

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS AMANDA FULKER

I, Amanda Fulker, will say as follows:-

Section 1. Introduction

1. My name is Amanda Fulker of GRO-C Surrey GRO-C I was born on GRO-C 1962 and I am a widow. I have 4 children and my eldest is Samantha (Sammy), aged 30, who is the child of my late husband Robert Fulker. I work full-time in Human Resources for a Local Council.
2. **This witness statement has been prepared without the benefit of access to Robert's full medical records.**

Section 2. How Affected

3. I met Robert in 1980 and we bought a flat together in 1985. H had severe Haemophilia A, which was continually treated with Factor VIII at St George's Hospital under Dr Professor Flute and at St Thomas's Hospital under Dr Savidge.
4. Robert was treated with Factor VIII as soon as it replaced the previous treatment until his death in 1990.
5. Robert was one of 4 Haemophiliac cousins; GRO-A and Robert. GRO-A and GRO-A were mild Haemophiliacs, whereas GRO-A and Robert were severe Haemophiliacs. GRO-A is the only cousin who is still alive.

6. As treatment for his Haemophilia, Robert continually received Factor VIII at St George's Hospital, under the care of Professor Flute, and at St Thomas's Hospital, under the care of Dr Savidge. He began this treatment at a very young age, which continued until his death in 1990.
7. I believe that Robert was infected with HIV and Hepatitis C at St George's Hospital in the mid 1980s, as a result of receiving contaminated blood products. Robert's death certificate confirms that one of the causes of death was HIV.
8. I believe that Robert was infected with Hepatitis C, despite the fact that this is not documented in his medical records, and have fought with the NHS Business Services Authority in this regard. I have recently appealed against their decision regarding Hepatitis C. **Exhibit WITN1652002** is a copy of my appeal dated 3rd December 2018 and **Exhibit WITN1652003** is a letter dated 22nd March 1983 from Dr Flute to Dr Savidge which confirms that Robert's "*alanine transaminase had been raised to 145 iu/l*", which is an indicator for Hepatitis C. **EXHIBIT WITN1652004** is a letter dated 19th December 2018 confirming that I won the appeal.
9. Robert tested negative for Hepatitis B in 1987 and I am unsure if he was tested thereafter. He may therefore have contracted Hepatitis B because he continued to receive Factor VIII up to 1990.
10. Robert was given no advice about the risks of receiving Factor VIII. However, he was very concerned about the risks of Factor VIII and specifically raised this with his consultants. He was reassured that there were no risks involved in the use of Factor VIII.
11. Robert was told that he was HIV positive in 1983. I attended the appointment at St Thomas's Hospital with Robert and the news was given to us by Jane Harrington, a Haemophilia nurse. The news was conveyed to us in a very matter of fact manner and as a result of this neither Robert nor I was particularly concerned about his HIV infection. We were given absolutely no information regarding what HIV was, or what it would mean to us and no information on the risks of transmission.
12. Originally Robert was given the news that he was not HIV positive; nursing staff then advised him that they had made a mistake and that he was in fact positive. After this, he

was then told that he did not have HIV after all. The way in which the consultants dealt with Robert, in relation to the diagnosis of HIV, was entirely unacceptable.

13. Once the consultants decided that Robert definitely had HIV, the advice they gave him in relation to the development of AIDS was contradictory, incorrect and extremely worrying. Initially Robert was told that the risk of developing AIDS was low and that I was not at risk of. About a year after this, Robert was then told that the risks to him and I were much greater than the consultants had previously thought.
14. We got married in 1987 and desperately wanted a family but by this time the doctors were now discouraging us from having a family. However, as luck would have it, I was already pregnant with Sammy, who was born in 1988. If I had not been pregnant already, Robert would not have gone against the doctor's advice for fear of infecting me and we would not have been able to have a child together. I was tested throughout the pregnancy but neither Sammy nor I were infected with HIV.
15. Robert started to get night sweats and other symptoms around 1989. He was constantly in and out of hospital and I thought that I was going to lose him on a number of occasions. By June 1989, he had become a little fragile man who was unable to walk and it was then that the doctors advised me that he had a brain tumour.
16. Some days he was more coherent than others but by this time, there wasn't much that the doctors could do for him. They advised me to put him in a hospice but Robert wanted to be at home with Sammy and me. I therefore engaged the services of a night carer to allow this to happen, which meant that I could get some sleep to enable me to hold our little family together. I continued to nurse him at home, having to change the sheets frequently and to ensure that the doctors and nurses came regularly to try to ease his pain. Towards the end of his life he was on a device which injected morphine at regular intervals to try and make him more comfortable.
17. Robert passed away on Saturday 22nd September 1990 aged only 39.

Section 3. Other Infections

18. I believe that Robert was also infected with Hepatitis C and probably Hepatitis B. He may also have been exposed to the risks of vCJD.

Section 4. Consent

19. Robert was definitely tested without his knowledge and consent. Every time we attended the hospital the nurses took blood from Robert yet we were never told for what purpose this blood was being taken.
20. On that basis, it is impossible to conclude that he was not used for the purposes of research.
21. To the best of my recollection, Robert was not treated without his knowledge or consent.
22. I can confirm that Robert was tested for HIV without his knowledge and therefore, without his consent.
23. Conversely, the doctors always made a real point of telling me when I was being tested for HIV.

Section 5. Impact

24. Mentally, there was a huge strain on me following Robert's diagnosis with HIV. He stopped wanting to touch me as he was scared of infecting me and our sex life completely dried up. He would also get very nervous of me helping him administer his Factor VIII and eventually he would not allow me to help him.
25. The effects of HIV and of the AZT were severe and Robert became very ill fairly quickly. He went from being a fine, broad and handsome man to a thin, frail shadow of his former self. He was extremely depressed and anxious. He also worried about picking Sammy up and having physical contact with her. Eventually he became confined to a wheelchair and more latterly just completely bedridden. During his more coherent days, he would ask for neighbours and relatives to visit him and he gave instructions to our close circle of friends as to how myself and Sammy should be cared for once he had gone. He knew that he was dying and it broke the heart of all those who knew and loved him. In particular, his mother and father came everyday and had to watch the deterioration of their son, knowing that the end was coming. There were days when his mother and I prayed for the end to come

because we could not bear to see him suffer so much. No parents should outlive their children.

26. Robert suffered with pleurisy, pneumonia, anorexia, lymphadenopathy, arthritis, fatigue and candida infections.

27. He had to give up work completely in 1989 when his health deteriorated. Prior to this, his attendance at work was intermittent, due to his poor health. Robert used to work for BT and then in 1983 he became a mini-cab driver.

28. Robert never disclosed his HIV status to his employer or work colleagues. However, he was a little more open in his circle of friends. He did tell people, but we suffered prejudice as a result of his openness. His group of colleagues employed at the minicab office would not have accepted his health issues and would have potentially not wanted to work with him. The office was staffed by men who made constant jokes and banter about people with AIDS in a derogatory and offensive manner.

29. As Robert's health worsened, I nursed him which included helping him with his night sweats and emptying his urine bottles. I was doing all of this whilst also trying to hold down two jobs, care for Sammy and juggle the ever dwindling finances. I worked for the London Borough of Lewisham in the day and waitressed at night. Mine and Robert's family helped out and somehow, between us all, we managed to keep a roof over our heads.

30. Robert passed away on 23rd September 1990 and I experienced prejudice when the undertakers came to pick Robert up. They were trying to force our doctor to tell them what Robert had died of and when they guessed that he was HIV positive, they immediately sealed his coffin. If I had wanted to say goodbye to Robert I would not have been able to. However, because Robert died in his bed at home, I had already said goodbye to him.

31. After Robert died, I was very cross and I emptied my anger in the press because I wanted people to know what we had been through and to try and raise awareness of the awful plight of other families.

32. Sympathetic readers wrote to me in response to a magazine article and also some articles in the newspapers which was lovely but there were a number of downsides to speaking out so publicly. I took Sammy to her playgroup one day, and one of the mothers who had seen one of my articles requested that I remove Sammy from the playgroup. The other mothers

stared at me and I experienced both stigma and prejudice. I was really shocked because our immediate families had known about Robert's HIV and had been supportive.

33. My employer at the time was the London Borough Council of Lewisham, and although they appeared supportive in terms of allowing me time off to nurse Robert, they specifically asked me not to mention that I worked for them in any future articles. I was shocked; I was aged 28 and recently widowed. Eventually they made me redundant but they gave me a bad reference which caused me difficulty with future employers. In the reference they stated that, although they were sympathetic to my circumstances, I had been absent from work far more than was deemed reasonable. I wrote to them to ask for the reference to be withdrawn but they did not have the courtesy to even acknowledge my letter or return my calls.
34. In addition, Robert's cousin **GRO-A** had died at roughly the same time as Robert. His mother specifically asked me not to mention any of their names in the press as her surviving son was already suffering awful prejudice.
35. This made me feel really awful, unsupported and I found it difficult to process. I felt awful as I could have been responsible for identifying somebody else with this awful disease but equally I felt that I was not being asked not to mention this awful set of circumstances by Robert's own family.
36. Following these incidents, I stopped going public and I stopped telling people about what had happened to my family. I did not even tell Sammy so that I could protect her from the stigma. She suffers from depression and anxiety and I think that this has been caused by growing up without a father and then finding out what happened to him.
37. Sammy found out what had happened to her father only relatively recently when she attended a party with our old next door neighbour. The neighbour said that he missed Sammy's dad and said in passing "*the government need to pay for this*". Up to this point, Sammy believed that her father had died from a brain tumour and I had a very difficult conversation with Sammy the next day; she was furious and upset with me for not telling her earlier. I felt that I had to lie to her for years and in some way that could have appeared as I was ashamed of what my darling Robert had died from.

Section 6. Treatment/Care/Support

38. In 1989, Robert was due to undergo a left knee osteotomy and he had his bags packed and was ready to go into hospital on the Sunday as scheduled, in readiness for his operation on the Monday. However, the doctors cancelled the operation and advised him that there was no room on the ward. However, I genuinely believe that they cancelled it due to his HIV status.

39. The NHS never offered counselling to Robert, Sammy or me. We received absolutely no psychological or psychiatric support. Personally, I think that it would have benefited Robert and I would have liked it for myself, as I struggled to process everything and ultimately just dealt with it alone.

40. The NHS did not follow either Sammy or me up after Robert's death and this was disgraceful. I had to source a Hepatitis B test some years later for myself as there was no follow up.

Section 7. Financial Assistance

41. I think that I made contact with The Haemophilia Society who put us in contact with The Macfarlane Trust. I think that Sammy and I were placed on their database but I did feel that they were a faceless organisation. They used to bombard me with copious amounts of paperwork and it was quite difficult to process all of this at a time when I was already struggling.

42. I received £60,000 in 1991 from the litigation that effectively set up The Macfarlane Trust. I had to sign a waiver because I was told that if I did not sign this, then no-one would be paid. The Courts of Justice put £45,000 of the payment on trust for Sammy which she received when she turned 18.

43. I claimed grants for Sammy's school uniform, school trips and a washing machine.

44. The process of applying was tough and it felt like I had to jump through hoops. I had to write a letter to The Trust setting out why I needed the items and it felt like begging. It was also hard to accept that I needed help to properly equip my daughter for school. The cheques

were posted to me and they had The Macfarlane Trust written on them so everyone knew that I was having help from The Macfarlane Trust.

Section 8. Other Issues

45. As previously stated, I fought hard to appeal the decision made by the NHS Business Services Authority in connection with Hepatitis C and my late husband. I am relieved that I won this appeal.

46. In addition and also as previously mentioned, I have been interviewed for quite a few press articles but this was just after Robert passed away and I stopped doing this due to the resulting stigma I experienced. My number one priority was to protect Sammy and our tiny family unit. However, I now feel stronger and I want to be fighting for justice for Robert, his cousins and the other families who have suffered.

Conclusion

47. I feel sick that this could have happened. I feel desperately sorry for the poorly victims who are still alive and have been left with no hope at all. This Inquiry has been a long time coming and the NHS and the Government must now answer serious questions. I want justice and for people to acknowledge how awful this was and to be truthful about what actually happened.

Anonymity, disclosure and redaction

48. I do not wish to be anonymous. I would like to give oral evidence at the hearings.

Statement of Truth

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

Signed.

GRO-C

Dated.

28/12/18