

# ANONYMOUS

Witness Name: Mrs. **GRO-B**

Statement No: WITN3012001

Exhibits: 0

Dated: 8 May 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF **GRO-B**

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I, **GRO-B**, will say as follows:-

### Section 1. Introduction

1. My name is **GRO-B**  
**GRO-B**  
**GRO-B**
2. I make this statement as the **GRO-B** of **GRO-B** who was born on the **GRO-B** and died at the age of 65 after being infected with HIV, Hepatitis B and C as a result of receiving contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my late **GRO-B**'s full medical records.

### Section 2. How infected

4. My **GRO-B** had Haemophilia type A, classed as severe with a clotting factor of nearly 0%. **GRO-B** was diagnosed as a haemophiliac in the late 40s/early 50s. **GRO-B** spent many months in hospital when a child.

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5. My [GRO-B] was treated with Whole Bloods, Packed Red Cells (PRBC's) and Fresh Frozen Plasma (FFP) in the early 1950s. In the early 1960s [GRO-B] began receiving Cryoprecipitate. My [GRO-B] was also treated with FEIBA.
6. My [GRO-B] began receiving Factor IX treatment for [GRO-B] haemophilia sometime in the early 1980s. Treating my [GRO-B] was complicated because of the severity of [GRO-B] haemophilia and [GRO-B] inhibitor. Even though [GRO-B] was lacking in Factor VIII as a haemophiliac, [GRO-B] had an inhibitor, which meant that [GRO-B] was unable to receive Factor VIII and therefore was treated with Factor IX.
7. My [GRO-B] attended University Hospital of Wales in Cardiff, where [GRO-B] was treated at the Haemophilia Centre. [GRO-B] consultants were Professor Arthur Bloom and Peter Collins.
8. My [GRO-B] was never given any information or advice beforehand about any risk of being exposed to infection from blood products.
9. As far as I am aware my [GRO-B] tested positive for HIV and Hepatitis Non A/Non B Hepatitis, now referred to as Hepatitis C, in 1984.
10. I'm not sure that my [GRO-B] was aware [GRO-B] had been tested for any infections. I remember my [GRO-B] told me that Arthur Bloom called them into the hospital and informed them that my [GRO-B] had been given blood that was contaminated. My [GRO-B] said [GRO-B] was almost crying when [GRO-B] told them my [GRO-B] had been infected.
11. The doctors were clearly devastated and visibly shaken by what had happened. The diagnosis was given in a sensitive manner and some information was provided. When my [GRO-B] was diagnosed [GRO-B] Hepatitis was referred to as Hepatitis Non A/Non B.
12. The information provided at the time was adequate in the sense that it was likely all they knew, but not in the sense of having to live with these infections. My [GRO-B] was given information but things kept changing all the time. At that

time they didn't know anything so couldn't tell them anything. I know my [GRO-B] was told [GRO-B] was probably going to die as a result of [GRO-B] infections.

13. I don't know exactly what information was given to my [GRO-B] other than that I know my [GRO-B] started taking precautions after the meeting, such as using condoms, so I'm sure they were told something.

14. My [GRO-B] [GRO-B] at home after suffering a brain haemorrhage. [GRO-B] died in bed. I was angry with [GRO-B] at the time for something that had happened. [GRO-B] emailed me to say [GRO-B] had a cold. [GRO-B] never really complained about having illnesses unless it was a cold so I didn't think it was anything out the ordinary. I knew [GRO-B] (who was an adult) were visiting [GRO-B] [GRO-B] partner stayed the night because [GRO-B] didn't want to leave him as [GRO-B] was unwell. [GRO-B] went to check on [GRO-B] in the night and [GRO-B] been sick, but the next time [GRO-B] went to check on [GRO-B] had passed away.

15. My [GRO-B] died at the age of 65 as a result of [GRO-B] haemophilia.

### **Section 3. Other Infections**

16. My [GRO-B] was told that [GRO-B] could possibly have vCJD by a letter from the NHS in 2004. I remember this really upset [GRO-B].

17. I remember talking to [GRO-B] about possibly having vCJD and saying to [GRO-B] there was no point in finding out as it would just be another thing to worry about. My [GRO-B] wanted to know and, after investigation, found [GRO-B] had been given blood from a batch that contained vCJD.

### **Section 4. Consent**

18. I personally believe my [GRO-B] was tested without [GRO-B] knowledge or consent. My [GRO-B] said many times [GRO-B] felt like a guinea pig. [GRO-B] often had treatment when it first became available which makes me think they were testing how it

would work on [GRO-B]. Articles have been written about my [GRO-B] and how hard [GRO-B] was to treat.

19. My [GRO-B] didn't necessarily feel like the tests were a negative thing because [GRO-B] knew the treatment being tested on [GRO-B] could possibly help people in the future who would be going through the same ordeal. I do not personally believe [GRO-B] gave consent to the tests that were carried out on [GRO-B].

20. I remember my [GRO-B] had a [GRO-B] replacement in 1997. There was great concern that they wouldn't be able to stop any bleeding due to the severity of [GRO-B] haemophilia and [GRO-B] inhibitor. At the time doctors were testing a new drug from Sweden. My [GRO-B] really wanted the treatment, as at the time [GRO-B] was struggling to walk and should have really been in a wheelchair. [GRO-B] went ahead with the surgery and they used the drug from the Swedish drug trial and injected it using their equipment, not the hospital's equipment. During the operation the equipment failed and my [GRO-B] almost died from loss of blood. [GRO-B] spent three months in hospital. During this time [GRO-B] benefits were stopped as [GRO-B] was in hospital and my [GRO-B] struggled, even though [GRO-B] worked full time, due to the increased costs of petrol to drive to visit [GRO-B] almost every day (a 40-mile round trip) and the cost of parking at the hospital. Those three months were a nightmare for my family.

21. At Christmas 2004, my [GRO-B] experienced a stomach problem and abdominal bleeding. There were tears somewhere leading to a great deal of blood loss. [GRO-B] was in hospital over new year and into January. It reached a point where the doctors could not stop the bleeding and attempted another test. They had long supposed that a large dose of Factor VIII might overcome an inhibitor, but had never been in a position to test the theory – or so I was told. The doctors decided to try and give [GRO-B] a great deal of Factor VIII as a last resort to see what would happen and they got lucky, it worked and stopped the bleeding. [GRO-B] had another long stay in hospital, but the experiment had saved [GRO-B] life.



22. My [GRO-B] was tested due to [GRO-B] unique situation. [GRO-B] was never really told what they were using [GRO-B] blood for.

### Section 5. Impact of the Infection

23. My [GRO-B] had a complete change of character. [GRO-B] had always been a bit grumpy but [GRO-B] became much worse. [GRO-B] suffered from really bad depression and had to be treated by a psychiatrist. [GRO-B] became a nightmare to live with, it was really hard work. [GRO-B] would behave irrationally, lose [GRO-B] temper and be really horrible.

24. [GRO-B] was lethargic. It was really hard because [GRO-B] had such severe haemophilia and it is difficult to know which illnesses were a result of this condition or [GRO-B] treatment or his infections. [GRO-B] was always in incredible pain and had arthritis. [GRO-B] had no muscles in [GRO-B] legs. Really it's amazing [GRO-B] stayed alive as long as [GRO-B] did.

25. My [GRO-B] had two brain haemorrhages, the final one killed [GRO-B]. I'm not sure what caused the first one. I remember [GRO-B] said [GRO-B] had a cold and my [GRO-B] and [GRO-B] took [GRO-B] to hospital and they managed to save [GRO-B] life. The second time [GRO-B] had one [GRO-B] was at home.

26. My [GRO-B] depression led [GRO-B] to often talk about suicide, [GRO-B] threatened it a lot. [GRO-B] would just say [GRO-B] felt really low and didn't see the point in carrying on and that [GRO-B] couldn't do it anymore and that [GRO-B] wanted to die. Imagine your [GRO-B] saying that to you, not once or twice, but regularly.

27. Throughout [GRO-B] life my [GRO-B] was very unpredictable. A few months before [GRO-B] died [GRO-B] bought a boat with my [GRO-B]. As [GRO-B] wasn't physically fit enough to handle it [GRO-B] wasn't allowed to take it out on [GRO-B] own; it wasn't safe. As no-one was available one day to go out with [GRO-B] when [GRO-B] wanted to go, [GRO-B] decided to take the boat out [GRO-B] without our knowledge and crashed it. [GRO-B] ended up calling the coastguard. [GRO-B] spent [GRO-B] life being irrational like this because [GRO-B] felt [GRO-B] had nothing to lose. This was a perfect example of a

temper tantrum, such as one that a small child might have, but my GRO-B was a grown GRO-B. This is the effect that GRO-B depression resulting from GRO-B infections had on GRO-B life.

28. When my GRO-B died GRO-B knew that GRO-B disappointed me as GRO-B had taken out the boat when GRO-B knew GRO-B should not have and crashed it. It is frustrating because I don't believe my GRO-B would have acted in the ways GRO-B did if GRO-B hadn't received contaminated blood. My GRO-B was robbed of GRO-B life and we were robbed of GRO-B. My GRO-B emailed me to let me know GRO-B felt unwell because we were not on the best of terms. It meant when GRO-B died we weren't as close as we usually were, which is difficult to deal with.

29. My GRO-B was a part of the Birchgrove Group. When I was young I assumed this was something to do with Hepatitis C, obviously I now know this group concerns HIV.

30. I wasn't aware that my GRO-B had HIV until 2006. At the time my GRO-B were a bit of a mess as they had separated earlier in the year. My GRO-B had always wanted to tell us that GRO-B had HIV but my GRO-B didn't want us to know. When they separated GRO-B decided to tell us and it caused a huge problem in the family. I remember that GRO-B told us in the autumn and my GRO-B. My GRO-B was already under a lot of stress due to this and I think this was too much. My GRO-B also had an issue with my GRO-B infection. GRO-B had enough education and a GRO-B degree, so knew full well what HIV entailed, but GRO-B emotions took over and she could not deal with the idea of having someone with HIV close to her GRO-B. Everything went into freefall as my GRO-B couldn't believe that my GRO-B had lied to us. The rift was so bad that they stopped talking shortly after.

31. Due to the huge problems my GRO-B HIV announcement caused, my GRO-B and GRO-B weren't talking and my GRO-B couldn't see GRO-B. GRO-B wasn't even told when my GRO-B. My GRO-B was reacting to the fact GRO-B been lied to and GRO-B was reacting to the fact my

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- [GRO-B] had HIV and she didn't want anything to do with [GRO-B]. You would expect [GRO-B] to know better as [GRO-B] but people are illogical when it comes to their kids. My [GRO-B] only made up after my [GRO-B] and [GRO-B] split up. My [GRO-B] really struggled after my [GRO-B] death because [GRO-B] missed out on so much because of their rift. They didn't talk for 2 years and [GRO-B] regrets the time [GRO-B] missed. My [GRO-B] very rarely got to see [GRO-B] grandchildren during that time, maybe once every 3 months when the [GRO-B] wasn't there.
32. I remember when my [GRO-B] was down about having received contaminated blood and I used to say *'at least you don't have HIV'* which [GRO-B] wouldn't really reply too. I now feel bad about this, looking back, because obviously [GRO-B] knew then that [GRO-B] did.
33. When I was told my [GRO-B] had Hepatitis C I was worried [GRO-B] was going to die. When you live with someone who has illnesses like this you become used to the idea your [GRO-B] can die anytime and you have slightly different perspectives, but it just felt like one thing after the other.
34. I was aware that my [GRO-B] had Hepatitis C because the hospital tested me and my [GRO-B] in 1995. This was part of a study to see whether Hepatitis C could be spread by close contact. It can't. This was a study to prove it. We were never told anything else with regard to infections.
35. My [GRO-B] had massive issues with [GRO-B] liver. [GRO-B] liver function was tested regularly. They were testing [GRO-B] for liver cancer. [GRO-B] had a lot of blood tests and scans [GRO-B] basically used to live in the hospital; [GRO-B] be there all the time.
36. [GRO-B] would sometimes look jaundiced because of [GRO-B] liver issues that stemmed from [GRO-B] Hepatitis C infection. At one time, my [GRO-B] made [GRO-B] drink a lot of cabbage water, utilising herbal remedies [GRO-B] found in some book. Hospital staff had been very concerned about [GRO-B] liver function at that point in time, but the cabbage seemed to have a positive effect on [GRO-B] body. There's no conclusive proof of course, but months of medication seemed to have had less effect than cabbage.



37. My [GRO-B] had treatment for Hepatitis C. [GRO-B] was given Interferon and Ribeverian, The treatment exacerbated [GRO-B] depression. It was difficult to distinguish how much of [GRO-B] issues were psychological and what was physical. [GRO-B] was constantly fatigued and lethargic.
38. I believe [GRO-B] started interferon in the 1990s. I don't think it cleared the HCV because [GRO-B] was still talking about having a liver transplant after [GRO-B] treatment was finished. [GRO-B] believed this was the solution that would make everything go away. I said 'no' because it was dangerous. We were still arguing about it as [GRO-B] was so near death during the [GRO-B] operation. I think the hospital was considering it. I believe [GRO-B] would have died if [GRO-B] had the liver transplant. [GRO-B] didn't do it because [GRO-B] didn't want to die, as much as [GRO-B] said it.
39. My [GRO-B] was a nightmare on the treatment. [GRO-B] was much worse in the 1990s than the 1980s. I was at university from the mid-1990s so I was only there sometimes, but [GRO-B] drove my [GRO-B] crazy.
40. My [GRO-B] separation was definitely a result of my [GRO-B] infections and the treatment [GRO-B] was receiving for it. [GRO-B] could be so horrible; I don't know how my [GRO-B] put up with it. [GRO-B] would do things quite spontaneously. [GRO-B] always wanted to live in Cardiff as, at the time, my [GRO-B] lived 20 miles away from the hospital, but because [GRO-B] travelled there so much [GRO-B] wanted to live closer. My [GRO-B] didn't want to move because of their ties to their community.
41. My [GRO-B] ended up buying a flat in Cardiff without telling anyone and [GRO-B] ended up leaving my [GRO-B] I don't know how they had stayed together for as long as they did. Even when they were divorced they were always in contact and couldn't live without each other. I truly believe their divorce was down to my [GRO-B] infections.
42. As far as I'm aware my [GRO-B] never had difficulty accessing treatment. [GRO-B] was in the hospital so often [GRO-B] formed a close relationship with [GRO-B] consultants and really liked the people [GRO-B] was treated by. [GRO-B] was usually



offered new treatments due to the uniqueness of [GRO-B] haemophilia. It was usually me asking [GRO-B] not to try them as they could prove to be very dangerous.

43. We didn't talk about [GRO-B] infections much. I remember once as a small child that we came back from an outing and someone had put a sticker with the Haemophilia Society logo on it on our back door and I remember my [GRO-B] saying, 'Oh no, it's started'. I could tell that whatever had happened was really serious and I couldn't ask anything about it. I knew something was going on that I didn't know about. It made me associate haemophilia with 'bad things' and I just knew that it was something that shouldn't be mentioned; it should be kept a secret. From speaking to my [GRO-B] recently I now know that [GRO-B] thought someone put this sticker on the door because people were associating his haemophilia, which people knew [GRO-B] had, with HIV. [GRO-B] believed [GRO-B] was being targeted because of this. We knew not to tell anyone else about my [GRO-B] haemophilia. At this time I was not aware that my [GRO-B] had HIV or HCV.

44. I have been taking anti-depressants on and off since 1994. I attribute this to the genes I inherited from my [GRO-B] and the way I was brought up, and the stress of dealing with everything. When you're brought up in such a negative environment you always look at the dark side of life. It has had a huge impact on me and was definitely a large contributor to my depression.

45. My [GRO-B] infections were definitely a contributing factor in my [GRO-B] and [GRO-B] divorce. They argued all the time. [GRO-B] had to choose between [GRO-B] [GRO-B] was only 4 months old so things must have been really bad for [GRO-B] to leave at that time. It was really difficult for [GRO-B]

46. My [GRO-B] was not in a condition to work from [GRO-B] early 40s. It would take [GRO-B] so long to get up because of the pain. We lost [GRO-B] salary and my family had to rely on my [GRO-B] salary as a result. My [GRO-B] retired early, so we lost out on [GRO-B] income and [GRO-B] received only a reduced pension. [GRO-B] was in pain from

GRO-B joints and was fatigued constantly. GRO-B wasn't the kind of person who didn't want to work but GRO-B haemophilia and infections didn't allow GRO-B too.

47. I believe my GRO-B retired at the age of 44 in or about 1991, so GRO-B received a much smaller pension than GRO-B should have. My GRO-B was a teacher GRO-B GRO-B at a GRO-B My GRO-B so we had to live off GRO-B salary. Unfortunately it was very difficult when GRO-B had to retire and I remember being worried about it. We couldn't travel and could only go on caravan holidays because there was no money. I remember being worried about what would happen in the future. As a child you tend to worry a lot about such things. I remember it being very difficult.

48. There was a substantial financial impact on the family resources. I'm sure GRO-B would have climbed the career ladder if GRO-B had been able to continue working.

## **Section 6. Treatment/care/support**

49. GRO-B usually faced no difficulties in receiving treatment because it was the University Hospital of Wales, which is a teaching hospital, and they have a dental department. GRO-B was registered with a GP, but GRO-B never went. GRO-B would go to the hospital for everything. As far as I am aware GRO-B faced no difficulties in this regard.

50. My GRO-B was treated by a psychiatrist that GRO-B was referred to by the hospital. The rest of the family weren't offered any psychological help or counselling to my knowledge. There was definitely no support offered to me or GRO-B before my GRO-B death. After GRO-B died, they did tell us we could contact them at the haemophilia centre at any time, but I took this to be an informal invitation rather than an offer of formal medical or psychological support.

## **Section 7. Financial Assistance**

51. My **GRO-B** received a payment of around £60000 through the Macfarlane Trust ("MFT") according to a note that I have found in **GRO-B** files. I do not remember seeing the money or any record of it. My **GRO-B** does not believe that the sum was this large. From 1992 to the early 2000s my **GRO-B** received around £100 a month from the MFT

52. I received, with **GRO-B** a £3000 grant from MFT for **GRO-B** funeral.

53. We received £50000 from the Skipton fund after my **GRO-B** passed away because he suffered from Hepatitis C and **GRO-B** liver was ready to fail according to the post mortem.

#### **Section 8. Other Issues**

54. I remember my **GRO-B** main issue in dealing with the fact that **GRO-B** had been infected was that no one would acknowledge they had done anything wrong. There was no accountability. It's one thing having such a terrible thing done to you but it's even more insulting for people to act like nothing has happened.

55. It's terrible that those infected have had to constantly fight for any information and help considering they were so ill. Those responsible should have been going out of their way to make sure those who received contaminated blood were given appropriate help.

56. Those infected and affected should have been given compensation rather than being made to jump through hoops and receive monthly payments rather than a lump sum. I believe this was all done with the belief those who were infected would die shortly after being infected and with the hope the Government wouldn't have to pay so much.

57. I'm disgusted that they didn't start to test the blood as early as possible. There were tests available in other countries that could have proven the existence of contamination in the blood, but they wouldn't use the tests in the UK as they



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hadn't been tested in the UK. This has always made me really angry. When the Government realised what was going on they didn't try to help people properly, they just tried to put off paying compensation.

58. It is obvious to anyone that taking blood from people such as prisoners and drug addicts was a risk. I was appalled when I first found out they were doing this—all because they didn't want to spend money. Some of the blood products had been rejected in other countries and the UK still bought them.

### Anonymity

59. I wish to remain anonymous. But I am prepared to give oral evidence if it will help.

### **Statement of Truth**

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

Signed.....

GRO-B

Dated.....

8/5/19