

Witness Name: GRO-B

Statement No: WITN1070001

Exhibits: 0

Dated: December 2018

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 My date of birth is GRO-B and I live at GRO-B
2. I make this statement on behalf of my late husband, GRO-B: H date of birth GRO-B My husband died on GRO-B from a GRO-B GRO-B
3. I married H in GRO-B and we had 1 children together. My husband was GRO-B when he passed away in GRO-B I was not aware until the mid 1990s that my husband had Human Immunodeficiency Virus (HIV) and Hepatitis C (Hep C).
4. This witness statement has been prepared without the benefit of access to my late husband's medical records. I have been told that his medical records have been destroyed.

Section 2. How infected

5. My husband had severe Haemophilia A with inhibitors to Factor VIII (FVIII). His brother similarly had haemophilia and died on his 8th birthday as a result. Our daughter GRO-B is a haemophilia carrier.
6. My husband attended the Royal Free Hospital, London (RFH) from the mid 1970s until 1981. From 1981 he attended Churchill Hospital, Oxford (CH) and he was under the care of Dr Matthews, Dr Giangrande and Dr Rizza. His local GP was Dr GRO-B.
7. My husband only required FVIII when he had a bleed and it was only administered at the hospital.
8. In the early 1980s my husband was invited by the Haemophilia Centre at CH to take part in an experimental test, which entailed blood transfusions. He attended the hospital every Saturday.
9. I believe my husband was infected with HIV and Hep C by FVIII blood products that he was given and/or by the blood transfusions he had during the experimental tests.
10. I do not believe my husband was given any information or advice beforehand about the risks associated with blood products. I believe that he would not have accepted FVIII nor would he have participated in the experimental tests had he been told there were risks involved.
11. I believe my husband was told that he was HIV positive in the mid 1980s. I do not know when he was told about Hep C. I do not know who told him or what was discussed.
12. In or about the 1990s my husband had a bad fall breaking the top part of his femur. He was taken to hospital and because he was a haemophiliac and had HIV and he was operated on very quickly. The surgeon put three screws

in to secure the bone. In haste he put in a screw that was too long and in time this started to bore into his acetabulum. Consequently my husband started to experience excruciating pain. The hospital refused to operate on him again to correct it. I believe it was because it was not life threatening and because of the risks associated with his HIV/Hep C status. It was at this stage that he became more or less wheelchair bound.

13. Due to the agonising pain my husband was going through he became more and more dependant on pain killers (Palfium). He was on a very high dose. The side-effects were extreme lethargy and slow reactions in speech and action. Dr **GRO-B** who prescribed the drugs made no attempt to manage my husband's intake. My husband was highly addicted to the drug. I eventually took matters into my own hands and went to the Warnford Hospital in Oxford which deals with drug dependency. He was then given a methadone regime which I controlled. This was not easy at all.

14. As previously stated I was not aware until the mid 1990s that my husband had HIV and Hep C. After his operation he was frequently in hospital. It was only by accident that I discovered he was HIV and Hep C positive when I looked at his medical notes at the end of his hospital bed. I confronted him and he told me that he did not tell me because he thought that I would leave him. I also confronted the doctors, but I was told that they could not say anything because of client confidentiality. I was angry and upset because I was at risk of being infected and nobody told me.

15. I do not believe that adequate information was provided to my husband to help him understand and manage the infections. I was not provided with any information in this regard.

16. I believe that the information should have been provided to me when my husband was diagnosed as there was a risk that I could have been infected.

17. I do not have any views regarding how the results of the tests were communicated to my husband as I do not know how my husband found out.

18. I was totally ignorant about the whole thing. I cannot say what was said to my husband about the risks of others being infected as a result of his infections.

Section 3. Other Infections

19. I do not know if my husband received any infections other than HIV and Hep C.

Section 4. Consent

20. I believe my husband was tested without his consent, knowledge and without adequate or full information in relation to his infections.

21. My husband had full knowledge that he was being tested for the purposes of research when he agreed to the experimental test and he believed it was in relation to his haemophilia.

Section 5. Impact of the Infection

22.

GRO-B

GRO-B

23. My husband started to look very gaunt in the last year or so of his life.

24. I do not know what treatment my husband was given in relation to HIV or Hep C.

25. I do not know if my husband faced any difficulties or obstacles in accessing any treatment.

26. I am not sure if treatment ought to have been made available to him.

27. In or about the mid 1980s I noticed that my husband's teeth looked like they had been ground down, they were just stumps so he had to have false teeth. I believe this was as a result of his infections. I know he went to see a dentist in London so it may have been a special dentist who dealt with him.

28. It was very difficult for me to live with someone who was drinking a lot and was dependent on pain killers. He was very bitter and he would take it out on me. His character changed and he became verbally abusive.

29. We did not go out very much because when he was taking the painkillers, he was always drowsy. I did not like him driving the car because he would forget where he was going.

30. When my husband was diagnosed with HIV, GRO-B
GRO-B I did not believe they were affected. I did not discuss anything with them and kept the problems that we had to myself.

31. When I found out about my husband's HIV I was worried about my own health. I did not get tested until after my husband's death as I found it extremely difficult to go to the hospital as I was scared of being told that I had HIV. GRO-B

GRO-B

GRO-B

I went to CH and got blood tests done. I had to wait a week for the results. I was terrified about the results. I telephoned the hospital on the day of my results and told them that I did not want to know the results, but the doctor telephoned me 10 minutes later and said I had nothing to worry about as the test was negative.

32. I believe the reason why I kept my husband's conditions to myself was because of the stigma associated with his infections and particularly HIV. My children were at the hospital when I saw my husband's medical records and found out that he was HIV and Hep C positive. I believe my children were aware of the stigma that was attached and I believe that was the reason they

did not tell anyone. I believe that if we had told friends and family about my husband's infections they would not have wanted to know us, or share a meal with us.

33. I believe my husband's work was affected as a result of the drug addiction. He owned a business and worked all his life and he had to give it all up.

34. Due to my husband's infections, he had a leg ulcer which covered the whole of his calf and it would not heal. He got very sick as a result and died in 1997.

Section 6. Treatment/care/support

35. I do not know if my husband faced any difficulties or obstacles in obtaining treatment, care or support in consequence of being infected with HIV or Hep C.

36. My husband and I had counselling when we went to GRO-B Hospital for drug addiction, but I do not think it helped. I do not know if any counseling was offered to my husband in relation to the HIV or Hep C.

Section 7. Financial Assistance

37. I believe my husband received a one off payment of £20,000 at some stage from the government.

38. I now know that he was in touch with The Macfarlane Trust but I do not know if he received anything when he was alive. When my husband died I received a monthly payment (I cannot recall the amount) for about 4 or 5 years, but I do not receive it anymore.

39. My sister-in-law told me about The Skipton Fund and I received a lump sum payment of £20,000, which I shared with my children.

40. The forms for The Macfarlane Trust and The Skipton Fund were straight forward. I do not believe any preconditions were imposed.

41. I received a further payment of £10,000 from The Skipton Fund in 2017. However, this application was complicated because I did not receive any support from Dr **GRO-B** nor the Haemophilia Centre. I had to approach the Macfarlane Trust and they helped me with the application.

Anonymity, disclosure and redaction

42. I confirm that I do wish to apply for anonymity.

Statement of Truth

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

Signed....

GRO-B

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Dated

15.12.18