Witness Name: Cherry Barbara Nurse
Statement No: WITN1695001
Exhibits: WITN1695002 - 3
Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHERRY BARBARA NURSE

I, Cherry Barbara Nurse will say as follows:-

Section 1. Introduction

1. My name is Cherry Barbara Nurse. My date of birth is GRO-C 1965. I live at GRO-C, Oxon GRO-C with my children.

2. I make this statement on behalf of my late brother, John Swift, date of birth GRO-A 1958. John died at the age of 31 on 06/05/1989 from pneumonia, acquired immune deficiency syndrome (AIDS) and haemophilia.

3. Whilst I have given this statement on behalf of my late brother, John Swift I have not given a statement on behalf of my second late brother, Paul Swift, date of birth GRO-A/1965 who died on 17/09/1994 because either no or otherwise no sufficient Award has been made available for this purpose.

4. This witness statement has been prepared without the benefit of access to my John's 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.

5. John was 13 months younger than me and we were very close, he was never married. He lived with our parents until he died.

Section 2. How infected

6. I am the oldest of my siblings and before I was born two of my male cousins were diagnosed with haemophilia.

7. In 1958, John was diagnosed with severe Haemophilia A at Paddington General Hospital (PGH) when he cut his finger. This is recorded in John's medical records from the Orthopaedic Department at the Royal Free Hospital, London (RFH).

8. When John was a small child he was under the care of St Mary's Hospital, Hammersmith and there was no treatment for his haemophilia. When he was around 9-10 years old he was given Cryoprecipitate which made a huge difference in John's life. Being treated with Cryoprecipitate meant that John was able to lead a normal life. Prior to this he was not allowed to play in a playground and was quite sheltered from life, due to the fear that he may injure himself and have a bad bleed. He also missed a lot of time off school when he had a bleed.

9. I do not remember when John's treatment changed from Cryoprecipitate to Factor VIII (FVIII). However, John's medical records show that he was treated with FVIII in or about the early 1980s. I cannot recall if this was a big thing at the time, but as far as we were concerned John had gone from being treated at the hospital to being able to have treatment at home. At this point, he was under the care of the RFH. My mother collected FVIII from the RFH and store it in a fridge at home, which was provided by the NHS.

10. John's treatment was on demand, so he received FVIII as and when he required it. However, my mother did not ever resist the treatment because it assisted John with the pain and made his life a lot easier. As such, if he had any signs of bleeding my mother would treat it with FVIII. Although John was

treated at home, he still attended the hospital as well. Other times he did not have any treatment for a few days, or even a week.

11. As John regularly attended the hospital, the Haemophilia Centre at the RFH were like a family to us. They regularly took blood from me and my mother and we were told it was for the purposes of research in relation to haemophilia. At this point, little was known about haemophilia and the doctors were very interested in understanding where it came from.

12. We were aware that John sometimes had reactions to the blood products, including terrible headaches, fever and tremors. We did not know this was in relation to HIV and/or Hepatitis C (Hep C).

13. No information or advice was provided about the risks of infected blood products, so we had no knowledge of the risks of infections. Back then we did not look into things the way that we do now. We thought FVIII was a wonder-drug that provided haemophiliacs with a better quality of life. We did not question this as we put our faith in the medical professionals.

14. In or about 1983/4, we became aware of HIV from the media. The media stated it affected gay people, and 1 in 100 haemophiliacs might also be affected by HIV. Around this time I recall that John had far more appointments and he was attending the hospital more regularly. Although we had heard about HIV/AIDS on the news, we did not really understand it and we never thought that it would affect our family. We were all hoping for the best and thought that it would not affect us.

15. By 1986 my mother and I knew that there was a chance that John could have contracted HIV. At this point, John was under the care of Christine Lee at the RFH.

16. I recall the RFH introduced a policy for all their patients to give them the option to find out if they were HIV positive. If they did not want to know, they did not need to go into the hospital and the hospital would not contact them to inform them of their status. By 1987 the hospital changed this policy, as they

felt they had a duty or obligation to tell people as it was a public health concern – they needed to inform people how to manage the infections and reduce the risk of transmission.

17. John did not tell me when he found out about his HIV status as he attended all his appointments alone. In the mid 1980s we were aware that John had been visiting the hospital a lot and was becoming poorly. At Paul's wedding in 1987 I noticed that John was behaving strangely when the topic came up in conversation and I believe he knew his HIV was converting to full-blown AIDS. There is a letter, dated 09/09/1985 from Angela Thomas (RFH) to Dr Faith exhibited at **WITN1695002**, which states that he was HTLV III antibody positive. There is no letter in his medical records about the discussion of HIV in June. I believe John was told prior to the hospital changing its policy. I found out about John's HIV status just after Paul's wedding.

18. During the next few years John was well looked after by the Haemophilia Centre at the RFH. I believe the information and treatment provided at the time was adequate. I believe HIV was new to everybody, and I do not think that the doctors and nurses knew any more than the patients.

19. My mother and I nursed John from 1987 until he passed away in 1989.

Section 3. Other Infections

20. I am unaware if John was infected with any other infections. There is no mention of vCJD in his medical records, but I have since heard that this could also have been present in blood products.

Section 4. Consent

21. I believe that John was treated and tested without his consent and knowledge.

22. I believe that the blood tests that John had were in relation to the haemophilia. They may have eventually told John he was being tested for HIV, but I am not

sure if this is was case. However, they definitely told John that he did not have to know the results of the tests if he did not want to.

Section 5. Impact of the Infection

23. When John knew he was infected with HIV he suffered from a great deal of hurt and anguish, and I felt as though he was depressed. He looked very forlorn and upset when we were discussing AIDS at Paul's wedding in 1987. Initially, I thought he was overreacting and needed to calm down. At the time, he looked terrible and not like himself. I thought the worry of it all was taking its toll on him. However, it soon became clear that he was unwell as he became poorly and his symptoms came on very quickly. I know that the initial symptoms were terrible fevers, tremor, aches and pains. Further information about his symptoms are in a letter dated, 28/04/1986 exhibited at **WITN1695003**.

24. In 1986/1987, John came to visit me in Spain. I thought he looked marvellous and I believed that he would be okay. However, by winter he was struggling and his health rapidly deteriorated. He found it very difficult to keep warm and he was very shivery and unwell. At this point, I moved back to the UK to look after him due to his ill health.

25. Between 1986-1988, John began to find himself and he became quite interested in arts and travel. However, he was unable to enjoy it due to his poor-health and this also affected his ability to work as a taxi driver. He struggled financially and lost his flat and his taxi, because he was in debt and not being able to pay for them anymore. This had a huge impact on him and he became even more depressed.

26. John's friends stuck by him and they are still friends of mine today. However, my parent's friends withdrew completely because they were scared of catching AIDS. This really upset my mother and she was annoyed that people were so ignorant. When my mother moved out to Oxfordshire in 1994, she did not want to tell people what had happened because she did not want to go

through the experience of ignorance and stigma again. She tried to put it behind her, but it was with her every day until she passed away.

27. Other than my parent's friends, I did not personally experience negative stigma. However, I saw on the news that a lot of people were being targeted. This made me feel sick.

28. I note from John's medical records that he was given AZT in or about 1987. Around this time I noticed that his health picked up, but it did fluctuate and he got very sick. I did some of my own research to see if there was a cure or alternative treatment. However, I found that AZT was the only treatment available at the time.

29. As previously stated, my mother and I nursed John until he passed away in 1989. Prior to this, I moved to Spain in 1986 and planned to start a life there with my children. When John became sick I moved back with my two sons. I was always very close to my brothers, but particularly John due to us being close in age; he was also a great uncle to my two sons.

30. When John became poorly after he started the AZT treatment we were very optimistic and tried to focus on helping him get better.

31. Losing John and Paul also had a huge impact on my parents. They spent their whole lives looking after the boys and trying to keep them safe. My dad gave up his greengrocers business to look after them, due to their haemophilia. He decided to become a taxi driver instead, because it was more flexible and he could look after the boys and only work when they were in good health. My parents never received a penny in benefits and struggled to provide for my family.

32. Both of my parents died with broken hearts. It was awful watching my brothers dying from AIDS, as it was a horrible and traumatic death. My parents lost two sons as a result of the infections. My mother felt so guilty because she

believed that she had given them the infected blood products which resulted in their deaths. She became very angry, bitter and guilt-ridden.

Section 6. Treatment/care/support

33. Counselling or psychological support has not been made available to me. However, after my brothers passed away, Riva Miller, a psychiatrist offered counselling to my mother and father at the RFH. My father took a few sessions, but my mother did not as she was unable to talk about it.

34. I believe that John received counselling from Riva Miller after he was diagnosed with HIV.

Section 7. Financial Assistance

35. My parents were involved in a previous litigation after John's death. I was not involved with it and I have no further information about it.

36. After John passed away, my parents received around £20,000, which I believe was a cheque from the government. My parents did not want to touch the money as they believed it was 'blood money'. By accepting the money, they had to agree to not take part in any future litigation. As my parents have passed away, and the money has been left to me.

37. I am now John's next of kin. I recently found out that I was entitled to £20,000 from the Skipton Fund because John had Hep C. This money has been available for a long time, but I had only recently discovered that John had Hep C.

38. I have recently applied for Stage 2 payment of the Skipton Fund, and I am waiting for the RFH to assist me with the claim. They have advised me that it is likely that I will be eligible, because John died from Hepatic Lymphoma, which I have been told is a direct result of Hep C.

39. The Skipton Fund and the MacFarlane Trust have been great and the financial support they have provided has been very helpful.

40. When my parents were unwell they applied for a Tender's Allowance for my father and a nurse asked if they had any savings. My parents declared that they had £20,000 in an account that they received from the government in relation to John, but they did not wish to spend it. As a result of having £20,000, they were not entitled to the benefits. Initially, when my parents received the money, they were told that the money would never be taken into account if they applied for benefits in the future. When they told the nurse about this, they received a very harsh, blunt response stating that this was not the case.

41. Although I have had little involvement with the EIBSS, I believe they are lovely.

Section 8. Other Issues

42. I believe that the government treated haemophiliacs like they were scroungers, when all they were fighting for was to get their mortgages paid to ensure their partners and children were not left penniless, as their life insurance had been withdrawn.

43. The government was too worried about admitting that they were at fault. If only they had apologised and offered to look after the people that were infected, these people would not have been left penniless – like John. By the time the MacFarlane Trust came about, it was too late for many people.

Anonymity, disclosure and redaction

44. 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.

45. I do not wish to give oral evidence.

Statement of Truth

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

Signed.... GRO-C ....C. B. NURSE

Dated 29/12/2018

Medical Summary

(This summary is not intended to exhaustive but sets out key points in the records relevant to the statement)

Virology Results

1982 – 1983	blood tests missing
1983-early 1986	blood tests missing
02/07/1986	Anti-HTLV III – Positive
20/05/1987	Anti-H.I.V Positive

Significant Entries/Absent Entries

Undated	Orthopaedic Department – Clinical Notes *Hospital attended* 1958-1961 Paddington General Hospital 1961-1967 Occasional visits to Hammersmith Hospital 1967-1972 referred to St Mary's Hospital 23/03/1972 to present day, The Royal Free Hospital *Early History* 1958 Admitted Paddington General Hospital, cut finger. Haemophilia Diagnosed.
17/10/1980	Treatment record sheet - Patient was given FVIII for swollen left knee. Patient has received FVIII from this date onwards for all his treatments.
25/02/1986	Letter to Dr Faith from Eleanor Goldman from RFH – HbsAg negative. HBsAb positive.

23/08/1988	Letter to Dr Firbank (RFH) from Dr Christine Lee - .... It is now 49 weeks since he was originally started on AZT and he continues on a does of 400mg......
22/11/1988	Letter to Dr d L Wilson from Dr Christine Lee - .... He has been infected with HIV since 1982, early 1983 and he was diagnosed as having AIDS with pneumocystis pneumonia in August 1987..........
20/06/1989	Letter to Mr and Mrs Swift from Dr Christine Lee – I thought I should write to you as we now have the result of the post mortem examination that was performed on John. The final cause of death was thought to be pneumonia which of course would be related to his profound immune deficiency. The additional findings from the post mortem examination that we did not know about was that the lymphoma had spread to his liver thus he quite clearly had extensive disease and really there was no treatment that could have saved him from this.
11/04/1989	Letter to Dr Furbank from Dr Christine Lee – this patient has severe haemophilia and has also Aids which was originally diagnosed in August 1987 with pneumocystis pneumonia.
Undated	post mortem report - .... Retrospective analysis showed he became HIV positive between 31 December 1982 and 14 February 1983.