IRO

Witness Name: Susan Violet Maggs
Statement No.: WITN3137001
Exhibits: WITN3137002-WITN3137006
Dated: 14TH September 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSAN VIOLET MAGGS

I, **Susan Violet Maggs,** will say as follows:-

Section 1: Introduction

1. My name is Susan Violet Maggs and my date of birth is GRO-B 1959. I reside at GRO-B. I am a registered nurse, and I am married to Rob, a paramedic. Rob and I married in 1977, and we have two children, a boy and a girl. We also have four grandchildren, three boys and one girl. GRO-C I have discovered since that GRO-C I are carriers. My daughter is also a nurse, as was my mother before me, so we are a medical family.

2. In this statement I will speak about my late father, Brian Smith, who died as a result of being infected with HIV through contaminated blood products administered to him for his haemophilia.

Section 2: How Affected

3. My father, Brian Smith, suffered from moderate haemophilia A. He used to have regular bleeds and when he was younger he was treated with plasma and transfusions, which normally necessitated long stays in hospital. I recall on one occasion, he had all of his teeth removed, which required a week's stay in the Bristol Royal Infirmary ("BRI"). My father was treated at the BRI throughout his life.

4. My father was always a very active man and he worked as a grave digger for the council. It sounds strange but he used to love it. It gave him a chance to be active, and he used to love being outdoors. He had previously worked in a bakery and would hate being indoors all the time, crushing his hands in the bread making machinery, and so grave digging was a much better fit for him.

5. As well as the plasma and transfusions, my father was treated with Cryoprecipitate that was also given to him at the BRI. This all changed in around 1975, when my father's treatment was changed to Factor VIII. My mother, who was a nurse, would treat him at home and they used to have a supply of Factor VIII, provided to them by the Bristol Haemophilia Centre ("BHC"), in the refrigerator at home. My mother spoke to some people at the BHC to learn about the quantities to administer and then took care of it all herself.

6. As a child I remember my father always being away receiving treatment in the BRI for long periods of time. He received no sick pay for these times, and between my father's hospital visits and my mother's salary, money was tight. However, Factor VIII really helped them. It gave them more control over their lives, freeing them up and meaning my father had to spend less time at the BRI or BHC. It was a wonder drug, or so we thought, and it was as though Factor VIII had enlightened our family.

7. In 1984 my father suffered a fall. He slipped on some ice going to work and badly broke his hip. We had to call an ambulance to rush him to the BRI where he had X-rays. He was not told anything about how his haemophilia impacted upon his injury. I cannot recall the doctors giving him any advice at all in respect of his haemophilia. My father was admitted to the trauma ward at the BRI and he was treated with traction and lots of Factor VIII, but had no operation.

8. It was quite often like that going to the BRI rather than the BHC and it always felt like a battle; nobody really knew about haemophilia and getting any treatment, when they were informed of my father's illness, was always hard.

9. My father spent about a fortnight in the BRI, and seemed really fed up with it. He was not happy at all with the nurses and it was not a good experience for

him being in there. I think this was based on a clash of personalities rather than any complaints he had about his treatment. At the very end of 1984 or the beginning of 1985 my father came out of the BRI but he noticeably began to struggle with his mobility. He had always been a tough nut and he tried to carry on as best as possible, and at this stage we were unaware that there was anything more wrong with him.

10. My father returned to work but his broken hip made this a struggle. From my point-of-view I did not notice a huge change in his condition. My father was still having regular bleeds, as well as nose bleeds and joint problems. In retrospect, I can see that he was beginning to struggle. He was 54 years old at the time.

11. In late 1985 my father was asked to go for a blood test at the BHC. He used to attend periodically for blood testing. On this occasion, however, he was informed that his blood tests showed that he had been infected with HIV.

12. I do not believe that my father was given much advice about managing or containing the infection, and he was given very little information in general. I do not know if he was even told that the Factor VIII was responsible, or when he was infected. I have a letter from my father's solicitors, which he instructed later as part of his involvement in the litigation in 1990, dated 14 May 1990, which states *"I am afraid that the medical records disclosed to date are in any event very skimpy, because the BRI have not kept blood samples which can be tested retrospectively, and even the records which were carried out have been poorly maintained. It is not therefore possible to tell from Mr Smith's notes when he contracted the virus, although we know that it was before December 1985"* [WITN3137002].

13. There was absolutely no support offered. My father was told not to tell people and he was told they did not need to inform anyone. He initially refused treatment for his HIV, with my mother having to coax him into taking any of the drugs prescribed.

14. In 1985 my father had to give up work. He had tried to carry on but it was becoming more and more difficult. The treatment he was receiving for HIV, the drug Azidothymidine ("AZT"), made him angry and he was becoming increasingly frustrated. His occasional refusals to have treatment were very

hard for my mother. My father thought she might have been put at risk of contracting the infection as well. GRO-C

GRO-C

I remember that when my mother treated my father with Factor VIII, she was always methodical, spotless and professional.

15. The AZT was an extremely daunting drug. It came with a tight regime and had to be administered throughout the night, meaning we had to set alarm clocks to get up through the night. Eventually sleep became another issue. My father became lethargic and anxious, and he continued to suffer bleeds throughout this period. The infection together with the medicine caused muscle pains, headaches and muscle wastage, and he felt that there was a death sentence hanging over him. My father went from being quite a robust man to being withdrawn. He tried to carry on but it was just not the same.

16. During this period my parents starting attending meetings at The Haemophilia Society who were making waves about compensation for those infected by contaminated blood products. They met the parents of a five-year-old boy who had been ostracised at school because of his infection. My father was so wild, so furious by what the boy had suffered, that he decided to start campaigning. This work gave him purpose and it quickly snowballed as he became involved in conferences, interviews and newspaper articles.

17. My father was approached by David Watters of The Haemophilia Society and together they worked on raising public support for the campaign, with David encouraging my father to go onto TV shows such as Newsnight and ITV News. I think that this campaigning helped him and gave him a purpose, which he desperately needed at the time.

18. My parents were involved in the Newsnight episode in respect of The Haemophilia Society's campaign on 6 June 1989, which is still available on YouTube. My mother said on the Newsnight programme: *"we just feel that there is no future, it's hard to explain… We're just in this little shell and there's no way of getting out of it."* My father said: *"you can't just sort of get a clear mind… your mind keeps reverting back to things… why should this happen?... To be honest I haven't got much of a future to look at."* My father explained

during the programme that he wanted to ensure my mother would be okay, and that was why he was fighting for compensation.

19. Sarah Spiller reported on the Newsnight programme and confirmed my father *"would get legal aid if the changes were in place; as it is, he is being refused help because he got a pension when he left work through ill health and because Margaret* [my mother] *works part-time".*

20. The financial burden at this point was becoming severe. My mother was still working, as well as providing medical support to my father, and treating him whenever he suffered from a bleed. They were both worried about the stigma that they might suffer as a result of their campaigning and going public. Fortunately, the hospital for which my mother and I both worked, Cossham Hospital, Kingswood in Bristol, was understanding and very supportive, and most of the family's friends were supportive too.

21. However, in October 1990 my mother sadly died of a heart attack. I believe that the stress of supporting my father got to her in the end and she had a cardiac arrest caused by blocked arteries. Her death really threw us all, my father especially, and from that point on he utterly refused all his treatment. He continued to campaign and to fight the legal battles they had started, however, the results no longer had any consequence for him. My father had just given up.

22. In November 1991 my father died, 13 months after my mother. I received a knock on the door from one of my neighbours, who told me that there was a man lying on the floor outside. We found it was my father who had collapsed outside our house. We tried to resuscitate him but we knew really that dad would not want it, that he wanted to go. He was taken to the Frenchay Hospital Accident and Emergency Department, but we were not allowed in to see him.

23. I remember that my father was bagged up like he was radioactive, and we never got a chance to say a proper goodbye. His death certificate said that his cause of death was 1A Hypertensive Acute Left Ventricular Failure, a heart attack [WITN3137003]. There was no mention of HIV. He was 61 years old. After his death, there was a newspaper article in the Evening Post dated 26 November 1991 [WITN3137004].

Section 3: Other Infections

24. I am not aware of any other infection that my father contracted as a result of infected blood products. I am not sure about Hepatitis C; it was always very "cloak and dagger". We were never told if he contracted Hepatitis C and I have no way of knowing. I see no reason why we would have been told if he did.

Section 4: Consent

25. I do not believe that my father was ever provided with adequate information about his HIV infection or about the risks posed by Factor VIII. My parents were very angry when they learnt about his infection, and I believe part of this was because they had not been informed that he was being tested for it.

26. Even after being informed about his HIV infection, I do not know if my father was ever told by the doctors that it was the Factor VIII that had infected him. He knew, so there must have been some information about it available, but whether this was from the media, The Haemophilia Society or the doctors I do not know.

Section 5: Impact

Impact on my father

27. The diagnosis of HIV had a huge impact upon my father. He felt angry, like an outcast, and I remember him saying *"I'm like an alien".* He was never the same after his diagnosis. According to a newspaper interview with my parents, my mother said *"the doctors say we must burn the mattress and pillows if Brian bleeds. How can we ever go away with this hanging over us?"* [WITN3137005]. My parents stopped going away after that. They could not deal with the risk of this anywhere other than their own home, and so they stopped going to hotels, and eventually stopped going away at all.

28. My father had also had to give up work because of his illness, and I believe he had lost some purpose, which he regained thanks to the campaigning. He was worried about the stigma of being so open about his infection and a couple of

the families of my daughter's friends began to shun and avoid us, although most of our friends were supportive.

29. Psychologically, my father did not react well to his diagnosis at all. He became withdrawn and angry. He gave up and did not want to mix with people, isolating himself away; I believe that he was depressed. However, he was of a generation that would never admit to this. He was given no support and very little information. He learned what he could from the media, and this was the period of the "tombstone" advert on the television, which only made his feeling of being an outcast worse.

30. After my mother's death, my father completely gave up. He no longer had any interest in the results of his campaigning, or the results of the legal action which he had been involved with. He eventually secured a payment from the litigation, as a result of the campaign, but there was no accountability and no apology, which I think is what my father really wanted. He thought the money was to try and hush them up, but he refused to sign any waiver in return for the money.

Impact on the family

31. For my mother, I believe that the diagnosis had a significant impact. I think the stress of having to care for my father, and be the sole provider to the family, eventually contributed to her death. I remember once offering to help her in administering my father's Factor VIII because I was also a nurse. She told me very firmly that she did not want me to risk getting an infection as well, and so I think she must have been worried about the risk of infection to her also.

32. I remember my mother telling me a story about one occasion when she had been to the BRI pharmacist to collect my father's AZT. The drug was prescribed free and the pharmacist held the bag up in front of the crowd and shouted at her "*why is this free?*", in front of everyone. My mother was devastated, and I was wild and angry when I heard about it. She explained the situation to the pharmacist, but received no apology and was made to feel really bad. This shows how much the stigma and ignorance affected us, and the terrible impact it had on my mother. During a newspaper interview, my mother said *"we are cut off from everyone because we know people's*

reactions. This is not a socially acceptable disease. People are afraid of it and rightly so" [WITN3137005].

33. As I have mentioned, fortunately we did not feel any stigma from the hospital where we worked, as the medical profession understood the situation.

34. For the rest of the family the impact was one of fear. We were frightened both for our parents and for ourselves, as we knew so little about it. We did not know if we could catch it from my father and I can remember one occasion being scared to even kiss him. I remember being concerned and not knowing how to treat my father, until I started doing my own research and learned that the infection was not as easily passed on as the media would have you believe. We were never given any information, and had to find it ourselves. We were told absolutely nothing and were kept in the dark, when it really would have helped for the whole family to have been told about it.

35. My parents did not tell me about the diagnosis for a couple of days, and I believe they were trying to shield me, as I had just had my daughter and had a five-year-old son at the time. However, my mother and I were close, and they told me a few days later.

36. My three brothers were all extremely frustrated and angry when they heard of my father's infection. None of them were infected or suffered from haemophilia themselves. We all stayed close-knit after the diagnosis; there was no ostracisation or stigma from the family.

37. Our children seemed to take the news about their grandfather in their stride. We told them to avoid their grandfather's bleeds, but apart from that they were shielded as much as possible.

38. In later life, however, my daughter has had some problems that stem from the impact of losing her grandparents. **GRO-B**

GRO-B

39. The infection is still having a knock-on effect on our family. My son is also affected but he has thrown his focus into sport, trying to take it on the shoulders and putting his energy into physical activities. GRO-B GRO-B but I know he initially debated about having children for fear of passing on the illness.

40. My parents' deaths left a big hole in our lives. We felt like orphans. My brothers were only in their twenties, and I was in my thirties, and we really felt their absence. They used to visit us every day and helped to look after the grandchildren, but then suddenly they were gone. We had lost both of our parents in 13 months.

41. I did not realise the impact my father's death had had upon me until 2000, when I was studying my university degree in nursing. It was while I was there that the grief really hit me. I had to go on anti-depressants and I have been on them ever since. At University it all came out of me; I felt lost and vulnerable, like a little child starting out at school.

Section 6: Treatment, Care and Support

42. Obtaining treatment for father's infection was always difficult. He was stubborn and often the GP and pharmacist were reluctant to help. We had to explain it again and again every time we went in, and it felt that there was a barrier between us and the doctors.

43. He was not initially given any information about treating his HIV infection, although over time a little more became available. This was not much however, just about sexual transmission, blood-to-blood transmission and basic "do's and don'ts". All of his teeth had been removed much earlier in his life so there were no issues with dentistry.

44. There was absolutely no counselling offered at all, although my daughter did later seek counselling to help with some of her problems which turned out to stem from my father's illness, and the effect of supressing her grief.

Section 7: Financial Assistance

45. My parents received a lump sum of £20,000 from the Macfarlane Trust which they received on 30 November 1989. This sum was specifically not for compensation, which was confirmed by my parents' solicitors. My parents did a newspaper interview after it was announced that the Government were making payments to haemophiliacs through the Macfarlane Trust. I have a newspaper clipping from the Daily Telegraph on 24 November 1989, which quotes my mother saying *"the news is almost too much to take in but it's a great relief to know that we will get some money. It has been a great strain on Brian. Hopefully this will take the pressure off... although their four grown up children are living away from home, the Smiths' weekly income of around £160 did not stretch to many luxuries."* My father said he *"did not consider the amount to be over-generous, but what are we supposed to do?"* [WITN3137006].

46. They also applied for regular, monthly assistance from the Macfarlane Trust but they were denied and considered not to be eligible for a regular payment. The was no formal application process that I can remember, they just sent a letter requesting assistance.

47. I recall that dealing with the Macfarlane Trust was not easy and they were quite "offish". After my father's death I rang to inform them, not to try and get anything, but simply out of common courtesy. The very first thing they said to me was, "*you can't have any money*". This was very hurtful, as I had just lost my father, it was never about the money, rather about justice. We had no more correspondence with them after that.

48. My parents were also involved in the 1990 litigation. They had financial burdens stemming from the legal action itself as they had to put aside £100 a month towards legal fees, which was about quarter of their income with only my mother working. This litigation did result in a one-off payment of £25,000 but again with no accountability and no apology. My parents did not sign a waiver in return for this money.

49. My parents were also denied Legal Aid for the litigation. The article in the newspaper referred to above, also details my father's difficulties with obtaining

Legal Aid [WITN3137005]. The newspaper article confirms that my father said *"he and most others might have to drop their claims – because they could be saddled with more than £100,000 debts if they lost".* It clarifies that my parents were denied Legal Aid because the combination of my father's pension and my mother's salary was higher than the upper limit for qualifying. My mother is quoted as saying *"we have brought up four children and we are not at all well off. We have had to struggle. I do not know how they can refuse us this help now".* Their solicitors could not understand this and it was like fighting a brick wall just to try start the litigation. It was as though they were trying to put people off from pursuing justice by making it too expensive.

Section 8: Other Issues

50. Most of all from this Inquiry I want justice and accountability, and for it never to happen again. I am angry about it, especially when you see how other nations reacted. Countries such as Finland learned of the risk of infected blood products and immediately stopped importing it. They had very few infections, and few deaths, so why did we continue importing infected blood product when we knew it was infected? They must have known and I cannot understand how they continued. It seems almost illegal, like knowingly administering a contaminated drug. Families were ruined and lives destroyed, and my father is just a small fish in a big pond in all this. I want justice and an apology. I hope that the Inquiry ensures that all stops are taken to ensure safety, and to make sure that this never happens again. I feel that I am finishing what my parents started with their campaigning; it has had such a wide impact and people have gotten away with it for far too long.

Statement of Truth

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

Signed .... GRO-C

Dated....14/9/2019..............................