

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3255001

Exhibit: 0

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF GRO-B

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 GRO-B: H GRO-B  
GRO-B  
GRO-B 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 husband's full medical records.

**Section 2. How affected**

4. H was born with severe Haemophilia A, with a clotting factor of less than 0%. He was diagnosed soon after birth when he was going to be circumcised. I

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am not aware of the name of the hospital where the operation took place. The operation almost killed him. He was cared for by his mum for a considerable amount of time after the operation.

5. I understand in the 1950s [H] was treated with Packed Red Cells (PRBC's) and pig's plasma, as there was no other form of treatment at the time. From about the late 1960s/early 1970s he was treated with Cryoprecipitate. In the 1980s he started to be treated with Factor VIII Concentrate products such as FEIBA (Baxter). He also was treated with Factor IX concentrate products due to the inhibitors in his blood.
6. [H] was first treated at the [GRO-B] in Cardiff, and then at Cardiff Royal Infirmary, in the [GRO-B]. He was also treated at the University Hospital of Wales (UHW). The latter hospital being where he had the majority of his treatment in the 1970s. He was initially under the care of Professor Bloom, then Dr Dasani and Dr Peter Collins and Dr Friedman. Everybody there loved him. He also spent a lot of time there. He often went there three times a week for his treatment. He also had hydrotherapy there in a pool. It is fair to say that he practically lived at the UHW.
7. I do not recall [H] ever mentioning being given any advice or warning beforehand about the risks of being exposed to infection from blood products and I certainly was not given any advice or information about the risk.
8. [H] found out about that he was HIV positive in or around 1984. He was asked to come to see Professor Bloom, at UHW and I went with him. I recall Professor Bloom sitting at the desk and telling [H] that he had tested positive for HIV, and that it had come from tainted blood taken from American prisoners. He also said that the HIV was going to lead to AIDS. I recall that [GRO-B] [GRO-B] at the time. I cannot recall any more other than it was a massive shock to both of us.

9. We were not provided with any information about the infection, how to manage it or about the risks of infecting others. I do recall that we were told about the dangers of blood contact, and were advised to use contraception, to always wash hands and to generally be careful, however, I am not sure whether it was in that meeting or at a later date.
10. I do not think any more information should have been given at the very first meeting, as it would have been too much for us to take in.
11. I do not have any particular views, as to how the information about the infection was provided to us other than Professor Bloom was very friendly and sympathetic. It was never suggested that I or our children be tested.
12. I am not sure when or how [H] found out he was Hepatitis B and C positive.

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

13. I am not aware of [H] contracting any other infections as a result of being treated with contaminated blood products. We divorced some time before his death, so even if he did find out about something between our divorce and his death, I would not have been informed about it.

### **Section 4. Consent**

14. I believe [H] was tested without his knowledge or consent as neither Norman or I were made aware of him being tested for HIV or Hepatitis C.
15. It is possible that [H] could have been tested and/or treated for research purposes, but I do not know as I did not go down to the hospital with him every time, as I was a full-time [GRO-B] and he attended the appointments on his own most of the time.

**Section 5. Impact**

16. It is fair to say that Hepatitis C affected [H] on a mental level more than physical. It led him to develop severe depression and extreme mood swings. His personality gradually changed from a loving and caring person to a controlling and domineering person.
17. This affected my life to a great extent. He was very difficult to live with. I recall that when he was taken in to the hospital over Christmas I was relieved that he was not at home, as that way I had some peace. However, his absence still caused me a lot of distress, as I had to go to the Chapel in the morning, then return home, cook a turkey, prepare the Christmas dinner for the whole family, and then I had to go to UHW to visit him, and then visit my father in a nursing home. It was a very stressful time for me, and it was all as a direct result of his illnesses. It put a lot of pressure on me, as I had to deal with it all on my own. He never said don't bother coming. The entire situation was very depressing for all of the family.
18. [H]'s infections and the treatments also put a massive strain on him physically, on top of the Haemophilia. He used to be a [GRO-B], but he eventually had to retire, as he was physically not able to stand. He used to use crutches when he had problems in his joints due to the Haemophilia, however, after his diagnosis his health deteriorated further, causing him more difficulties.
19. [H] suffered medical complications as a result of the infections. He experienced two brain haemorrhages. The first one was in 1989, and he had to be admitted to the UHW. It caused him a terrible headache. He was under the care of Dr Dasani, at the time, who showed me [H]'s x-ray, and explained there was a massive haemorrhage in the brain. I am not sure what exactly



caused the haemorrhage, but I was told by the Dr Dasani that he believed it was the Hepatitis C. The second brain haemorrhage was just prior to his death.

20. In or about 1992 [H] suffered a terrible bleed in his stomach. He was admitted to the UHW where he stayed for three months (from the 4<sup>th</sup> November to the 4<sup>th</sup> February). I am not sure what caused it. He had to have an operation for it and we almost lost him as a result.

21. During the course of his illnesses [H] was given some treatments; I am not sure what he was given for the Hepatitis, but I know that he was given antiviral drugs for the HIV. I know the treatments had many side-effects, both physical and psychological, such as stomach problems and mood swings. He was not the person that he was at the beginning of our marriage. He used to be very loving. He also suffered from severe fatigue. Before he was infected he was able to drive our caravan for hours but during the treatment he started to get more tired a lot quicker. Eventually, his mood swings and depression became even worse. He used to lash out a lot. I recall at one point, when our [GRO-B] was washing dishes in the sink and then she suddenly ran up to me in tears, as [H] had shouted at her and she did not know why.

22. I do believe that the illnesses and the treatments really changed him. He changed from being a nice and loving family man to someone not nice to be around.

23. [H] also had to be treated by a specialist dentist at the hospital who specialised in patients who had [H]'s type of Haemophilia. I never went with him to his appointments, but I recall that they were very strict with the timing of his appointments, which I believe might have been due to his infected status.

24. As mentioned above [H] had to retire early from his job as a [GRO-B], as he was no longer physically able to carry on; I believe this was around 1992. This affected us financially, as prior to retiring [H] had a lot of unpaid time off

work, and after he retired, we did not have his income anymore. He also had a greatly reduced pension due to retiring so early.

25. Once he retired he kept on being in and out of the hospital. We travelled to the hospital at least three times a week, which also proved to be very expensive. I was the main breadwinner at that point. It was problematic because after [GRO-B] [GRO-B] I gave up work for 9 years to focus on looking after our children on my own. This affected my earnings later in life. If I knew that this would have happened to us in the future I would not have stayed at home for 9 years. Eventually also my pension was affected.

26. [H] was also in a [GRO-B] so he often had shows. His arms were in bandages, and I recall nurses coming to his shows to inject him with blood products right after. He tried to stay active after he retired. However, as his mental health deteriorated, [H] began to lose his temper even with the people from the [GRO-B] eventually even they were able to see the real side of him.

27. [H]'s illnesses and his mental health had an awful affect on our family life. We had to keep it all to ourselves and were not allowed to confide in anybody. I recall on one occasion we returned back home from his parents' house and there was a small sticker from the Haemophilia Society on our back door. We panicked, as we thought that somebody found out about his status, however, thankfully we were proved to be wrong. We were worried that if anybody was to find out we would lose our jobs, as [GRO-B] [GRO-B]

28. Overall, we did not suffer from any stigma, as we have never told anybody about his status.

29. We also did not tell our [GRO-B] until a lot later, as we did not want to trouble them and we believed that we were doing the right thing. It was very hard on them when they found out. [GRO-B] found out, soon after his wife to be's sister

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**GRO-B** It was just before his wedding. It was a very difficult time for him. After finding out about **GRO-B** illnesses, **GRO-B** did not allow us to see our **GRO-B** in our family home; it always had to be their home. In fact, our **GRO-B** never came to terms with **H**'s illnesses.

30. I am not sure when **GRO-B** found out about it, but she was told by **H** at an earlier date. I believe that it might have been when she was at University.

31. The major affect on our family while **H** was still alive was that he decided to leave our family home. It was a very strange event, as he never discussed it before leaving. I recall being at home one day; when he did not expect me to be there and an estate agent called saying that **H** was looking for places in Cardiff. This was about 2005, and our children were already living away from home. I recall that he did a lot of strange things at the time, and I do believe that it was the mental effect of his illnesses on him. He became very controlling over me. Even after he moved out he would turn up to my house for a dinner with a group of people and cause trouble. Looking back I know now that it was because of his illnesses and the frustration he felt, but I was not aware of it at the time. Our daughter was fed up with what was happening at home so she left home.

32. **H** became very unpredictable. In the week before he died **GRO-B** and her husband had bought a boat which **H** contributed to. **H** was told not to go out on it on his own as he was not well. He did not listen and he went of on it on his own and damaged the boat and other boats.

33. **H**'s infection affected me greatly on the psychological level; different people deal with things like this in different ways. **H** did not want to talk about his illnesses at all, whereas I felt I wanted to talk and that this would help me to cope. However, I had to keep it to myself to respect his wishes.

34. We did travel abroad as a family in 1994. We went to France in our caravan. We always had travel insurance, however, I am not aware how difficult it was to organise, as [H] was the one to make all the arrangements so I did not know much about it. In the end it proved to be an amazing holiday.

#### Section 6. Treatment/Care/Support

35. As mentioned above, [H] did have some treatment for his illnesses, and I do not believe that he experienced any difficulties or obstacles accessing them. The medical staff were always very helpful to him. I recall that he was very close to a nurse called Christine, as well as Sister Jenny Jones, who was originally a Sister in the army. I also recall another sister called Mary, who was always very professional.

36. I am not aware of any treatment that [H] ought to have received but was not made available to him.

37. I came across information in [H]'s medical notes that he had a social worker and they were treating the whole family. This was not the case.

38. I did not receive any counselling for a long time after finding out about [H]'s status. We both eventually received some support from a social worker directly as a result of [H]'s status. I believe that it was offered by the hospital. I found it very helpful, particularly because I had nobody else to confide in about what was happening. These sessions also involved some marriage counselling and [H] did not like it when the social worker would speak to me a lot, regardless of the fact that I found it very helpful. Eventually, the counselling stopped, because [H] was not happy to see my side of the argument.



39. I received the counselling from the social worker for about a year. She supported [H] for about another 3 years. This was around 2000; not long before [H] left home.

### **Section 7. Financial Assistance**

40. I am aware that [H] received around £23,000 from the MacFarlane Trust.

41. We have received some financial assistance for our holidays, but I am not aware of the details, as [H] dealt with all the financial issues, because he was retired and at home.

42. I have received no money and have not made any applications for grants.

43. There were a few issues with the Trusts and Funds. One of them was every time we would ask for money we were told that as we already had the work done, such as new windows, or we had bought, a new comfortable chair for [H] we were not eligible as the grants could not be applied retrospectively.

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

44. I believe that the amount received was disgusting; they should give people proper compensation for the damage caused. I wrote a letter to the Haemophilia Society expressing my opinion that the money should be shared equally between all the people infected. I also do not find it fair that people in Ireland received more money, than us in Wales.

### **Anonymity, disclosure and redaction**

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45. I wish to be anonymous and understand this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence.

## Statement of Truth

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

Signed...

GRO-B

GRO-B

Dated 23<sup>rd</sup> July 2019