Witness Name: Valerie White
Statement No: WITN1725001
Exhibits: WITN1725002-WITN1725008
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF VALERIE WHITE

I, Valerie White, will say as follows:-

Section 1. Introduction

1. My name is Valerie White of GRO-C Cardiff, GRO-C My date of birth is GRO-C 1947. I am currently retired and I live with my husband. We have two grown up sons who are 51 and 53 and both married.

2. I make this statement in relation to my third and youngest son, Martin Alan White, who died as a result of receiving contaminated blood products.

3. **This statement has been prepared without the benefit of access to Martin's full medical records.** If and in so far as I have been provided with limited records the relevant entries are set out as exhibits to this statement.

Section 2. How Affected

4. My son, Martin, was born on GRO-C 1970 and died on 11th June 2003.

5. Martin suffered with severe Haemophilia A.

6. I exhibit at WITN1725002 Martin's Haemophilia database records. Martin's Haemophilia database record shows that he received the following products between 1977 and 2003: FVIII (BPL), Cryoprecipitate, Factorate, Travenol/Hyland/Hemofil FVIII, FVIII (PFC), Profilate, Oxford FVIII, Replenade (BLP), Kogenate, Recombinate, Tranexamic Acid and Beriplex.

7. Martin was treated at Professor Bloom's clinic at the University Hospital Wales prior to and after being diagnosed with HIV and HCV. He may have attended other facilities for tests as indicated in his medical records, however I do not recall this. On one occasion we were in Derby to visit Martin's brother Andrew on a scout camp. Martin had a bleed and we had to go to the local hospital for him to be treated. He was also treated at University Hospital Llandough, Cardiff as an inpatient but I do not recall the year he received treatment there. Unfortunately, I cannot recall the names of any doctors who treated and prescribed medication to Martin.

8. I am unsure of the dates on which Martin was given contaminated Factor VIII, but I refer to the record of treatment at exhibit WITN1725002. I do not know if this is a full record of Martin's treatment.

9. We were never informed of the risk of Martin being infected with HIV or HCV despite health professionals being aware of the risks prior to him becoming infected. A letter in Martin's medical records from Professor Bloom to Dr Mathews dated 08.03.1983 states "At the present time, there is certainly no evidence that he has developed the acquired immune deficiency syndrome recently reported in Haemophilia in the United States". I exhibit this letter at WITN1725003. I believe that we should have been informed of the risks associated with blood products when the medical professionals became aware that Haemophiliacs in the United States had been infected with HIV, to enable us to make informed decisions.

10. I believe Martin should have been given heat treated Factor 8 as soon as it became available and as soon as the medical professionals became aware of the risks associated with blood products. I believe this would have prevented Martin from contracting HIV and HCV.

11. Martin was infected with HIV and HCV.

12. I became aware that Martin had been infected with HIV and HCV when I received a telephone call from a Sister Jones requesting that I return the Factor VIII which I had been treating Martin with at home. Upon returning the Factor VIII products to the hospital, Professor Bloom explained to me that that batch of blood had come from a person who was infected with and had died from AIDS. Professor Bloom said that he didn't think that Martin would be infected, as it was only one person from a large pool of donors who had died.

13. A short time later, I was asked to return to see Professor Bloom. He told me in a very matter-of-fact way that Martin had in fact been infected with HIV. I hadn't even heard of HIV or AIDS at that point. The way in which he told me was insensitive. I wish I had been provided with more information and support, instead of the devastating news just being blurted out.

14. The information provided in relation to managing the infection was vague and limited. To the best of my recollection, Professor Bloom just stated that it was an infection. I don't recall being told a great deal at all. Our knowledge about Martin's infection came from what we found out ourselves. I don't recall being told by Professor Bloom that Martin's life expectancy might be reduced or that he might become unwell. At that time, it was a shock that Martin had become infected by treatment that was meant to be helping him. At the time, what Professor Bloom was telling me didn't strike me as serious. He didn't appear to know much about HIV/AIDS himself. He presented it as if it was as much of a shock to him as it was to us.

15. I don't think that I was given enough information to understand and manage Martin's infection. We were told not to share toothbrushes with Martin, to wear gloves when giving him his Factor 8 and at a later stage we were told to be careful of his bodily fluids.

16. We were not given advice about how to manage the physical or emotional impact of Martin's infection. We were offered no support to enable us to give

Martin the information that he needed to understand what had happened to him or to enable us to emotionally support him.

17. I don't recall precisely when I was told about Martin's infection, so I'm not sure whether I should have been told earlier.

18. The medical records that I have for Martin indicate that his last negative test for HIV was on 15th July 1984 and his first positive test was on 15th March 1985. I exhibit this test result at WITN1725004.

19. I feel that the manner in which I was told that Martin had HIV unacceptable. There was no explanation as to how it had happened and no acceptance of responsibility for the situation. I didn't feel that I was shown any empathy and I felt like I was just expected to get on with it.

20. When Professor Bloom told me about Martin's HIV infection I had attended the appointment alone, as Martin was a teenager at the time. Professor Bloom said that I should not tell Martin about his diagnosis. However, I insisted that Martin be told due to his age. I was conscious that he was likely to become sexually active in the near future. I also didn't want to hide the news from my son. It would have been awful if he had later found out we had hidden it from him. Eventually, Professor Bloom agreed and shortly after this discussion, I drove Martin to the hospital to be told.

21. I think Professor Bloom told Martin on his own. Martin's reaction upon learning of his HIV diagnosis was very negative. Again, he did not understand all the implications of his infection like the rest of us. He was both angry and upset. It was a very difficult time when we got home from the hospital. It was difficult having to tell my other two children. They did not speak much about it, and to this day they will not talk about it. It was an uncomfortable feeling of the unknown.

22. There are absolutely no notes in Martin's medical records to say that he was being tested, when he was being tested, when he was diagnosed, or when we were informed of his infections. It seems as though one minute he was normal

and the next minute his notes report that he was HIV positive. When I applied for them, I had hoped that Martin's medical records would clarify what had happened to Martin for me, but to my disappointment, they did not.

23. When Martin was older, he told me that he had found out that he had also been infected with HCV as a result of receiving blood products. I do not recall when he told me this or whether he told me when he may have been infected. I remember he saw it as just another blow. He did not mention whether his HCV was severe or not. We were certainly not told about it when he found out he had HIV.

24. Martin's medical records state that Martin was entered into a Hepatitis trial on the 01.06.1978 and was only to be given Factor VIII marked H.S. We were not told about this or asked to consent to it at the time and I don't understand what the Hepatitis trial was. I only learnt about it when I received Martin's medical records after his death. I exhibit the reference to this from Martin's medical records at WITN1725005.

Section 3. Other Infections.

25. Martin's medical records indicate that on 20.10.2001 Martin had been given Replenate, batch number FHE4579, which had come from a donor that was known to have had new variant CJD. Martin's medical records indicate that he had used this batch of Replenate from 31.08.1997 until 02.01.1998 totalling twenty bottles of Factor VIII. Therefore, he was certainly exposed to the risk of being infected with vCJD. Martin was told about this risk, which I detail further in paragraph 33. I exhibit at WITN1725006 the medical records relating to this.

26. When Martin died I gave permission for a part of his brain to be tested for vCJD. The result was negative.

Section 4. Consent.

27. Martin was a child when he was diagnosed with HIV. My husband and I were never told that Martin was being tested for infections.

28. My husband and I were never asked for consent for Martin to be tested.

29. My husband and I were never given any information about testing.

30. I do not know whether Martin was treated or tested for research purposes.

Section 5. Impact

31. The mental effects of his infections were devastating for Martin. His life changed forever the day he was diagnosed with HIV. He suffered with depression. There was so much stigma surrounding HIV around that time that it was very difficult for a teenage boy to deal with. Despite this, he was not offered any support by the medical professionals to deal with the emotional impact of his diagnosis.

32. Martin's depression and low self-worth had the biggest impact on his life and this prevented him from fully engaging with professionals.

33. In terms of the physical impact of his infections, Martin was never big and was always thin. He had problems keeping weight on. He always looked ill - sickly, pale and gaunt. Martin also had low energy levels.

34. In 2001, the news that he had been exposed to vCJD, threw Martin over the edge and he turned to alcohol. A letter dated 22nd March 2001 written by his psychiatrist stated that Martin "*clearly distrusts the system... wondering what will affect him next*". I exhibit this letter at WITN1725007.

35. I recall that his drinking escalated after this. Once when I confronted Martin about his drinking, he told me that it was his way of blocking it all out, because whilst he was drinking he did not have anything wrong with him.

36. Due to his infections Martin suffered from liver damage, PCP pneumonia and an enlarged spleen. Martin suffered significantly due to his liver damage and the advanced stage of his HIV. He frequently required medical assistance. He had a lot of blood transfusions due to being anaemic as a result of his HIV. Martin suffered fits and his lungs were damaged by the PCP pneumonia.

37. Martin died on 11th June 2003.

38. Martin had treatment for his infections, but I'm not sure what it was as he didn't live at home when he started receiving treatment. I do think the treatment made Martin more ill than his infections.

39. I am not aware of any obstacles or difficulties Martin had in obtaining treatment for his infections.

40. I am not aware of any treatments which ought to have been made available to Martin which weren't.

41. Martin suffered from terrible side effects as a result of the treatment he received for his infections. He looked ill and was constantly violently sick.

42. I do recall that Martin regularly didn't comply with his treatment due to the horrendous side effects.

43. I am not aware of Martin's infections impacting upon his treatment for any other conditions.

44. Martin got married when he was 20. He was resentful because he could not have children due to his infections. Martin would have loved to have children.

45. Martin's marriage only lasted for 5 years because he felt depressed and felt that his life was not worth living. This inevitably put a destructive strain on his

marriage. Martin's parents-in-law did not know about his infections until after he died.

46. Martin had a few relationships after his divorce but they all failed. I believe this was due to the strain he was living under with his infections. I recall that after Martin got married, his behaviour became erratic. He would throw things, punch doors and get very angry. This escalated in his mid to late 20s. He found everything too hard to handle. He just wanted to live a "normal" life like his brothers. He was the only boy in our family with Haemophilia and I am not a carrier, which made the situation much harder for him to accept.

47. After Martin moved out, it was very hard for me to judge how he was dealing and coping with his infections. He only told me what he wanted to.

48. The relationship between my husband, Martin and I became strained after his diagnosis. We tried our best not to tread on eggshells around him and to treat him like he was normal. I tried to encourage Martin to be positive and I used to tell him that he might get lucky and a new treatment might be developed to help him. My husband and I attempted to reason with him when he turned to drinking without any luck.

49. In terms of the effect on Martin's social life, he had no problems with his friendships. Although he suffered with the stress of finding out that he was infected with HIV as a teenager, he carried on with his social life. He was always bubbly and he tried to take everything in his stride.

50. Martin told a few of his close friends about his infections, but I don't recall how many. They certainly did not keep away from him once they found out.

51. Martin continued to have girlfriends after finding out about his diagnosis. He was like a magnet to girls. He continued to be brave and strong throughout his teenage years. As parents, my husband and I did the best that we could for all of our kids. I do not recall Martin being depressed as a teenager, but maybe he just never showed it.

52. Martin's infections and subsequent death have taken a significant toll on my mental health. I have had two mental breakdowns and have suffered with severe depression since the late 1980's. This was when everything came to a head for me. I needed psychiatric help and I was referred to a Psychiatrist at the University Hospital of Wales at the time. I was prescribed Lithium for a while and various antidepressants. I still continue to take a low maintaining dose of anti depressant medication.

53. I worked in a hospital at the time as a nursing auxiliary. Nobody knew anything about HIV at the time. There was a lot of ignorance. I recall hospital porters refusing to take Haemophiliacs in wheelchairs in case they were infected. This has improved over the years, but in the 1980's and 1990's everyone was frightened by HIV.

54. I have not had a problem discussing Martin's infections with my friends, because I believed that the close friends we had who knew us as a family would support us and I was right. They understood and tried to help us. They all felt sorry for Martin. This was valuable support. I have always felt that a problem shared is a problem halved. I tried to be like that as an example to Martin and my two other boys.

55. I think by being honest and upfront I avoided a lot of stigma. I feel it was an easier option than trying to hide everything.

56. Martin's infections were shattering for our family. Martin's brothers coped with it by never speaking about it. Their attitude was that Martin would be alright as he was their youngest brother. They became more protective of Martin which further impacted their relationship. Martin became frustrated about being restricted in what he was able to do.

57. I believe that Martin's diagnoses were shattering for his brothers. They still don't share their feelings with me about Martin's infections to this day. I think they tried to put it at the back of their mind and pretend that Martin wasn't infected. They continued to get on with Martin after he received his HIV diagnosis and it did not affect the fact that they loved each other.

58. At the time of Martin's diagnosis, there was so little information provided to us, I was unsure of the risks to my two other children, which changed the way I treated my children. I told my two other sons that they needed to keep their toothbrushes away from Martins. I didn't let them use the same towels or cutlery as Martin. Life became extremely difficult and stressful. In trying to protect all my children, I believe I made Martin feel isolated and resentful. I felt guilt and shame over this and I believe this contributed to my own mental health difficulties.

59. At the time there were adverts on the TV which were frightening for all of us. I feel these added to the stigma and fear surrounding HIV.

60. This fear caused our family to be anxious about being open and honest about Martin's condition beyond our close friends due to the fear of people's reactions and the possibility of rejection.

61. Martin's infections, losing Martin and my subsequent mental health difficulties put a big strain on my marriage. The situation with Martin lead to arguments, but we always stuck together. My husband felt it the same as I did. As a man, like with my other sons, he did not really say a lot about the situation with Martin or discuss it very much. He did not tell anyone and I don't think his colleagues at work knew about Martin.

62. I told Martin's school about his infections and they were very good about it. There only two teachers who knew, the nurse and the Headmaster.

63. One day, I can vividly recall receiving a call from the head master, Mr Issacs, asking us to go to the school. When we got to the school, we were told that the press were outside asking pupils to point out the boy who had Haemophilia. Mr Issacs gave Martin permission to leave school with immediate effect due to him only having around 2 months left. Martin had enjoyed school up to this point and to have to leave and become isolated from his peers was devastating for him.

64. Martin passed a couple of his "O" levels. He wasn't particularly academic.

65. After leaving school, Martin worked in a shop selling sportswear. He worked his way up to be the Manager at Giles Sport. However, he found working on his feet all day too exhausting with his health, so he got a job at British Gas in their call centre.

66. Martin found it hard to work, but it was the only thing he did that made him feel normal. As far as I know, he only had a few days off sick. As Martin was so sociable, he preferred to be with people at work than at home on his own. Martin managed to keep working until a few years before he died.

67. In terms of the work related effects on me, because of my mental health, I had to go from working full time to working part-time. My psychiatrist told me not to get tired or to work too much. I do not recall the drop in my wages or how much I earnt. I retired in 1992. I continued to work part time until I retired.

Section 6. Treatment/Care/Support

68. I am not sure of any difficulties Martin had in obtaining treatment care and support in consequence of his infections.

69. I have had psychiatric treatment on the NHS for my mental health problems. I believe I accessed this help through the Haemophilia Centre.

70. My husband, sons and I have never had any counselling in relation to Martin's infections and death.

71. As far as I'm aware, Martin was never offered any counselling in relation to his infections.

Section 7. Financial Assistance

72. I don't know how Martin found out that financial assistance was available.

73. Martin received financial assistance twice. Once he received £4273.77 from the MacFarlane Trust. He also received another amount in the 1990's, however, I do not know how much this was and who the money was paid by.

74. Following his death, The MacFarlane Trust contacted us asking for the money to be repaid from Martin's estate. I exhibit this letter dated 12.11.2003 at WITN1725008. I was shocked by this and I decided to ignore it. I never heard anything further about it.

75. As an adult, Martin had financial problems and got into debt. He suffered a brain haemorrhage in 1998, which I think may have been related to his Haemophilia but I'm not sure, which affected him. He found it a struggle to handle money and he became a bit like a teenager.

76. After Martin's death when we were clearing his house we found letters from debting agents, bailiff's and companies pursuing unpaid debts.

77. In 2011 we found out about the Skipton Fund from a Sister at the Haemophilia Centre. We made an application and received £70,000.

78. We did not face any difficulties in applying to the Skipton Fund.

79. As much as the money was appreciated, I felt frustrated that Martin didn't receive this financial assistance before he died, as it would have helped him.

80. I do not believe that Martin received enough financial assistance given the negligence and deceit surrounding his infections. If appropriate action had been taken when it was realised that Haemophiliacs in the United States were being infected, then Martin's life as well as my family's may have been very different and he may have still been alive today.

81. I do not recall the process of applying to the Skipton fund.

Section 8. Other Issues

82. Although, I will never forget the struggle, I have managed to put this to bed for my own sanity.

Anonymity, disclosure and redaction

83. I do not wish to be anonymous.

84. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C ....

Dated........20th March 2019