

Witness Name **GRO-B**

Statement No: WITN1275001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

GRO-B will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** and I was born on **GRO-B** 1965. I live at **GRO-B**. I am married and I have a son and a daughter and one granddaughter. **GRO-B**
GRO-B

2. I am aware that my wife **GRO-B: W** and son **GRO-B: S** also intend to provide a witness statement to the Inquiry. I am also aware that my sister-in-law, **GRO-B: Si** and her two sons, **GRO-B: N** and **GRO-B: N2** also intend to provide statements in regard to my late brother **GRO-B: B** who was born on **GRO-B** 1952 and died from AIDS on **GRO-B** 1992. It is only recently that my nephews have been able to look into this as it is so upsetting.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I have severe Haemophilia A with less than 1% clotting factor, as did my brother [B] I would need 8, 50ml syringes of blood products for treatment.
5. I only ever went to the Heath Hospital in Wales (now University Hospital of Wales) and was treated by Professor Bloom and Dr Dasani. [B] was always at the Cardiff Haemophilia Centre but was treated at John Radcliffe Hospital in Oxford when he was a child, as that was the only centre in the country at the time that could deal with it. He then went to the Royal Infirmary before moving to the Heath Hospital under Professor Bloom, where I was also treated.
6. I became jaundiced when I was around 10 or 11 (in around 1975 or 1976) but I was never told why; only that it was from an infection. I only recently found out that I had also been infected with Hepatitis B. [B] had Hepatitis B when he was younger, I believe in his teens and we both cleared it naturally.
7. [B] and I were given the same blood batches and therefore were both infected with HIV in or around 1979. I remember seeing my notes from the American litigation. I was given the following: 1978, 1982 Hyland Hemofil; 1982, 1983, 1985–1988 Alpha Profilate; 1979–1980 and 1982 Armour Factorate; 1980–1983 Immuno Kryobulin; 1985 Cutter Koate; 1981 Humanate and 1983–1990 BPL.
8. I was a lot younger than my brother [B] so I had new treatments available to me that he did not have the option for. Cryoprecipitate was still being made at the time and we did not even know, but for [B] it was a new product in the 1970s. [B] and I were always on the same Haemophilia treatments so we would share if we needed to.
9. I was given no information or advice about the risk of infection. Nor was any information given to [B] or me about risks of the Factor VIII; we were told that it was a 'wonder drug'. He was about 27 and I was about 13 or 14 when we were first given Factor VIII.

10. Looking back on it, there was an option of cryoprecipitate, and had B and I known of any risks in taking Factor VIII, we both would have chosen not to have it and stuck with cryoprecipitate instead. There was no way either of us would have taken the risk of contamination. Some people were still on cryoprecipitate so it was not a straight and immediate swap of all treatments to Factor VIII. We were one of the first few people to go on to Factor VIII in Cardiff.
11. I was also infected with HIV. Professor Bloom and Dr Dasani called me and my wife to a meeting. We were informed of HIV by Professor Bloom on the same day as my brother B which I believe was in or around July 1984. They told us about having to buy in blood from America and the background about why they needed the blood. They then explained how HIV can be spread and then told me not to discuss any of this with anyone else; even B
12. Professor Bloom did not know enough about HIV but he advised me to use my own cutlery, toothbrush and towels. The meeting was very matter of fact and blunt. It was like I was dropped a bombshell and then sent away for 3 months to deal with it on my own.
13. I only found out about my Hepatitis C infection much later. I received a letter saying that I should go and see Professor Bloom, which I think was just before I found out about vCJD. I went to see him and Dr Dasani was there too. He said that I had nothing to worry about from Hepatitis C and that it might not even come to anything and it was not an instant thing.
14. I do not believe that B ever knew that he had Hepatitis C (Non A non B Hepatitis). I was told a long time after I was told of HIV and believe it was after B had died; there was so way he could have known of Hepatitis C.
15. Everything was much like it was before I was told about the Hepatitis C infection. In hindsight now I realise how much my infection was played down. It was while I was already infected with HIV and so because HIV was the main

thing at the time, that was what we all concentrated on and it was considered to be more serious.

16. I definitely believe that I should have been told about the Hepatitis C illnesses sooner that I was. I would much rather have known about everything as early as possible. I cut out alcohol as soon as I was told of the infection; I would have taken more precautions had I know earlier. I was taking precautions due to HIV but I was never told anything about Hepatitis C. I was not even told that it could be passed on, let alone take precautions in case it was.
17. When my wife became pregnant in 1983 we were called in to see Professor Bloom at University Hospital, Cardiff. He said that he wanted **W** to have a termination to 'wipe our Haemophilia'. I found Professor Bloom's reason strange as haemophilia doesn't need to be passed down and can appear in families for the first time due to a mutated gene. We kept the baby and **S** was born on **GRO-B** 1983 and he does not have haemophilia. Both my wife and son were tested for HIV and were fine. We opted not to have any more children because of what Professor Bloom told us, but I now know that we would have been fine as my blood could have been screened.

Section 3. Other Infections

18. In 1995 I received a letter about vCJD. I was told that I had been given a batch of Factor VIII from someone who was a victim of vCJD. I was then told that I would contract the disease at a future date which frightened me more than anything to be honest. The doctor said that he could not tell me anything as he did not have a clue himself. They said that I had been exposed, however, they did not know if it would come to anything. They cannot do any tests.

Section 4. Consent

19. I remember being put on experimental, unlicensed Hepatitis C treatment which was Interferon and Ribavirin, although I cannot remember the exact

date but I think it was in or around 2002. This must have been for research purposes.

20. When [B] and I went to have our blood taken we were told that 5 vials had to be taken for the purposes of giving us the AZT treatment. They would always use 3 pairs of gloves when they were taking our blood. Dr Dasani then came back in and said he needed to take one more vial of blood. I questioned him as to why and he replied that he had forgotten one vial. Dr Dasani kept this last vial of blood separate and said it would not go to the laboratory as it was for their own separate '*special research*'. We were never told about this extra vial of blood until I questioned it.

21. I do believe that [B] and I were tested and treated without our consent and without adequate information being provided to us.

22. [B] and I were given an HIV treatment drug called AZT as part of a trial. We later found out that he had been given a placebo, and I had been given the actual drug. I therefore believe that we were tested and treated for the purposes of research as we had always had the same batches and we were brothers so they wanted to see whether one brother responded while the other did not.

Section 5. Impact of the Infection

23. I was fine for a long time and did not suffer from any mental or physical effects. When [B] started to get ill at the end of the 1980s, I prepared myself to get ill. Everyone was getting ill and dying in hospital so I was effectively just waiting my turn in line. I did not think anything mattered anymore; I always just used to say that I was going to die.

24. I took each day as it came and just lived for each day. I was always led to believe that my days were numbered and so I never really took too much care.

25. I was on the AZT trial at the same time as my brother [B] but we did not know whether we would be given the placebo or the drug. We were told that some people would be on a placebo and some would get the treatment. I felt a lot of guilt as I later found out that I had been given the AZT treatment and my brother was given the placebo. It was not fair. I did not even take the pills religiously like [B] and in hindsight I could have shared the AZT pills with [B]

26. [B] and I only really had each other to talk to and after he died in [GRO-B] 1992 I did not really have anyone to speak to in the family. I could not talk to my father or my sister [GRO-B: Si 2] I could only talk to [W] I went off the rails and drank excessively. I was never told by a doctor to stop drinking; I figured that out on my own. After [B] went it destroyed my father and sister as well as [Si] family, so I felt a lot of pressure on me. I had to look after myself for the sake of everyone.

27. I developed PCP pneumonia in or around 1993 and I was given just a few weeks to survive. There were 3 to 4 of us in hospital at around the same time and people were dying weekly. At this time [S] was only about 10 years old.

28. We lost all our friends as we shut ourselves off away from everyone. We moved home to get away from everyone as when I developed pneumonia as I thought people would guess and assume things as I looked so ill, as especially this was after [B] had died. I did not want to see anyone and risk them finding out. I therefore lost contact with all my friends and did not want to leave the house.

29. I suffered from my body weakening due to muscle wasting, fatigue, weight loss, mood swings and not being able to sit out in the sun due to being on the drug Septrin.

30. I was given AZT treatment I think between around 1993 and 1998, then other drugs, but nothing was licensed. I was just asked if I wanted to try a new drug and whenever I was asked, I always said yes. I would try a drug for about 6 or

8 months and then they would just change it if it did not work. I had check ups every 6 weeks.

31. In about 2002 I had pancreatitis due to my first Hepatitis C treatment of Interferon and Ribavirin. This, with the combination of my HIV treatment AZT, sent me into the ICU unit in hospital. Due to my condition I therefore halted all treatments. I was given a lot of fluids and had to just ride out the pancreatitis. I had been on Hepatitis C treatment for about 16 weeks and had cleared it; however, the virus then came back after I had stopped treatment.
32. A few years later I had a second lot of treatment for Hepatitis C, consisting of just the tablet (Ribavirin), which was not as bad. I had this for about 6 months and again cleared the virus before it came back just 3 weeks later.
33. In 2017 I had a third treatment with Harvoni and after 3 months I was cleared of the Hepatitis C infection.
34. I always told my hospital that if any treatment was available then I would have it. When I was told about the Harvoni treatment, I was put on a waiting list for it due to funding issues. As soon as I was offered it though I took it up.
35. Hepatitis C did not really affect my liver as a recent fibro-scan showed it is fine. It went up to level 7 but has returned to level 4. They monitor my liver with these fibro-scans twice a year as it helps with my peace of mind.
36. While I was on the treatments I suffered mental and physical effects; especially with AZT which was not nice stuff. Dr Dasani had explained to me that the side effects of the treatments would be bad. The long term side effects of HIV tablets was not known but they affected my memory, mood and sleeping.
37. I hated my food and lost my appetite completely. I suffered with sickness, diarrhoea and weight loss. I never knew if these symptoms were the HIV taking hold or the side effects of AZT. I was meant to take 8 AZT tablets morning, lunch and tea. I was not taking all my tablets though so I do not know if the side effects were lessened due to this. Each set of tablets had

their own side effects. Every time I changed tablets then 3 weeks later I had different side effects.

38. In around [GRO-B] at the time. From the second injection of Interferon and Ribavirin I went downhill and felt that I went mad. [GRO-B]
[GRO-B] I was always angry and directed it at anyone around me. I was constantly aggressive and just angry at life. I was doing the treatments from home and I even had an argument with my son, for the first time ever. Also, I remember one occasion where someone cut me up on the road; [GRO-B]
[GRO-B] I just could not control myself; it was horrible. I could not cope with anything.

39. However, the second course of Hepatitis C treatment was 100 times better than the first when I was on both Interferon and Ribavirin. I had night sweats, vomiting and went off my food, which were just the 'normal' side effects.

40. I suffered no side effects from the Harvoni treatment. My body is just knackered and has probably now given up. I do not think I even notice the side effects of treatments anymore.

41. I always had to see the hospital dentist due to my conditions, and he told me that my teeth were crumbling due to the infections I had. He offered to pull them out and give me implants but I could not have these because of my Haemophilia.

42. I never told anyone that I had HIV or Hepatitis C except for my wife, [B] and [Si] I eventually told my wife's parents, after I had been suffering from the infections for a while.

43. As I said earlier, we were a well known family in our area. Our close friends knew about the Haemophilia and started asking questions, so I lied about my health but I was very worried that this would lead to more probing questions. So in around September 2001 we moved away from everyone and cut them off as we could not deal with the constant questions. I almost became a

recluse as I was so closed off due to being worried about stigma. We now have different friends who know nothing about all this. As a farmer we are quite isolated so if I become ill and do not want to see someone it is easier.

44. I think only told my son about my infections when he turned 18.

45. My whole family worried about me, as they did with [B]. After [B] died, it became harder to see [Si] (my sister-in-law) and her children [N1 and N2]. We all used to be so close but meeting up would just remind us all of [B] and so it became less frequent. We had always used to go for family meals and we are all very family orientated so it was difficult to deal with.

46. I never went to school because of my Haemophilia. I started school when I was about 5 years old but had a bleed in my first 3 weeks and so they did not accept me into the school and the local authority gave me a home tutor instead. After Factor VIII came out in or around 1978, I tried going to school again for another year but I had so many bleeds on and off that I left school again when I was just 15, without having sat any exams or got any qualifications.

Section 6. Treatment/care/support

47. Apart from waiting a few months on the waiting list for Harvoni, I never really suffered any obstacles to treatment.

48. I have never been offered any counselling or support.

Section 7. Financial Assistance

49. I knew [GRO-B]
[GRO-B] I heard about the 1991 litigation from the [GRO-B]. We had to go to a meeting and they stood us up individually and asked if we were married or

had children as the payments were means tested with peoples circumstances. There were over 100 people in the room but as we all thought we were going to die anyway I guess we did not really think it mattered that it was not in private.

50. [B] and I were told to sign the waiver in 1991 or no one would get a pay-out. I was told that I had a 2 to 5 year lifespan and that if the case continued in court it could last for years. However, my brother and I knew people that were receiving the money already and so we refused to sign to the waiver. Then the payment came and I received about £60,000 from the MacFarlane Trust, but neither [B] or I ever signed the waiver forms.

51. At one point, I needed a new car and so I asked [GRO-D] at the MacFarlane Trust for a deposit for a Motability car. She denied my request even though I was personally infected with HIV and Hepatitis. I therefore showed them proof that I knew someone who was not infected but affected by this all, however, she had received money for a laptop for her son, and I felt that this was extremely disproportionate. I told them that I would take the story to the papers and the next day I received a cheque. However, they did not trust me and so sent the cheque to my garage. I therefore had to complain again before I got the cheque sent to me.

52. I also received monthly payments from the MacFarlane Trust. It used to be around £600 but then increased to around £1,200. Now the payments come from EIBSS and they were at £1,500 a month, but have been temporarily increased to around £2,200 by the Welsh government as they have honoured the extra means tested payment for everyone; however, the they have said that this top up payment can end at any time.

53. Gareth and Hayden Lewis then went on to bring the American litigation against the pharmaceutical company Baxter's. I received about US\$20,000 ex gratia from this. I am not sure if I signed a waiver.

54. I also received a £25,000 Stage 1 lump sum payment from the Skipton Fund. Initially I was refused before the criteria changed and I was then accepted.

55. I do not think the trusts were fit for purpose at all. They were means tested and they made us feel as if we were begging for the money. They always used to just say no to any requests anyway. They wanted to know too much detail and I could not manage. It really put us off applying for certain things.

56. Before the MacFarlane Trust was wound up they told us that they had millions of pounds in reserve, so we applied for some money as we needed help; however, they then told us that they had spent it all, but they then gave it all to the Terrance Higgins Trust. I have no problem with this, but we were not consulted.

Section 8. Other Issues

57. Dr Dasani was Professor Bloom's right hand man. Just before he left the hospital, he called us into the Centre to tell us why he was leaving. He said that there was a lot in the Centre that he was not happy with, for example where the money was coming from and what they were doing. He did not elaborate further. I think that he should be called as a witness to give evidence and I believe that he would be an asset to the Public Inquiry.

58. I believe that there were originally 1,243 Haemophiliacs infected with HIV in the UK but now there are less than 250 left as the others have passed away. I have complete faith in Sir Brian Langstaff.

Anonymity

59. I would like to be anonymous. I would like to provide oral evidence provided that it could be given on a private and anonymous basis.

Statement of Truth

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

Signed.....
Dated.....

GRO-B

8 - 5 - 2019