2000, I was advised by National Women's Hospital that the date of my operation would be 1 February 2000. I was told that I had to be at the National Women's Hospital on 31 January 2000 for a pre operation check up.
25. John and I went to National Women's Hospital for the appointment at 2pm on 31 January 2000. On our arrival, we were told there were no doctors available and although my appointment was for 2 pm, they could give me no definite time as to when I would be seen. As it was Auckland Anniversary Day, there was only one doctor on duty to look after the whole hospital. We waited until about 5pm when I kicked up a fuss. A nurse did some blood tests, asked a few questions and then sent me off home. Why this could not have been done when we first arrived I do not know.

26. As I was not sure about the procedure for my operation, I was given a pamphlet to read. I had no consultation with anyone at this stage as to what was about to happen. I must admit that although I tried to read the pamphlet, it meant nothing as the words did not sink in.
27. On the morning of the operation, I met Dr Whittaker, the doctor who was to carry out my operation. I found him a brilliant doctor as he treated me as a person and not an object. The last thing I asked of Dr Whittaker before my operation was to save my ovaries. It was also the first thing I asked when I awoke as to whether I still had them.
28. I remember waking after the operation and being so freaked out because of all the tubes that were coming out of me. I had to learn all over again how to pass urine and how to have a bowel motion, simple things we all take for granted. I noted in my diary afterwards that the operation was not the worst part, it was what I had to endure after it.
29. After the operation, I thought I was going to die. I felt as though I had been hit by a bus because of the pain, the stiffness, and the numbness. I wrote in my diary at the time, "*please make this all be a dream*". I remember I threw up this black liquid, it made me feel like my staples were going to burst and the excruciating pain of my abdominal muscles contracting while I was throwing up, I will never forget it.

30. While in hospital, there was only one nurse I trusted. She was the only one to inquire whether I would like some counselling. This nurse was great and I looked forward to her starting her shift each day, as I knew that I could trust her to do her job well and I felt secure with her. With the other nursing staff, I knew not to wait for things to happen, but to ask. All I wanted was to heal quickly and to go home and put this all behind me.
31. I was discharged from hospital on 6 February 2000 I was not given any discharge forms to sign and knew only because Dr Whittaker had told me, that I would receive my results in approximately ten days.
32. On 8 February 2000, I returned to National Woman's Hospital to have my staples removed. I had eighteen staples in total but when the bottom four were removed, it was found that my skin had not fused together. I was therefore left with a surface hole. The nurse just slapped on a bit of bandage tape said it would be all right. For her it may not have been an issue, but for me this was distressing. I had never been in hospital, or had to look after wounds or dressings.
33. I flew home to Gisborne that day. When I met my husband at the airport I just broke down and sobbed. I felt I could not cope anymore and had reached breaking point.

34. After two days of trying to nurse myself and to deal with what I had just been through I called my GP. Dr Cloete contacted a public health nurse to come and attend to my dressings that day and for 3 to 4 days. I was told by my GP and the public health nurse that I should have had after care organised for me by National Woman's Hospital. This was obviously never done.

35. John and I took one day at a time as we anxiously waited for the results of my operation. I received a telephone call on the 11 February 2000 from Dr Cloete. I was told that my cancer was confined to my cervix and had only just begun to progress to my blood vessels so my lymph nodes were clear. This was such a blessing and the best news we had heard in almost eight months. To me this meant the end of it, no more doctors or hospitals no chemotherapy or radiation I was ecstatic.

36. On 9 March 2000, I went to see Dr Cloete. I was upset that I still had not had the results of my re-read smears. I finally received those results from Dr Cloete on 13 March 2000. These results reported by Medlab Central were:

17 May 1993: Evidence of HPV. No dysplasia detected.

14 January 1994: (Not reread)

6 June 1996: Normal ecto and endocervical cells.  
Few fungal spores noted. No  
displasia.

15 October 1997: *(Slide misplaced, not reread)*

37. I subsequently received a letter from the Health Funding Authority in early April 2000 which confirmed that the smear read by Dr Bottrill on 18 June 1992 as normal was high grade. It also confirmed that the smears dated 4 January 1991 and 21 August 1991 read by Dr Bottrill as normal were in fact normal.
38. When I saw Dr Van De Mark for my check up on 14 March 2000, I spoke to her about the results of the rereads. She said that smears are not always accurate and are really just a guideline. Dr Van De Mark said she was shocked that the reread results had come back as normal. She told me that the type of cancer I had does not develop over months but over years. She told me that if it did develop as quickly as my cancer had, smears would need to be taken every six months.
39. Dr Van De Mark said she could not explain the re-read results. However, she did comment that when smears were taken if they did not have sufficient squamous cells it would not be an accurate reading.

40. It was much later that I discovered that a smear taken in 1993, was originally read as showing evidence of HPV and being outside normal limits. The recommendation was that it should be repeated in three months repeat. I was never told of these results and I was definitely never told to repeat the smear in three months.

### **Our Feelings**

41. I am so lucky to be coming away from this with my life, and I feel for the poor women and their families who have not. The traumatic experience many other women, their families, and I have had to go through should not have happened.
42. John and I were waiting until we were financially secure before we started a family. This was so that we could offer the best for our future children. Because of this disastrous botch up the goal posts in our lives have been moved, without consultation or permission from John or me.
44. This process has placed a heavy strain on our marriage. John had his good days and bad days just like me. It has been tough for John and his family because they have relived the nightmare of the loss of John's cousin to cervical cancer. John knew very well what this terrible disease was capable of.

44. No amount of money can make up for what we have been through or what we have lost. I feel I have lost my womanhood because I cannot do what is my right, to produce children.
45. While our marriage is strong, I worry because John is still able to have his own biological children and I do not know what this will do to our relationship.
46. Both John and I would love to have children. We have applied to the fertility clinic, as we want to participate in the surrogacy programme. We have also asked ACC to fund us on this programme. We have also applied to become adoptive parents. I know that we could provide a loving home to a child.

## **Conclusion**

47. I do not want revenge nor do I hate anyone. Dr Bottrill made a mistake, but it is not just him that I blame. The health authorities paid Dr Bottrill but failed to check that he was doing a good job. I do not understand why the health authorities allowed the situation to continue and why they did not check what was happening.
48. I do not want this whole Inquiry to be completed and nothing done to stop this unforgivable mess from happening again. I want to know the pain that my family and I have suffered and continue to suffer has not been in vain. I want an assurance that this will never happen again. I do not want anyone else to be subjected to such a cruelty.

49. I consent to giving evidence in public and do not want name suppression.

## SUMMARY

## ANDREA MALITIA WINMILL

DATE	BOTTRILL	GISBORNE HOSPITAL	OTHER	RE-READS AUSTRALIA	RE-READS MED LAB CENTRAL
7.1.91	<b>Smear</b> normal (Not on register)			Normal	
23.8.91	<b>Smear</b> normal (examined by Y-FC) (not on register)			Normal	
19.6.92	Smear normal (not on register)			Abnormal squamous cells present, a HG lesion cannot be excluded.  ASCUSH (Australia) HSIL (Register)	
17.5.93			<b>Smear</b> Scanty evidence of HPV. Outside normal limits. Repeat in 3 months ( <b>not told</b> ) (Not on register) (Medical Diagnostics Palmerston		Evidence of HPV No displasia (Dr Temple -Camp)

			<i>North).</i>		
14.1.94		<b>Smear</b> normal			Not re-read
6.6.96		<b>Smear</b> Normal			No displasia
15.10.97			<b>Smear</b> normal <i>(Medlab Palmerston North)</i>		Smear misplaced not re-read
22.6.99			<b>Smear</b> CIN III <i>(Medlab Hamilton)</i>		
17.8.99		Colcoscopy	<b>Histology</b> HPV infection with CIN III <i>(Medlab Central)</i>		Re-read <i>National Women's Hospital (23.12.99)</i> Squamous cell carcinoma Stage 1B
9.12.99		LLETZ Biopsy	<b>Histology</b> HPV with CIN III Invasive carcinoma <i>(Medlab Central)</i>		
1.2.2000			Radical hysterectomy <i>(National Women's Hospital )</i> <b>Histology</b> Stage 1B Carcinoma of the cervix		