

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1133001

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** of **GRO-B**
GRO-B I was born on **GRO-B** 1964 . I am a widow and I live alone.
2. My late husband, **GRO-B H** died on **H** 1991 having been infected with HIV following his use of Factor VIII.
3. This statement has been prepared without the benefit of access to **H** medical records.

Section 2. How Affected

4. My late husband **H** was infected with HIV before we met. He had Haemophilia A and received Factor VIII. He attended St Thomas's Hospital in London for treatment and it was here that **H** underwent 3 operations for silastic elbow implants in 1985.
5. When **H** was a young child he was hospitalised for days when he had bleeds. After the introduction of Factor VIII this was a thing of the past. **H** received Factor VIII when he was aged about 10 and he used to inject himself.
6. I am not aware that **H** was advised about the risks of using Factor VIII.

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7. I believe that [H] was told that he had HIV in or around 1987. He attended a routine appointment, alone, at St Thomas's Hospital. He was taken to a very small room and was told that he had HIV and he was not given any adequate information regarding the infection. If [H] had known that he was going to be given such devastating news he would probably have taken his parents to the appointment.

Section 3. Other Infections

8. I do not think that [H] was infected with, or was exposed to, any other infections.

Section 4. Consent

9. [H] was tested for different viruses, including HIV, without his knowledge and therefore without his consent.
10. I am unsure as to whether [H] was used for the purposes of research. [H] had blood taken every time he attended St Thomas's Hospital and later having moved to a different area at Lord Mayor Treloar Haemophilia Centre in Alton. He thought that this was to ascertain the progression of his HIV, but this may not have been the case.

Section 5. Impact

11. [H] told me that before we met, he had contemplated suicide on a number of occasions. On one occasion he took the carving knife out of the kitchen to slice open his wrists, but his mother managed to stop him. Even during our time together he would tell me on the way home from appointments at the Haemophilia Centre he used to overtake, when driving, on blind bends in the hope that a vehicle was coming the other way would finish him off.
12. As far as I am aware, [H] was not offered any psychological support.
13. Following his HIV diagnosis [H] was reluctant to use Factor VIII, he would try not to use it even though it was pretty inevitable that he would have to. He was afraid of any further infections like Hepatitis or a new as yet unknown virus in the way HIV had been. This meant he suffered more pain and damage to his joints than was necessary but he was determined to minimise his risk at whatever cost.

14. Physically [H] was quite well until October 1988 when he developed bowel cancer. He underwent surgery for this and the hospital treated him like a leper. They left his jug of water outside his room and they did not feed him for 3 weeks. It was only when someone fed him by accident that feeding was resumed. I believe they were over cautious about resuming food and that he was 'quarantined' because he had HIV. Following the results of the tests on the removed tumour, a nurse came into his room and informed him that, now he had cancer 'that was it'. He told me later that day it felt like she'd put him in his coffin and nailed down the lid with the words she used. I assumed she was trying to say that he was no longer just HIV positive now that he had AIDS.
15. [H] then underwent 12 weeks of chemotherapy and whilst he was undergoing this he was put on steroids. The steroids actually made him feel a little better. However, as soon as the 12 week course had concluded and he stopped receiving steroids his health declined.
16. [H] underwent a number of treatments for his HIV including AZT.
17. His body did not take the AZT well he was constantly very anaemic, leaving him exhausted and he struggled to function normally, the dosage was cut a number of times but without much effect on his tiredness.
18. [H] then underwent a routine scan to check if the cancer had returned. He was told that the cancer had spread to his kidneys and that they would undertake a bone marrow transplant. [H] family were tested and the hospital found that his brother was a match and therefore everything was set for the transplant.
19. Throughout this time, [H] was insistent that his cancer had not spread but no-one would listen to him. Finally, just before he was due to undergo the transplant, someone finally listened to him and an old scan was compared to a new scan and they realised that he had a horse shoe shaped kidney and that he was cancer free after all. It was a misdiagnosis with the result of [H] being put through unnecessary stress and almost embarking upon an unnecessary bone marrow transplant. The mental strain was almost too much for both of us and his family.

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20. [H] then developed a problem with his foot in about the middle of 1990. The medical professionals thought that he had a bleed in his foot but [H] protested that this was not the case. The foot pain persisted with no apparent cause until things came to a head in December 1990.
21. On 6th December 1990 [H] and I were having dinner with my parents and [H] knocked over a glass of wine but no one thought anything of it. However, later when he came out of the toilet he had not zipped up his trousers or put himself away. He was not aware of this and also demonstrated extreme slurred speech. I took him outside to get some fresh air and he said that he felt really odd but had no idea why he was very embarrassed about the toilet issue and said his hand had felt odd and that is why he'd knocked over the wine.
22. Within about a week of this incident, [H] had a fit in bed during the night. I managed to push him over onto his side and kept talking to him and tapping on his arm. Eventually he stopped fitting and regained consciousness. I told him that he had had a fit and he did not believe me but when he realised that he had wet the bed he accepted what I had been saying.
23. [H] was then sent for a brain scan at a London hospital but I don't know which hospital he went to because his father took him to this appointment. Normally he went to appointments alone; he would never allow me to go with him, I think that he wanted me to mentally pick him up after his appointments and if I was present during the appointments, we would both be very depressed and I wouldn't then be so able to bolster his spirits afterwards.
24. In fact, this was why I would not have an HIV test while [H] was still alive as I needed to be mentally strong to be able to keep [H] spirits up. I finally had an HIV test after [H] died and thankfully it was negative.
25. When [H] returned from the hospital with his father he told me that he his brain was shrinking; that the protective coatings on the nerve endings in the brain were being destroyed leaving the nerve ends exposed to the brains' electrical impulses, which were damaging them until they stopped working. The doctors estimated that the progression of this damage would mean that he only had 6 months to live. That was just before Christmas in December 1990. It was unimaginable, that someone so full of life would not be there next Christmas.

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26. Following this [H] rapidly declined. Sometimes he lost the use of one side of his body and other times he was unable to speak properly. He spent a lot of his time asleep, particularly after a day at work as an Assistant Accountant. Remarkably he managed to work up to 13th March 1991.

27. [H] passed away on [GRO-B] 1991.

28. [H] was a truly phenomenal man who never let anything defeat him. He dealt with his Haemophilia so well and defeated his cancer. However he could not fight the virus damaging his brain slowly taking his life from him. When he finally died, he was unable to move or speak and his lungs filled with fluid and he drowned in his own body fluid. He was so proud when he had beaten cancer against all the odds but could not fight this in same way.

29. [H] was absolutely terrified of infecting me with HIV and this greatly affected our relationship, we did not have a sex life to speak of, we tried but he was afraid of infecting me and I was afraid of infection. The fear would always hit one of us and we would be physically unable to continue. However, he always thought that he could fight the HIV just like he fought everything else in his life. I am remarkably proud of him.

30. [H] did not let his HIV affect what he planned to do. He carried on socialising with his friends but in the end due to the HIV and AZT he was too tired to go out and as soon as he got back from work, he would fall asleep on the sofa. In hindsight, I think that [H] would have been happier if he had never embarked upon the AZT; he would perhaps have had a shorter life span but experienced a better quality of life.

31. [H] parents knew about his infection, but I am fairly sure that he had not told any of his friends, certainly no one that he met during our time together. When [H] found out that he was HIV positive he was living in [GRO-B] and then later he moved to [GRO-B] following his parents. [H] did not tell anyone at work about his HIV. He therefore avoided any possible negative stigma. He was angry when his boss told everyone at work that he was a Haemophiliac because of the association with HIV. He took it personally when leaflets were handed out at work regarding HIV/AIDS, although I believe they were given to all companies by the Government but it coincided with him arriving in a new job and he felt that it was because of him. It also made him afraid of people asking his status.

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32. I recall a time when [H] successfully obtained a new job and had to undergo a medical as part of the life insurance and pension schemes. The doctor in the medical asked [H] if he was HIV positive and [H] refused to respond. Fortunately, the doctor did not press [H] any further.

33. Initially, I didn't tell my family that [H] was infected with HIV. I did, however, finally tell them when he was told that he had 6 months to live. I think that my parents told my brother. However, once [H] died my mother told everyone that he died from cancer because of the stigma attached to HIV and because everyone knew he'd had cancer a couple of years earlier.

34. The HIV did impact part of mine and [H] life, but I think that we just got on with things. We accepted that it was there, and we just did the best we could in spite of it. We always tried to look forwards. However, it has robbed me of a soul mate and my chance to have children with my soulmate. [H] longed to have children and I feel very sad that our wishes could not materialise.

35. I was offered bereavement counselling, but I did not accept it as it was all a bit strange because the person the hospital wanted to send to conduct the bereavement counselling was the same person who the hospital had previously sent to our house when [H] was alive to discuss benefits. When she attended our house to discuss benefits, she did not really talk about benefits and spent most of the time discussing how she lost her husband. She was so depressing that [H] said that he never wanted to see her again. I was in complete agreement with him.

36. I did not have anyone to confide in or talk to about [H] HIV. When he was alive [GRO-B] [GRO-B] it felt wrong to go out with my friends and leave him alone at home. I would not have discussed his HIV status with them anyway as it may have affected the way people treated him. When he died people used to ask me to go out but it was too depressing seeing happy couples everywhere so I stopped going and then the invites stopped coming after a while. I therefore didn't have anyone to confide in following [H] death.

37. In terms of the educational effect, [H] had to give up studying for his Accountancy Course as he could not concentrate, and he felt that there was no point because he was not going to live for very long.

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38. In terms of employment; it was only because [H] was so dedicated and had such a determined outlook that he managed to continue in his role as an Assistant Accountant right up until only a month before his death. [H] also attended work on Saturdays to make up for any missed time as a result of medical appointments or chemotherapy.
39. As a result of [H] infection, I realised that I would have to pursue a career at a higher level than I would otherwise have liked. I was not particularly interested in being an Accountant and was happier to stay in a less pressured role, but I had to study and qualify to pay the mortgage and I did it for [H] because he never got the chance.
40. We did struggle financially because we had stretched ourselves to purchase the house of our dreams. The mortgage was large and there was no life insurance for [H] only for me because [H] was unable to obtain any and if I had disclosed that [H] had HIV, I would probably not have been able to obtain life insurance either. When he died the monthly mortgage, payments were greater than my monthly income. I paid the first month after his death, with money from a collection his work colleagues had raised following an event. I suspect it was intended for me to donate it to charity in his name, but I had no choice.
41. For [H] the worst thing about his impending death was the thought of me moving on and being with someone else, who I could have a conventional sex life with; this tortured him despite my assurances it was unlikely, I couldn't imagine anyone taking his place and so far they haven't.
42. [H] wanted to be buried but his will requested a cremation because he had once been told that he must be cremated to avoid the virus contaminating the ground.

Section 6. Treatment/Care/Support

43. I have already discussed above the fact that [H] was treated like a leper when he underwent surgery for his bowel cancer.
44. [H] also experienced delays in relation to operations and treatments and prejudicial behaviour from medical staff. I am unsure as to whether this was due to his Haemophilia or his HIV.

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45. I used to visit [H] in hospital and on one occasion I lay down next to him on his bed. A nurse told me that I should not be doing that in case I caught something from him.

Section 7. Financial Assistance

46. [H] found out about The Macfarlane Trust from The Haemophilia Society and received a payment of about £20,000 from The Trust.

47. We used some of this payment towards the house and purchased a replacement car. We also ensured that we saved some as a cushion for me but at the time of his death it was tied up and couldn't be accessed immediately.

48. We also received about £1,000 to help with the cost of our wedding.

49. I also received the final payment of £32,000 which only came to me because [H] had died. I used this to bring the mortgage down to a sum that I could manage on my own.

50. Of the £32,000, £4,250 was payable to me and the rest went to [H] estate.

51. [H] and I were unaware that we could apply for any other grants.

Section 8. Other Issues

52. We were involved in some earlier litigation, but I don't know if there are any records regarding this still in existence.

Conclusion

53. I don't know that the Inquiry can achieve anything for me personally but for [H] want justice to be done and for those responsible to be held accountable. I want the truth to come out and I want answers as to why this tragedy was allowed to happen.

54. The contaminated blood scandal destroyed my life. I would describe myself as only existing for a very large portion of my life. I have never felt the same about anyone else as I felt about [H] and I have therefore remained single. I was robbed of a soul mate and robbed of having children with the man who I loved and still love so dearly.

Anonymity, disclosure and redaction

55. I confirm that I want to apply for anonymity and I don't want to give oral evidence at the Inquiry.

Statement of Truth

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

Signed GRO-B

Dated... 27-12-18