

Witness Name: GRO-B

Statement No: WITN3403001

Exhibits: WITN3403002 - WITN3403003

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on the GRO-B I live at GRO-B I am retired.
2. I am an affected person in relation to my uncle, GRO-B: U (known as U by all family and friends) who was infected with Hepatitis C as a result of receiving contaminated blood. He passed away following an attempt to replace a heart valve that had been infected in 1989
3. This witness statement has been prepared without the benefit of access to my late uncle's full 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.

Section 2. How infected

4. [U] was my mother's step-brother and therefore my maternal uncle. He lived with his parents for most of his life. When his parent's passed away he moved in with my mother and father.
5. [U] was more like my brother than my uncle. He was only 15 years older than me; we had a very close relationship.
6. [U] suffered from Haemophilia and I am not sure when he was first diagnosed. He suffered with Haemophilia type A. I am not aware how severe his Haemophilia was but I know that his mother also suffered from haemophilia as a result of her parents being first cousins and one being a carrier.
7. [U] had bleeds quite frequently. He required an automatic car as driving manual caused issues with his ankles. I don't know any other haemophiliacs so I can't compare his severity to anyone else's.
8. I do not know the entire history in regards to the blood products that [U] was treated with. I do know that he was given blood products as and when he needed them. He received Factor VIII concentrate (FVIII) when he had a bleed or joint issue. I exhibit [U]'s medical records from the National Haemophilia database at WITN3403002
9. [U] was very much in control of making his own appointments and taking himself to the hospital. It was usually the John Radcliff Hospital that he attended and he also had regular checks up there. I think at one time he was also registered at Lewisham Hospital and in the 1970s and 1980s he would go to the Churchill Hospital for appointments because it had a Haemophilia Centre. I do know that [U] was under the care of Dr Mathews and Dr Rizza.
10. [U] was told in the late 1980's that he required a replacement heart valve. He was told by a doctor that he would '*become a cabbage within five years*' if

he didn't. His heart valve had become infected in the early 1980's and as a result had started to leak.

11. The Haemophilia Society helped and advised [U] in the run up to the operation because he required so much blood and blood products for the operation. In the autumn of 1989 he underwent the first of three attempts to replace his heart valve at the John Radcliffe Hospital in Oxford. I understood from [U] that he was the first haemophiliac to undergo such an operation.

12. [U] was infected with Hepatitis C as a result of receiving contaminated blood. I do not have the information relating to the exact dates that [U] received contaminated blood. However, from memory of my conversations with [U] believe he felt that he had been given the contaminated blood in the early 1980s.

13. I do not believe that [U] was ever given any information about the potential risks associated with receiving blood and he only became aware that he was at risk due to the articles that he read during the 1980s. By the end of the 1980s he was certainly aware of the seriousness of the situation but he felt helpless to do anything about it. He needed the Factor VIII and the blood transfusions to treat his Haemophilia and he didn't have any choice but to take the blood.

14. I do not know what information was provided to [U] to understand and manage the infection. I do know that he was under medical supervision as a result of his condition.

15. I do not know when or how [U] was informed that he had been infected with Hepatitis.

16. I feel strongly that the medical profession as a whole were slow to deal with the contaminated blood and action should have been taken to prevent the products being used in the first place.

17. I had young children at the time and I don't believe [U] was told about any potential risks to others as he used to stay with us for recuperation. If he thought that there was any risk to me and my family I do not think that he would have come to stay with us at all.

18. I vividly remember that a lady who was a medical professional came to see my husband and myself. I don't recall where she worked but she interviewed us and spoke to us about [U] contracting Tuberculosis (TB). She undertook a BCG skin test on our children on [GRO-C] 1984 and they were vaccinated on [GRO-C] 1984. The BCG vaccination cards at exhibited at WITN3403003.

19. [U] had suspected pneumonia or bronchitis in early 1984 and he was given medication but he wasn't getting better. That same year he had a tooth extraction and received blood products. [U]'s illness was finally diagnosed as Tuberculosis in 1984 which I believe was a result of his infection with contaminated blood. His Hepatitis infection also caused jaundice on a number of occasions. [U] also had a stroke on the back of the treatment for his heart infection.

20. I remember [U] told us *'The virus has eaten around the edge of the valve of my heart'*. The doctors at the John Radcliff hospital told him there was a possibility of doing an operation around the valve. [U] didn't tell anyone in the family about this until he had worked it all through in his own mind. He told us when he had made the decision to go ahead with the operation because he didn't want to worry us. I remember really clearly he was told that he would end up a 'cabbage'. I questioned this use of terminology and he said that's the word the doctors had used which is why it stuck with me. It seemed completely inappropriate to say something like that to him. I do remember it took about 6 months for all the blood to be gathered for the operation because it was such a complicated and serious operation.

21. I believe that the surgery took place in the November of 1989 and initially everything seemed fine. Then [U]'s body rejected the first valve and he had

to have a second operation. As soon as [U] had the second operation we knew that it had not been successful.

22. The third heart valve procedure was completed but he was taken into intensive care straight afterwards. We were called at midnight to be told he may not last the night and he wasn't a pretty sight because he had a lot of wires and that his wound post surgery was still open. We were advised not to see him and approximately three hours later [U] died.

23. [U] was the first Haemophiliac to have that procedure and I have always felt that the doctors made an experimental decision to try it out on him because he was a single male with no dependants. I believe the surgery was taken with the view to further their research into Haemophiliacs

Section 3. Other Infections

24. I don't believe [U] received any further infections as a result of the contaminated blood.

Section 4. Consent

25. I do believe that [U] was tested without his knowledge and consent. I also believe that he was treated and tested without being given adequate or full information.

26. I also believe that [U] was treated and tested for research purposes.

27. I know that [U] would not have consented to being the recipient of any blood products that carried any risk of being contaminated.

Section 5. Impact of the Infection

28. I believe that [U] suffered significantly both mentally and physically as a result of being infected. He felt helpless and when he needed the most help he was treated badly and with blood that could kill him.

29. [U] became incredibly yellow from jaundice. The whites of his eyes turned orange which was unnerving to see. He had at least 2 attacks of jaundice that left him looking very unwell. I cannot imagine that he was ever completely clear of it and I think he found it quite debilitating.

30. [U] did not survive the 1980s and I do not have any information on any further medical complications or conditions that resulted from his infection.

31. I believe [U] was frightened and helpless as a result of what happened to him. He was scared for his future and he found it difficult to talk about. I don't believe he had been able to assimilate it all himself. As far as I know he was talking to people at the Haemophilia Centre about things but I cannot be sure.

32. [U] did talk to me about his condition in the late 1980s and I know that he was quite involved with the Haemophilia Society at that time. He became aware that there was a problem with the blood that had been given to haemophiliacs and he was concerned that he could have been contaminated. We started to look back and we soon realised that all of his issues occurred in conjunction with the time that blood products were coming into the UK. [U] died in 1989 before the full extent of the issue came to light but he was reasonably certain he had been infected at that point.

33. I know [U]'s fear of his infection and the affect it was having on him was a contributing factor in him making the decision to have the heart valve replacement. It was something he was in control of and something that could possibly prolong his life.

34. [U] felt helpless about his condition at the time. People are unified and supporting each other through this now but in the early years you were very much on your own. It was impossible to tell how people would react or treat you.

ANONYMOUS

35. I believe [U] did have some issues with treatment on visits to the dentist but I have no further details.

36. I am not aware fully how [U]'s relationships had been affected as a result of the infection but I do know that as a family our relationship with [U] never changed. He still had many friends and when he was able he joined in with social events and continued to work.

37. My family and I miss [U] enormously to this day and we often speak about him. Our children, who are now in their forties, have very fond memories of their great uncle. My husband and I still feel great sadness that he was taken from us at only 53 years of age. He was in good health when he had the surgery to replace his heart valve and they would not have performed the operation otherwise.

38. We have never felt any stigma as a result of [U] being infected with Hepatitis C.

39. [U] lived with my parents in a home they jointly owned. He had been a part of their lives from the early days of their courtship. My mother had helped her stepmother with [U] since he was a baby.

40. [U] continued to work within the NHS in an administration role after he had been infected so he was not affected too much financially.

41. There were no direct effects on my work, education or finance as a result of [U]'s infection.

42. The pain of losing [U] is not something that will ever end. When my parents were married they were all very close. He was always there and he was more of a brother than an uncle.

43. [U] and my parents bought a house together and they all lived in that house. When they lost him they lost a huge part of their life and he also

contributed financially to the household but the mortgage was in [U]'s name and was therefore cleared on his death by insurance.

Section 6. Treatment/care/support

44. I am not aware of any difficulties that [U] encountered in obtaining treatment, care or support.

45. Neither I, nor my family, were ever offered any assistance, counselling or any other form of support before or during the time of his infection or following his death.

Section 7. Financial Assistance

46. I do not believe any financial assistance was offered to [U]

47. I have not received any monies from any Trust or Fund. I would probably not qualify but I have never enquired.

Section 8. Other Issues

48. I would like to know why there weren't any safety measures implemented when importing contaminated blood from the US. In my opinion it is a criminal act and if it was done to save money then it is despicable. I would like an explanation as to how they believed this to be acceptable.

49. Following the death of my uncle, I did not closely follow the process which led to the Inquiry being set up and I was not aware of any earlier investigations enough to be involved.

50. I want to speak up for [U] and have his illness, suffering and death recorded. I hope in the near future the true impact of this scandal can be uncovered.

ANONYMOUS

51. I do not have any paperwork to back my story of what happened to U

However, I feel that his medical records must still be somewhere especially given the significance of the heart valve operation. Following advice, I am currently investigating what is available and will share this information when I have any results from my enquiry regarding his medical records.

52. I don't know why people who have been put into this devastating position don't have the basic assistance they deserve. There has been no apology, compensation or even general support. To make those infected and affected have to wait all this time is wrong.

53. I try and feel confident that justice will be done but it was such a long time ago and the people who made those decisions have probably covered their tracks by now.

54. Somebody out there knew as soon as they started importing from the US there would be a problem and yet they still went ahead and did it. I don't believe in the early days that the people who received the blood were aware at all. They were just given the option 'do you want this transfusion or do you want to bleed to death'.

Anonymity

55. I wish to remain anonymous.

56. I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B

Dated... 3 October 2019