Witness Name: Amanda Patton

Statement No.: WITN0042001

Exhibits: None

Dated: 15 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF AMANDA PATTON

I, **Amanda Patton,** will say as follows:-

Section 1: Introduction

1. My name is Amanda Patton. My date of birth is GRO-C 1960 and my address is GRO-C West Sussex, GRO-C. I am making this statement about my brother, Simon Cummings, and his infection with HIV and suspected Hepatitis as a result of receiving contaminated blood. Simon was born on GRO-C 1958 and died on 28 December 1996.

2. At around the time Simon died, my own marriage was breaking down and I am now divorced. I have two daughters, aged 28 and 26 years old. GRO-C
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3. The first known haemophiliac in our family was my mother's brother who died just before his fifth birthday from internal bleeding caused by a fall from a swing. I have also discovered that it is possible that my mother's

uncle (her mother's brother) may also have been a haemophiliac. He died in his early 50's from "complications in his joints".

Section 2: How Affected

4. Simon was only 16 months older than me and so I cannot remember a great deal about his very early childhood. My parents have told me that when he started moving around by himself as a toddler, they noticed how easily and often he was bruising. He sustained a cut to his lip that bled a lot and he was taken to hospital, either St Peter's Hospital, Chertsey or at Great Ormond Street Hospital ("GOSH"), where he was diagnosed with severe haemophilia. He had a 0% clotting factor. Simon also had inhibitors from birth and when he was young the doctors dealt with it by giving extra doses of blood and blood products to flood the system in the hope that some of it would "get through".

5. Simon grew up with his condition and so did I. A lot of his childhood, and consequently mine, was spent at GOSH where he was initially treated with whole blood, which was later replaced with Cryoprecipitate. There were no crèche facilities or separate rooms for other children and siblings and so I would be with him when he had these transfusions. I work as a garden and landscape designer now, and one of the projects I have done is to create an outside space for a hospital where siblings of ill children can play.

6. Simon transferred from GOSH to St Thomas' Hospital for his general haemophilia care for a little while. Then, when Simon was 12 years old, he went to boarding school in Somerset. Whilst at school, he had a bad knee bleed. Bristol Royal Infirmary, which would have been the closest hospital to him at the time, was on strike, so he was taken to Churchill Hospital in Oxford. He stayed with the Churchill Hospital for all of his general haemophilia care thereafter, until he went to film a documentary at Treloar College ("Treloars") in 1984 and transferred his treatment there. I discuss this further below.

7. Haemophilia did restrict Simon's education in my view. He had wanted to become a lawyer because it would have meant he could work from home and still earn a good salary. In the run up to his A-levels he was in hospital a lot and sat the exams from hospital whilst in a lot of pain. He was due to go to Guildford Law School but he did not get the grades he needed. I believe he could not get the results he deserved because of his haemophilia. Instead, Simon went to Surrey University and studied Law with Russian. Whilst at University, he discovered radio and began broadcasting. Had he gone to Guildford Law School, he might not have discovered his true vocation.

8. I cannot remember when Simon first received treatment with Factor VIII but I think it was in 1977 or 1978, after leaving school. He had a bleed that was too severe for him to travel to the Churchill Hospital in Oxford, and so he was treated with Factor VIII locally in Guildford.

9. I recall Simon had to have the Factor VIII injections at the Churchill Hospital, Oxford, in the early days but this cannot have been for long, because I remember he was self-treating when he was at University. I expect he kept a store of Factor VIII with him. He would self-treat at the first sign of a bleed and I think this suited him well at the time.

10. Simon was a good sportsman. Obviously, due to his haemophilia, contact sport was avoided, but he was a keen table tennis player. He would take the Factor VIII treatment before a game so he could keep playing for a couple of hours more. He would also take the treatment on holiday with him. It allowed him to live a more normal life.

11. Simon graduated from University in 1981 or 1982 and became a radio presenter. On leaving University, Simon's first job was at Radio 210 in Reading. He was not there long, as he became the afternoon presenter

with County Sound from the inauguration of the station. County Sound first aired on 4 April 1983.

12. Unfortunately, the team lost the franchise and they all moved to Star Radio in Slough for three years, before County Sound reacquired the franchise in November 1991. I remember at the time that the Surrey Advertiser, a local newspaper, ran a full-page advert with a picture of Simon that just said *"he's back!"*. He was well-loved and popular and he worked with the same team for all of his career.

13. When Simon was working at County Sound, early in the history of the station, all of the presenters were asked to make a documentary for one of the shows. He chose haemophilia as his subject, as he had always been open about having haemophilia. For this programme he went to Treloars to interview doctors, other haemophiliacs and their families there.

14. While Simon was at Treloars working on his documentary, one of the doctors, which may have been Dr Aaronstone, said to him *"your legs don't look right"*. Simon had had a number of severe knee bleeds into his joints and this had affected his legs from a young age. His joints would swell, sometimes his knees were as large as a football, and he would be in such a lot of pain. A lot of damage was done to his joints with every bleed. I do not remember him ever not limping, though it never slowed him down.

15. I remember one family holiday in particular, both of his legs were in plaster and there was only a very small bathroom in the hallway. Whenever he went in there he had to have his legs sticking out and he could not shut the door. Simon told this as such a funny story. He had a great sense of humour, and he never let his condition get him down.

16. The documentary he had made about haemophilia for the County Sound was commissioned and broadcast in 1984. It was called *"Do they really die if they cut themselves?"*. The documentary talked about the available

treatment for haemophilia at the time. He also interviewed a Business Manager at a company producing the Factor VIII product.

17. I have recently looked at the transcript of the documentary again, and particularly noted the comments from GRO-D, a Consultant Haematologist from Guildford Hospital, who spoke about *"the new problem of AIDS"*. He said that AIDS was:

"a disease that has got a great deal of publicity over the last few years but one which few people know anything about. It is basically a condition which makes people more liable to infections than members of the normal population. It is similar in many ways to Hepatitis B and this is the reason it is associated with blood and blood products. It's not a problem with blood products produced in this country, but in other countries where blood is given for monetary reward there is always a higher incidence of diseases like hepatitis and AIDS in the blood. It is something I think has to be kept in perspective because considering the large number of blood transfusions and infusions of blood products which are given in the UK, the number of cases is still very small indeed."".

This makes me think that they knew the blood was contaminated at that point but they thought it was worth the risk to carry on regardless. I find this chilling, and I cannot help thinking, how many people infected in this way are still alive now?

18. At the time the documentary was commissioned in 1984, Simon did not know he had been infected with HIV. He also needed treatment and physiotherapy for his knees, as his legs were bent, which he had at Treloars. Simon also had traction in April 1987 at Treloars.

19. Simon continued to broadcast his show from Treloars. He interviewed patients, doctors and other staff members. Many famous people also came in to be interviewed by him from his hospital bed. His treatment of

all people equally, however small a cog or however famous, made him justifiably popular and everybody adored him.

20. It was while he was having physiotherapy sessions at Treloars that he was told he had been infected with HIV in around 1985 or 1986. Simon was having regular treatment there for his legs and one day, he and a group of other patients also receiving physiotherapy were called into a meeting. They were told *en masse* that blood tests had been undertaken and they showed that ALL ~~many~~ of the group had been infected with HIV. I do not believe Hepatitis C was mentioned at all.

Aup

21. Simon did tell the family when he was told about his HIV diagnosis, but it was downplayed so much that we thought little of it. He was told the doctors did not really know what HIV was, but that if nothing happened within the next six years, it probably would not happen at all. They did not mention that HIV could lead to AIDS.

22. I think, at the time, no-one knew more than that HIV would leave you more prone to infection than others. The implication was that haemophiliacs were a healthy group of people that would not contract HIV.

23. At no point was Simon told that this infection was a risk associated with his Factor VIII treatment. Simon was still being treated at Treloars and his self-treatment with Factor VIII continued.

24. Now that I have read the stories of some of the other people that Simon knew at Treloars in the same group, it is apparent that by 1986, they were being told that they had about two years left to live. To me, that suggests there was a change in the knowledge that medical professionals had about HIV, within a year of him being informed of his diagnosis. I remember that Simon stopped going to Treloars when his friends there started dying. He knew they were all looking at each other and thinking *"who's next?"*.

25. Simon remained relatively healthy for 10 years after that. I know he took Azidothymidine ("AZT") tablets for his HIV, but I do not know when this treatment started, where he was given the treatment, or how long it continued for.

26. In around 1989 Simon initiated and took part in making a charity record called *"Everybody's Got a Crisis in Their Lives".*

27. The first incident I can remember that was related to AIDS was when Simon had septic arthritis of his knees. This happened on my wedding day on 21 April 1990. He was admitted to Basingstoke Hospital and he was there until mid-May 1990. He was being treated with multiple drugs but I do not know what these were and how long this continued for. I know now that septic arthritis was common for haemophiliacs with AIDS, but we did not know this at the time.

28. At that time, Simon was engaged to his long-term girlfriend. When he was hospitalised for the episode of sepsis, she could not cope and their relationship ended. I remember that when this happened, Simon said *"that's it, no-one will take me on."* He met Juliet, his eventual wife, at work. She was 10 years younger than him and they knew by then that Simon was likely to die from HIV. However, they loved each other very much. He was the love of Juliet's life, and he was lucky to have her with him at the end.

29. During this period in Basingstoke Hospital, I remember my mother went to visit Simon one day. She walked past a room and saw a man lying in bed with a massive distended stomach. She walked back after taking a few steps having registered that it was Simon. This incident has made me think that he did have Hepatitis C and he did not know this. I am quite sure that if he had known, he would have told us about it.

30. Simon also had pneumonia but I cannot remember exactly when. He began having night sweats in 1994 and by this point I think he knew he may not have very long left. I was in denial about the prospect that I was going to lose him; I kept hoping there would be a last minute cure and he would get well again. I recall he was given a subcutaneous port in his chest to administer drugs but I am not sure when. It would have been around a year before he died.

31. Simon called me a few months before he passed away in September 1996; I recall I was living in Dorset at the time. I remember exactly where I was when he called me. He told me there was good news and bad news. The good news was that he would never have to go to the dentist again. The bad news was that he had between two and six months left to live.

32. Simon was still working on his radio show while he was having treatment for AIDS, and possibly Hepatitis C, at Basingstoke Hospital. He worked until the October before his death, but even then he did not know at the time it would be his last broadcast.

33. I always thought they would find a cure for HIV because everyone had made such a big deal about it. I could not believe that this would not be fixed, or that the disease would kill Simon. He told me once that it did not matter if they did find a cure, his liver was *"shot to pieces"* so nothing would work anyway. I do not know how he knew this.

34. Simon went into Basingstoke Hospital briefly in November 1996 before he died. He was sent home as the doctors told him there was nothing more they could do. Simon died at home on 28 December 1996 which was a special date for him. The 28th of any month was important to him as that was the date he had met his wife, and the date he had proposed to her. I think that at the end, he held on to make it to this date.

35. Simon was a very positive person. I do not think he knew the extent of what is coming to light now about the contaminated blood scandal. When

doctors spoke to him, I believe they downplayed his condition, especially in the early days. We did not realise at the time what the significant issues were with these infections, and by the time we did realise, we just felt hopeless and desperately unlucky.

Section 3: Other Infections

36. I do not know if Simon had any other infections aside from HIV. I believe that he had Hepatitis C, although this was never officially confirmed to my knowledge. When people wrote articles claiming to be close to a cure for AIDS, he told us not to get our hopes up because such treatments would inevitably have had side effects on the liver and he would not have been able to take them. I do not know if he knew he had Hepatitis C but if he did, he did not tell us, and I do not know why he would not have told us. It is only in retrospect, looking at the symptoms he had, that I believe he must have had Hepatitis C as well.

Section 4: Consent

37. I expect that any tests and treatment Simon had were with his consent. Certainly the treatment for his legs at Treloars was. He may have consented to the blood tests in principle, but as far as I am aware, he did not know he was being tested for HIV.

Section 5: Impact

Stigma

38. The impact of stigma associated with HIV would have been enormous for Simon. He was a public figure and was locally very popular. He would talk openly about haemophilia but he could not talk about the HIV infection, particularly when it became associated with AIDS. He was known to have a "long-standing illness" and nothing more. He would not mention "AIDS" publicly for fear of nullifying his life insurance.

39. I do remember my mother saying to the doctor after Simon's death that nothing mentioning "AIDS" should go on his death certificate. I am fairly certain this was adhered to and his cause of death was something specific, even though it had been caused by AIDS or Hepatitis C..

40. As far as I am aware, only Simon's family and close friends knew about the HIV diagnosis, and some people at work whom he considered friends. I believe everyone around him was very supportive, especially at the radio station. He had worked with many people there for a number of years.

Impact of Simon's illness and death

41. I remember vividly, in November 1996, it was a beautiful autumn. Simon was sent home from Basingstoke Hospital and told there was nothing more they could do for him. He did not see any specialist doctors after that, but his local GP would visit him every few days to check that he was comfortable.

42. The last few weeks of Simon's life were particularly traumatic. He was living in Shamley Green and I was living in Dorset, travelling to see him as regularly as I could. Those last few days of Simon's life were awful. In the end, he was taken from us violently, in a terrifying way, which left me traumatised.

43. On the day that Simon died, a locum GP was at the house. The GP sent me to the pharmacy to pick something up for Simon and I remember the doctor saying *"it's not going to be long now"*.

44. I believe I suffered PTSD for a couple of years after Simon's death. I could not think about Simon without thinking about how he died. The trauma of Simon's death was the worst part; I could not get the images of his final moments out of my head. It took at least two years before I could think of Simon as he was when he was alive, and remember him as just "my brother, Simon*"*, rather than remember how he died.

45. There was a collective shock in the local community when Simon died. Over 300 people came to his funeral and a lot of people in the area still remember him fondly.

46. Simon's death hit our family very hard. Our parents are now 86 and 84 years old. They say they do not want to dwell on what might have been and do not want to give evidence to the Inquiry. They are happy they have me and their grandchildren. I do often think that they may have benefitted from counselling had it been made available to them.

47. Juliet, my sister-in-law, remains unable to talk about Simon or even hear his name. She was quite young when they were married and she was devastated by his death. I am still close to her and her second husband, who has also become part of our family. She does not want to give evidence to this Inquiry either, and so it is for me alone to represent my brother and tell his story.

48. Simon and his wife did not have children. They were told that they could try for a baby within a particular six-month window, but low sperm count as a result of the impact of the medication Simon was taking, made it unlikely. I do not know whether they tried to have children or felt the risks were too great. Simon's wife, Juliet, feels that the possibility of having children was denied to her, GRO-C GRO-C.

49. There are so many "might have been" scenarios that still make me sad to this day. I have no nieces or nephews; my children have no cousins. We are a very small family. My younger daughter was three years old when Simon died and my eldest daughter was five years old. They do not have any real memories of him, so I keep his memory alive when I talk to them about him.

50. Now that my parents are getting older I am terribly aware of missing Simon. I have no-one to share my concerns for our aging parents with and I feel very alone without him. He was a really positive force in our family.

Section 6: Treatment / Care / Support

51. I recall one incident when Simon had a really bad bleed and he would not have made it to Oxford to be treated at Churchill Hospital. He was taken to the Guildford Hospital who would not give him the Factor VIII injection. I do not think they knew how. The Consultant from Churchill Hospital had to call and make the doctors at Guildford Hospital give him the treatment. Beyond that I do not know if there were any obstacles to Simon's treatment or care because of his HIV.

52. There was no question of receiving support or counselling throughout Simon's illness. I am sure it would have been helpful to all of us, but I was not offered any and I do not know if Simon or Juliet were either.

Section 7: Financial Assistance

53. As I have said above, Simon continued working at the radio station until near enough the end of his life. When he was sent home from Basingstoke Hospital in November 1996, effectively so that he could die at home, neither Simon nor Juliet were working at the time. I do not know if the radio station paid Simon any sick leave. Juliet was able to stay at home to care for Simon, although she may have been working on an ad hoc basis. They did not appear to struggle financially, so I presume they were receiving financial support in some way, either through Simon or through savings.

54. I remember Simon was given a one-off payment of £25,000 from the Skipton Fund on the condition that he did not talk about it. The payment helped him buy his house which gave him a better quality of life. I think this was in 1990.

Section 8: Other Information

55. As I have said above, I am a garden and landscape designer and I have been working on a project for the RHS Chelsea Flower Show in 2021 with The Haemophilia Society, titled "Simon's Garden", but for all haemophiliacs and particularly those affected by the contaminated blood scandal. I have designed what I think is a beautiful, conceptual place for reflection and resolution and we continue to search for private funding from individuals who have suffered the same experiences.

56. I want to bring the haemophilia community together with this piece of work, and I firmly believe haemophiliacs have a particular story to tell which seems to have got lost in the wider picture. I have found designing the garden a very cathartic process.

Sections 9: Conclusion

57. Part of the reason for being involved with this Inquiry is to look for answers about what happened to Simon. I want to know when the Government and medical professionals knew that something was wrong with the blood products they were giving to patients, and why it was being used if they knew about contamination. Was this a tragic accident or a calculated risk?

58. I do not believe that Simon was ever told about the risks of treatment with Factor VIII. I need to know if this was just an unlucky accident or if my brother could have been saved from his illness and death. It frustrates me that there was a general attitude that all of this was just "part and parcel" of being a haemophiliac. I believe it was an avoidable risk.

Statement of Truth

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

Signed: GRO-C

Dated: 15.10.19