

Witness Name: Derek Frank Martindale

Statement No: WITN1688001

Exhibits: WITN1688002-4

Dated: 17 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF DEREK FRANK MARTINDALE

I, Derek Frank Martindale will say as follows:-

Section 1. Introduction

1. My name is Derek Frank Martindale. My date of birth is the GRO-C 1963 and I live at GRO-C with Mary Margaret Martindale, my wife of almost 27 years. We have a son, John Paul aged 26. I worked in the Public Sector from 1985 to 2016 when I resigned and have been a self-employed contractor in IT since then.
2. I was born in York the second eldest of five children. Two of whom are now deceased.
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement or exhibited to this statement.

Section 2. How infected

4. I was diagnosed at about the age of 1 with severe Haemophilia A. My younger brother, Richard was also born with severe Haemophilia A and was diagnosed around the same age as I was.
5. I have received various blood products and there is now produced and shown to me marked Exhibit 'WITN1688002' my medical records received from York Hospital showing the date I received the blood product, the type of blood product and the batch number.
6. There is also now produced and shown to me marked Exhibit 'WITN1688003' the extract I have received from the National Haemophilia Database with similar information.
7. I was initially treated at the York County Hospital and then the York District Hospital from 1964 to 1987. The Haemophilia Consultant at the York District Hospital was Dr Wylie. As there was no Haemophilia Centre there, treatment was provided through the Haematology Department. I just adapted. In April 1987 I moved to London and came under the care of St Thomas' Hospital (St Thomas'). The consultant at the time was Dr Jeff Savage.
8. I have received blood products since 1964 to date and whilst the actual date of infection is unknown it appears to have been sometime during the period August 1984 to August 1985.
9. I am not aware that my parents were told beforehand about the risk of being exposed to infection from blood products, I certainly was not told.

10. As a result of being given blood products I have been infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).
11. In 1985, Acquired Immune Deficiency Syndrome (AIDS) was very much in the news. The media started to report on contaminated blood and identified Haemophiliacs as a high risk group of infection. The word 'Haemophilia' began to appear in articles on AIDS.
12. In August 1985 I went to York District Hospital and asked to be tested for HIV. No-one from the hospital had previously contacted me about this.
13. On Friday the 13th September 1985 I took a long lunch break from work and went to hospital to see Dr Wylie and find out the results of the test. Dr Wylie informed me, in a matter of fact way, that the test results had come back and that I was HIV positive. I was told that I would be dead within 12 months, I was 23 years old.
14. Dr Wylie was very upset when he told me; he had been treating me and my brother since we were very small. Also, I was told not to tell anyone, including my parents, as the stigma associated with this infection would mean I would become a social pariah if anyone knew. I did not tell anyone and the 'secret' of being HIV positive became a crippling burden.
15. The information provided was that I was going to die. There was no managing the infection. There was no treatment available at that time.
16. I feel the NHS should have been proactive rather than reactive at this time. I feel they knew of the possibility of infection earlier and they should have approached me about being tested not the other way around. No follow up appointments were offered. No counselling. I felt very isolated.

17. As for my views on how I was informed of the infections, in practical terms, how could it have been any other way? Everyone feared AIDS. There was no treatment and no cure. Newspapers were referring to it as a 'pandemic'. Any words of comfort or glossing over the truth would have been a lie.

18. I do not recall being given any information about the risks of others being infected or the methods of transmission.

19. I became aware that I was infected with HCV in 1997. I do not remember being told of the infection, however my wife does. It did not register as anything significant with everything else going on.

Section 3. Other Infections

20. I am not aware that I have received any other infections as a result of being infected with blood products. I do not know if I have been exposed to CJD.

Section 4. Consent

21. I requested to be tested for HIV. I did not give consent to be tested for HCV nor was I aware that I had been tested for HCV.

Section 5. Impact

22. The mental affects were worse in the early years particularly being told that I had one year to live, later two years and then five and then ten. Always a deadline. Always the knowledge that my lifespan had a known expiry date. My life goals were reduced.

23. Also, there was the knowledge that I could not live a normal life, I should not have sexual relationships, I would not marry and have children as no-one would

be willing to take me on. Further there was the responsibility brought on from knowing my HIV status and how I needed to behave to protect others. Whereas those who engaged in what could be termed as 'risky' sexual practices and who chose not to be tested, could live freely in their ignorance.

24. In the early days, the HIV diagnosis impacted my mood, emotions and behavior. I had no future. I was also emotionally suppressed. I used to think people would not want to know me if they knew I was HIV positive.

25. The physical effects have come from the side-effects of treatment. The 'blunderbus' approach of drugs such as AZT and the chemotherapy of HCV treatment.

26. As my CD4 count was decreasing, I was advised to start taking AZT. This was the only available treatment at the time. I was reluctant to do so, I was against starting as AZT was a 'safety net' something to fall back on when things became bad. Once on AZT there was nothing else, there was no other 'safety net' that could be relied on if AZT did not work, it was the end. Also, I had heard from others that it had not worked.

27. As a result of the advice I received, I took AZT for a period during the mid 1990's.

28. During the time I was taking AZT I developed a foot fungus and node infection. I was told it was a result of my HIV infection and that I would have it for the rest of my life. Once I stopped taking AZT, they cleared up.

29. Whenever I get a cold there is a high risk that I will go on to develop pneumonia or pleurisy. This has occurred on numerous occasions over the years requiring prescriptions of antibiotics, hospital stays and leading to many periods of sick leave from work.

30. I still have HIV which is managed with antivirals, I take three tablets once a day.

31. In 2002, I had a six month course of Interferon to try and eradicate my HCV; the side effects were horrendous and included constant flu-like symptoms, severe depression and weight loss. It was worse than the AZT treatment. During the treatment I withdrew from family and social interactions. I became a shadow of myself. The treatment ended in failure.

32. In 2010, I undertook another twelve month course of Interferon which resulted in success. During this course we were more proactive. We knew about the side-effects. I was prescribed anti-depressants and had regular appointments with a psychiatrist, and it helped. The physical side-effects were just as bad as during the period of treatment in 2002. Fortunately, the treatment cleared the HCV. The treatment started in January 2010 and by August or September 2010 it was eradicated and I have had negative results ever since.

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34. My brother Richard died of AIDS in November 1990 as a result of being treated with infected blood products, one month short of his 24th birthday.

35. The biggest regret in my life occurred one night in August 1990. It was the night before my sister's wedding, and I was back in York staying the night with my younger brother Richard after a night out with friends and relations. Richard had full blown AIDS then and he knew he was dying. When we got back to the accommodation at the end of the night, and it was just the two of us, he wanted to talk. He was scared and he wanted to talk about his fears and about dying. He

knew he was dying. But I could not do so. It was too close to home. It was like looking into my future. I kept changing the subject. My biggest regret in my life is my brother needed me that night and I was not there for him. I let him down. He died less than 3 months later.

36. My HIV status and death of my brother in 1990 tore our family apart. My father, a regular but not particularly heavy drinker, took to seeking solace in alcohol and 'drank himself into an early grave'. He died in 2000 aged 61.

37. My mother struggled to cope with the HIV diagnosis. It was a subject that was never raised.

38. Due to my haemophilia I was placed at Northfield School in York. A special school for children with physical disabilities. The council philosophy was that we should be taught to read and write and that was about all. We had various disabilities and 'would not amount to much in life'.

39. I was lucky. There was a teacher, Mr James, who recognised that we had greater academic potential and I was a member of the first class to study for the Certificate of Secondary Education (CSE's). I left school in 1979 with 5 CSE's. I went to Technical College for a year and studied IT and thereafter advanced my IT knowledge through remote learning.

40. From 1981 to 1987 I worked for the Ministry of Defence (MOD) in the Regimental Pay Office. (I was diagnosed HIV Positive in August 1985). Due to the stigma associated with HIV I feared I would never pass a pre-employment medical in the Private Sector and felt I had no choice but to remain in the Public Sector. In 1987 I applied for promotion via the Civil Service internal trawl scheme and took up a position at the Royal Botanic Gardens Kew (Kew Gardens) a Non Departmental Public Body. No further medical was required.

41. As a member of the Civil Service pension scheme upon my death my wife was entitled to a Death in Service benefit which would provide some financial security. As I was unable to partake in any form of life assurance remaining in the Public Sector this was my only means of providing financial benefit for my family after my death. I felt trapped but unable to pursue a career in the Private Sector whilst my wife and son were dependent upon me. In a sense, I was worth more dead than alive.

42. Prior to meeting Margaret, I had had one long term girlfriend. We were together about 2 years. I hadn't told her about my HIV status but as the relationship progressed and she envisioned a future together, I felt I had to tell her. She ended our relationship shortly afterwards. Her last words to me were, "I do not want to watch you die. It is too much to bear". I then found forming relationships more difficult, I feared for further rejection and that I was too much for anyone to take on.

43. I met Margaret in 1991. I was in love with her but blew 'hot & cold' during the first few months of our relationship. I was wracked with guilt and frightened to tell her 'my secret' due to fears of rejection again. After 6 months she delivered an ultimatum as she was confused and hurt by my behaviour, "tell me what is going on or we are finished". Her immediate response when I told her was "is that it? You love me. I love you. I don't see what the problem is". I cannot explain my feelings of euphoria and relief. I warned we would probably have 2 good years at most before my health started to deteriorate. We married in March 1992. Our son, John Paul was born in December 1992.

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44. All our friends and family know of my status. When Margaret and I married it was a condition asked by her that it would not be a secret as she had seen what internalising it had done to me. We have had no negative responses. I do not

consciously hide it but it is not a subject of conversation. Everyone is very accepting and very supportive, so I don't have a problem associated with stigma.

Section 6. Treatment/Care/Support

45. On the whole I have not faced difficulties or obstacles in obtaining treatment. The treatment I have received has been very joined up and monitored. I have appointments for all my conditions together: Haemophilia, HIV and HCV. At the clinics each consultant for each condition would be present. In the early days I had appointments quarterly; though when I was in receipt of treatment the appointments were every one or two months, they are now every six months. I feel St Thomas' provide exceptional levels of care and support.
46. I have only had one occasion with regard to dentistry and specifically to the scare that I may also have been exposed to CJD. It was not that treatment was denied, just that I was made to feel 'unclean'. Everything was disposed of after the appointment and everything in the surgery fumigated.
47. I receive general dental treatment (check-ups, fillings, etc) at my local dental practice who are aware of my status. For more complex dental issues I go to the dental department at St Thomas' and Guy's Hospital Trust.
48. In 1987 when I moved to St Thomas' I was offered counselling. It was in the form of group sessions on a Saturday afternoon with a clinical nurse specialist facilitated. However, I did not find these sessions helpful as every time I went people were a little more unwell than before or someone would have died since the last meeting. For me, the sessions became more depressing than supportive. As people died, the group became smaller and smaller and was closed down in the mid-90's. St Thomas' have also offered individual counselling, Margaret availed herself of these and found them beneficial. Margaret has been, and remains, my main bastion of support.

49. We chose not to tell our son about my HIV status until he was 18 years old as we had seen the negative impact on children of others in the same situation. My wife and I knew the burden of an impending death sentence and we did not want him to have that same worry. We wanted him to have as normal a childhood as possible (not withstanding how often 'Dad' was ill).

Section 7. Financial Assistance

50. In 1991 I received an ex gratia payment, the minimum amount as I was single. Twelve months later I was married, and my wife was pregnant. Single people received £20,000 and married people with children received £64,000.

51. This ex gratia payment was made available with the stipulation I signed a waiver stating that I would take no further legal action against the government with regard to my current and any possible future infections.

52. I have also received regular payments from the MacFarlane Trust as well as the winter fuel payment allowance. I received additional payments when John Paul was young until he was 16. I also received one off grants to assist in moving home and when John Paul started school.

53. I have also received payments from the Skipton Fund, stage 1 and 2 lump sums prior to my HCV clearing due to cirrhosis of the liver.

54. I currently receive two quarterly payments @ £4,500 (£36,000 per annum) from the NHS Business Services Authority – England Infected Blood Support Scheme (EIBSS). I am also in receipt of the annual Winter Fuel payment.

55. I believe I was informed that I was entitled to the payments by St. Thomas' Hospital. I found the application procedure straightforward as St. Thomas' were

very helpful and facilitated the process. I did not find any obstacles or difficulties in the application process.

56. I was also part of the US litigation and received between £20,000 and £30,000 from that action.

Section 8. Other Issues

57. In 2003, as part of the US Litigation, I applied for my medical records under the Freedom of Information Act.

58. From birth until April 1987 I was under the care of the York County and York District Hospitals. The majority of documents received are from them. From 1964 up until July 1984 they appear to be fairly comprehensive. After July 1984, apart from a mention of Dental Surgery in April 1986, there is nothing until a reference letter to Charing Cross Hospital in May 1987 following my move to London in April 1987.

59. There is no record of my appointment with Dr Wylie in September 1985 when I was informed I was HIV positive. There is no documentation / record of my request to be tested for HIV.

60. I believe I must have attended hospital after July 1984 and before I moved to London in 1987 for: treatment, tests or check-ups.

61. I asked St Thomas' if any notes had been transferred from York when I came under their care for treatment. I was told not.

61. I asked St Thomas' if any notes had been transferred from York when I came under their care for treatment. I was told not.

62. Speaking to other Haemophiliacs who were involved in the US Litigation it appears I was not the only one whose notes are missing during this time period.

63. There is now produced and shown to me marked Exhibit 'WITN1688004' a copy of a document, referred to as a "York Health Authority Identification Sheet", that has a stamp "Danger of Infection" with a written note "CR Wylie Aug 85 – HTLV III Pos". As I was informed of my HIV status in September 1985, this note may have resulted from my request to be tested which probably was in August 1985.

64. The UK National Haemophilia documents, Exhibit 'WITN1688003' refer to a diagnosis and a "date last negative" and a "date first positive". Unfortunately, I do not understand their coding so not sure what this is referring to.

Anonymity, disclosure and redaction

65. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

66. I am willing to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed:

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Derek Frank Martindale

Dated 17 February 2019