

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1347001

Exhibits: none

Dated: January 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 of GRO-B
GRO-B born on GRO-B I was married to my late husband GRO-B:H
GRO-B:H for GRO-B years. I am retired but previously worked as a GRO-B
GRO-B I live alone and
have GRO-B
2. I provide this witness statement in response to a request under Rule 9 of the
Inquiry Rules 2006. I am aware that both my GRO-B and
GRO-B will also be giving statements.
3. This witness statement has been prepared without the benefit of access to
any of my late husband's medical records.

Section 2. How Affected

4. I make this statement in relation to my late husband, H
born on GRO-B who was infected with HIV by contaminated blood

ANONYMOUS

products in the early 1980s. He died in [GRO-B] on [GRO-B]
[GRO-B] aged [GRO-B] years old after a big bleed in his head.

5. My husband suffered from severe Haemophilia A.
6. I believe that my husband was given cryoprecipitate as a child and then he was given Factor VIII from 1980s onwards.
7. Due to complications when he was a child he had to go to [GRO-B] for treatment as an inpatient. He was then later treated at the [GRO-B] [GRO-B] which is now called [GRO-B] [GRO-B] I cannot remember the name of the treating doctor.
8. My husband was told of the change of treatments from cryoprecipitate to Factor VIII but neither of us were ever informed by the hospital of any risks in taking Factor VIII.
9. [H] was infected with HIV, Hepatitis B and Non A Non B Hepatitis, which later became known as Hepatitis C.
10. There were rumours about infections circulating in the Haemophilia Community in the early 1980s, but I believe it was around 1983 that [H] was officially told about having HIV by doctors at the [GRO-B] I was not there when they told him but it was during one of his regular check ups. I believe that he was also told he had Hepatitis B around this time.
11. Then in or around 1986 or 1987 he was further diagnosed with Non A Non B Hepatitis. There wasn't much of a fuss made about the Non A Non B and it was only really mentioned in passing.
12. He was not given any information regarding any of the infections and he had to come home and research them himself. I was able to help him with the research due to my background [GRO-B] but I feel that he should have been given more adequate information at the time that he was told. I should have also been invited to the meetings as his wife.

Section 3. Other Infections

13. In or around 2000 or 2001 he was told, during a regular three month check-up appointment, that he may have been exposed to vCJD. He was told that it was only a possibility and it was unlikely to materialise for a few years at least, but he was still given no information on it. Thankfully he never actually developed vCJD.

Section 4. Consent

14. I believe that my husband may have been tested for HIV before 1983 without his knowledge and therefore without his consent. Blood was taken from him regularly, at routine clinic appointments, but he was never told why.

15. I do not believe that my husband was ever advised that he was being tested for non-A non-B Hepatitis. He was therefore tested, probably numerous times, without his knowledge or consent.

Section 5. Impact of the Infection

Psychological effects of infection

16. Before my husband was diagnosed with HIV he was a very normal person. He helped out around the house where he could and he was always working hard in full time employment.

17. After his diagnosis with HIV he changed a lot. He developed a very bad temper and kept himself away from the rest of the family as much as he could. He had no patience with the children and just didn't want to be around anyone. He also became very paranoid and felt that everyone was against him and he could not be persuaded otherwise.

Physical effects of infection

ANONYMOUS

18. Before his HIV diagnosis he only used to have one or two bleeds a year and used to treat himself for them. After the treatment he couldn't do this anymore and he deteriorated very rapidly upon having a bleed.

19. His knees and legs became very weak and he developed arthritis. GRO-B
GRO-B
GRO-B
GRO-B it really made him depressed and very quiet. He didn't think it was fair.

20. He also developed problems from his Hepatitis C infection with his GRO-B
GRO-B

21. His health then really started to deteriorate when GRO-B
GRO-B
GRO-B so we decided to tell the children that their dad was HIV positive and was going to die soon.

22. GRO-B
GRO-B
GRO-B
GRO-B
GRO-B There were a few times where he had to be hospitalised to clear these terrible bleeds.

23. His liver was also infected.

Treatment

24. He was initially given AZT as a treatment for HIV but in 1998 he changed HIV treatment to a new tablet and he had to take three tablets, twice a day.

25. He never received any treatment for the Hepatitis C.

Impact on private, family and social life

ANONYMOUS

26. Before he was depressed he was very close to the children. He used to take [GRO-B] and we had a very close knit family. All his involvement with [GRO-B] stopped after he was diagnosed with HIV because he became scared of infecting them and he wanted to avoid them suffering any prejudice.
27. He was on home treatment too so kept the treatment in the fridge. We had to be careful and make sure the children didn't touch anything.
28. All this had a great impact on our family life and soon the kids didn't want to be around him either. He used to inflict mental torture on them. If they wanted something, such as [GRO-B] he would say no, and then a short time later he would buy whatever it was they wanted and just keep it for himself.
29. Prior to his diagnosis he used to socialise with friends and come on family holidays, so this was all a big and sudden change. His friends cut him off once they heard about his infection. He didn't tell them, but word got around in our village and so he became ostracised very quickly. People even used to say nasty comments to him so he simply stopped going out.

Impact on me

30. I was his carer for at least 17 years and his consultant told me at the time that if I did not care for him like I did, then he would have been dead a lot sooner. However, being his carer really put a strain on our relationship and [GRO-B] [GRO-B] His behaviour made life much harder for all of us.
31. My friends just stopped all contact with me. Everyone cut me off and no one wanted to know either of us. I used to hear horrible comments behind my back, even when I was out with the kids, shopping or dropping them to school.
32. I started smoking heavily due to the extreme stress that I was under; I was providing constant care to my husband while our family was becoming more distant. [GRO-B]

Stigma

33. We never told anyone about his infection. Not a soul. We were too worried about the stigma that was around. In a village like [GRO-B] we worried that everyone would find out very quickly. We didn't even tell the children straight away as they were too young to understand.

34. The stigma towards HIV at the time was significant and [H] really felt that first-hand; people just didn't want to know him, or our family. He stopped going out with [GRO-B] as he didn't want to expose them to the taunts due to the stigma, such as 'Your dad's got AIDS'.

35. The nasty comments became less frequent as the HIV stigma started to die down and people understood more about HIV, however, we found ourselves naturally staying away from people and being wary of them, in anticipation of their horrible comments.

Impact on our sons

36. This really affected [GRO-B] even though they tried very hard not to show it. They were a lot more affected than I thought at the time and it is only now I am beginning to realise how affected they truly were.

37. [GRO-B] really changed his behaviour from when he knew his dad was disabled. As a teenager, [GRO-B] was always angry, dropped out of school at [GRO-B] His behaviour became even more terrible once he knew his dad was infected with HIV. I believe that [GRO-B] wouldn't have gone the way he did if his dad wasn't infected. It is only in the last 10 years that he finally [GRO-B] [GRO-B] and has got his life back on track. He only told me [GRO-B] that he suffered a lot and was bullied at school.

38. I feel that my [GRO-B] kept himself to himself and became distant. It upset [GRO-B] when [GRO-B] had to leave home.

Work related and financial effects

39. [H] had worked full time at the [GRO-B] for his whole working life. He never used to take time off work until after his diagnosis with HIV and then his health forced him to take quite a lot of time off. In or around [GRO-B] he was offered voluntary redundancy and due to the combination of both haemophilia and HIV on his health, and he decided to take it.

40. My husband didn't get a large payment when he took voluntary redundancy; he only received about £8,500. We were living on disabled living allowance, sickness benefit and towards the end, a care component, from the government.

41. I was still [GRO-B] when [H] became ill, and had been for over [GRO-B] years. However, soon after his illness [GRO-B] [GRO-B] He was still relatively alright at the time but after I started working as a [GRO-B] his condition got worse and I had to reduce my hours and could only work [GRO-B] as I became his carer. I wanted to work more, and I was even offered a position as a [GRO-B] but I couldn't accept this due to the long hours, as I had to be around [H] to care for him.

Section 6. Treatment/care/support

42. Due to resultant bleeds from his haemophilia, [H] required a [GRO-B] [GRO-B] By this time there were new HIV treatments and the stigma had died down. Therefore there was no delay or restriction in him receiving treatment.

43. He received excellent support from his GP [GRO-B] [GRO-B]

44. [H] was never offered any type of psychiatric support throughout any of this and I strongly believe that he would have been much better equipped to deal with matters if he had been given such support. At one point I had suggested

that he see his GP to get anti-depressants but he said he had had enough of tablets.

Section 7. Financial Assistance

45. We received £21,000 from the McFarlane Trust in or around 1991. They contacted us about this.

46. We received nothing from the Skipton Fund until a few years ago when they contacted me saying that they were closing the fund and so were giving out the last of their money to Haemophiliacs and their widows. I therefore received £10,000 from them after filling out their forms.

47. It was only when I received the letter from the Skipton fund that I found out that we could have applied for more money, contrary to what we were originally told.

48. We never received any monthly payments from anyone and were always told that this was due to the fact that [H] earned too much to qualify for these payments. I was never told by the hospital about any further support I was entitled to.

49. [H] also used to receive £100 a year from the government as a winter fuel allowance and only since very recently this has become £200 a year for me.

50. I think the McFarlane Trust were quite good when I dealt with them, but I only found out about the Skipton Fund recently when they wrote to me so I don't have a comment on them.

Anonymity

51. I wish to remain anonymous.

52. I do not want 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... 9 | 2 | 19