

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1206001

Dated: February 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 live at GRO-B Northants GRO-B I am divorced with two teenage children who are 16 and 19 years old.
2. This witness statement has been prepared without access to my full medical notes and records.
3. I make this statement as the fiancée of GRO-B: F who was born on GRO-B GRO-B 1969 and died on GRO-B 1993.

Section 2. How Affected

4. In or around 1986, when I was 16 or 17 years old, I met my future fiancé GRO B: F. He was born on the GRO-B 1969 and although I did not know this at the time he suffered from severe Haemophilia A.
5. As treatment for his Haemophilia, GRO-B: F received Factor VIII. He received this at Lord Mayor Treloars College, a special school which admitted a number of

ANONYMOUS

haemophiliacs, and also at [GRO-B] Oxford. [GRO-B: F] was originally from Northamptonshire so it is possible that he may have also received treatment there. Due to the severity of [GRO-B: F]'s Haemophilia, he received treatment prophylactically.

6. I do not know the exact date that [GRO-B: F] was informed of his infection but I believe he was around 15 years old. He told me that all of the Haemophiliacs were brought into a room together at Treloar College and none of their parents were there. A teacher went around the room and addressed the children one-by-one, saying "you're infected... you're not... you have HIV ...you have not". [GRO-B: F] was told that he was HIV positive. [GRO-B: F] told me that he was not provided with any support or information about his infection and his father was not told anything about it. He had an older brother who was also infected. His mother had died when he was younger.
7. As a result of receiving contaminated blood products, [GRO-B: F] also contracted Non-A Non-B Hepatitis, which I now know to be referred to as Hepatitis C. However, his body naturally cleared the virus, which was something that [GRO-B: F] seemed quite proud of. I do not know how long [GRO-B: F] had Hepatitis C, but when he spoke about this virus it seemed as though he had it for a substantial period of time, perhaps ten years.
8. When [GRO-B: F] and I met, we were taking our A-Levels at college; [GRO-B: F] was studying an art course. We started dating in around 1986. Initially [GRO-B: F] did not disclose that he was a haemophiliac or that he was HIV positive.
9. We began a serious relationship and started to fall in love with one another. I noticed that he had a limp and I remember asking him why he limped. He made light of it by saying that it was an old rugby injury. One day I went into [GRO-B: F]'s bedroom and he had not hidden his needles and medication. I remember being shocked.
10. I remember that [GRO-B: F] was always very careful about using protection when we had sexual intercourse. As a young girl this was my first sexual experience and I thought he was being considerate to me by being careful

ANONYMOUS

with protection. We were intimate for six to seven months before I found out about [GRO-B: F]'s HIV status. This occurred after an incident in or around 1987/8, when the condom broke and [GRO-B: F]'s reaction was terrible. As a young girl I thought I was going to be pregnant, so was thinking about what we could do about it. [GRO-B: F] became very quiet and would not talk to me. I recall him being utterly shocked and upset that this had happened.

11. A while later, I had a telephone call from [GRO-B: F]'s step-mother, [GRO-B: F] who asked me to go to their house as they needed to talk to me. I thought this was a bit strange, especially because [GRO-B: F] did not have a positive relationship with her. When I went to their house, she sat me down and I could see that [GRO-B: F] was really upset. She said "[GRO-B: F] loves you so much. He can't tell you this but I need to tell you... he is a Haemophiliac. But don't worry because the treatment was all heat-treated, so you will be okay." I had no idea what any of this meant. [GRO-B: F] had looked to his step-mother for help to tell me that he was HIV positive but she did not say this and did not tell me what I needed to know. They knew he had HIV but did not tell me. I remember thinking that was the reason why he had had all the needles in his bedroom.
12. The fact that I now knew he was a haemophiliac made me love him more. I told him that I did not care about his bleeding disorder and we continued our relationship. However, I could tell that things were on his mind and he seemed worried.
13. In about 1987/88 we became intimate again but he was very worried about using protection. I told [GRO-B: F] that I loved him and he became very upset and blurted out "I'm HIV positive". I could not believe what was happening and I said that I needed to take him home. I drove [GRO-B: F] home and he said "Stop, you're treating me like a leper... I love you!".
14. I remember getting home and throwing myself into my mother's arms and telling her that I think I might have HIV. I explained that I had been exposed and did not know what to do; I was utterly hysterical. I thought my life was over, because at this time AIDS meant death.

ANONYMOUS

15. My mum contacted [GRO-B: F]'s step mother and asked what was going on, she said he was very upset. By this time my family loved [GRO-B: F] and they understood that dealing with something so cruel was not his fault. We also knew that he had not deliberately put my life at risk so [GRO-B: F] and I continued [GRO-B: F] and I still loved him very much.

16. I attended the [GRO-B] in Oxford and blood was taken from me for testing on a regular basis. There was no practical support or advice on what HIV was or how it was transmitted. The staff looked like they were in despair; no one knew what to say as they did not know anything and it was a new thing that they had to deal with. Fortunately, my test result was negative.

17. I was not given any advice or spoken to about safe sex. They assumed I knew what this meant and fortunately I was intelligent enough to understand what this meant.

Section 3. Other Infections

18. Other than HIV and HCV I was unaware of any other infections that [GRO-B: F] may have contracted as a result of receiving contaminated blood products. As far as I am aware he also was unaware of any other infections.

Section 4. Consent

19. I do not know whether [GRO-B: F] provided consent or had knowledge that he was being treated or tested for any infections.

20. After I was initially tested for any infection, the hospital knew that I had tested negative and [GRO-B: F] and I were practicing very safe sex. Despite knowing this they regularly sent a nurse and I had up to a dozen blood tests taken. I did not question this but I do not know where these tests went and I do not know what I was being tested for.

Section 5. Impact of the Infection

21. [GRO-B: F] had no one to talk to about his infection, as it was such a taboo subject in their household; it was considered shameful. [GRO-B: F] had lost his mum, his brother did not want to talk about it and his dad did not talk about it with him either. This put more pressure on me because I was the only person he could talk to.
22. At this time, there was a lot of stigma associated with AIDS and we were unable to tell anyone. It was considered the worst plague and we kept it very private and secret. Even though we did this, people often connected his Haemophilia with HIV so we were ostracized and treated differently.
23. We tried to continue with life by leaving college and getting jobs. [GRO-B: F] studied photography at college as this was his passion but he struggled to make any money from this. He got a job with an Estate Agency. This started off well but after six months they told him that they needed to let him go because it was not working out. This coincided with someone who knew [GRO-B: F] joining the office and knew about his Haemophilia. If you were a haemophiliac people were putting two and two together and I believe they worked out that this likely meant that [GRO-B: F] was HIV positive.
24. Following this job, [GRO-B: F] began working at a printing company called [GRO-B: F]. [GRO-B: F] He had the same issue there and within a few months people began bullying him out of the job, as someone had found out that he was a haemophiliac. I recall him coming home in tears and telling me that they had said they will throw darts at him to see how long he bleeds. People used to say that he had AIDS. Management would not do anything and treated him with total disregard.
25. [GRO-B: F] tried to get other jobs and I also tried to help him. He started working at a local jewellers. They loved his personality. One day however the daughter of the owner said they would have to let him go. He was achieving everything he needed to but we believe they had found out about his haemophilia. This

ANONYMOUS

was his last job and he didn't work again. As such, I had to work to pay the mortgage and all of the bills.

26. We got engaged in 1990 and we bought a house. We had a mortgage of around £700 per month. We wanted to be independent and live our lives, and I had a good regular salary to pay for our mortgage. [GRO-B: F] was unable to obtain life insurance which made purchasing the house more troublesome.

27. After we purchased our house, [GRO-B: F]'s health began to deteriorate. It was a very difficult period as I had to work to pay the mortgage but I also had to be there for [GRO-B: F]. Work was my salvation. From around 1992 [GRO-B: F]'s health quickly deteriorated. He became very lethargic and lost a great deal of weight. He had constant flu and had lesions on his chest. He had chronic diarrhea, thrush and a lot of infections. When [GRO-B: F] got really ill I never thought that he was going to die. He was hospitalized regularly. I used to go to the hospital from work and stay with [GRO-B: F] overnight in hospital at weekends curling up in the bed next to him. I found this extremely difficult as I had no support; I could not talk to anyone at work about our private life and the difficulties we were facing.

28. [GRO-B: F] died in hospital on [GRO-B: F] 1993. There were no problems as far as I can recall with his funeral arrangements.

29. After [GRO-B: F]'s death, I started having panic attacks. I went to the GP and told him what happened, he said "oh my god, no wonder you're not coping". I had also lost several stone in weight.

30. I felt unable to tell people what [GRO-B: F] had died from, due to the stigma associated with his infection. I can remember feeling so embarrassed that I would say that it was cancer, but people knew the truth. It was a constant feeling that people were looking at me and thinking that I probably had AIDS too.

31. Looking back I abused alcohol afterwards.

Section 6. Treatment/care/support

32. [GRO-B: F] received treatment from the [GRO-B: F]. He took part in a trial of AZT. I cannot recall the exact dates but I believe it was around the time he first started to get poorly in the late 1980's early 1990's. He did have terrible side effects with constant diarrhea, headaches, night sweats. The drug also made him shake and he could not write because his hands shook.
33. I remember that [GRO-B: F]'s dentist was reluctant to treat him. When we moved house we needed to sign up to a new dentist. He filled out the questionnaire that he was asked to do. When he went for a check up the dentist appeared with a shield over his face and treated him like a leper. [GRO-B: F] said that he was never going to go to the dentist again as he felt so upset and embarrassed.
34. I have not received any support or counselling. I have never got over what happened and I am still grieving [GRO-B: F]. It was only when I became aware of support groups through social media that I finally had some support.
35. After [GRO-B: F]'s death, my GP referred me to a bereavement counsellor for my panic attacks. However, I struggled with this because I was working full-time and I was only able to have sessions outside of work time. This was difficult, because the counselling was provided by the NHS and they said they could not give me anything else.

Section 7. Financial Assistance

36. In or around 1988 [GRO-B: F] received a lump sum payment of around £20,000. In order to receive this payment, he may have had to sign a waiver. I cannot remember the details.
37. When [GRO-B: F]'s health deteriorated, I had to carry him up the stairs to take him to the toilet. We did not have a downstairs toilet. I had to do this frequently because he was suffering from chronic diarrhoea. We applied to the

ANONYMOUS

Macfarlane Trust for financial assistance to fit a downstairs toilet. A man came to see us at our house and he treated us really badly; he said that we had "no idea how worse off other people were". I do not know if this was because he thought that [GRO-B: F] did not look ill enough, but he did not provide any support or assistance and told us that the funds were not available. We were made to feel like we were trying to get money undeservingly. At this time we were only receiving a small amount of disability benefits for [GRO-B: F] and I was working full-time to pay the mortgage.

38. When [GRO-B: F] passed away, I did not receive any financial assistance from the Macfarlane Trust and they did not get in contact with me.

39. Likewise, I did not receive any financial assistance from any other trusts and funds that were related to HCV, as I was required to prove that he had it. This was not possible as he had cleared it himself.

40. Our house was in joint names but the mortgage was only in mine. We had bought the house for £40,000 but when [GRO-B: F] died it was only worth £20,000. I could not sell the house as I was responsible for the whole of the mortgage. All I could do was keep working and pay the mortgage.

41. We led a secret life. The only people that knew of [GRO-B: F]'s illness were my close family and they forgave [GRO-B: F] for putting me at risk as they knew I loved him so much. They were the only people that treated him without attaching stigma. He did not have a good relationship with his family and left specific instructions to say that his family was not welcome at his funeral. I was only 23 when he died and I had to deal with his family. They became like a pack of wolves as they thought [GRO-B: F] had left some money when he died. He did not. The money that he had received had been spent.

Section 8. Other Issues

42. We did not receive any support from any organisation. I remember that the McFarlane Trust were absolutely awful to us and provided neither support nor assistance.

ANONYMOUS

Anonymity, disclosure and redaction

43. I confirm that I would like to remain anonymous and that I understand this statement will be published and disclosed as part of the Inquiry. If required, I am prepared to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-B

GRO-B

Dated

20-2-19