

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3254001

Exhibits: 0

Dated: March 2020

## 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 was born on the GRO-B and I live alone at GRO-B I have GRO-B GRO-B and I no longer work.
2. I make this statement both as an infected partner and as the widow of GRO-B: H H who was infected with HIV and HCV as a result of receiving contaminated blood products. H was born on the GRO-B and sadly passed away on the GRO-B aged GRO-B
3. H and I were infected with both HIV and HCV.
4. This witness statement has been prepared without the benefit of access to mine or H's full medical records.

**Section 2. How infected**

5. [H] had moderate/severe Haemophilia A. He was diagnosed when he was quite young after he had lost a tooth and it would not stop bleeding.
6. I remember [H] telling me that he used to be in the [GRO-B] in [GRO-B] in the children's ward for weeks when he had a bleed; so he must have been quite young when he was diagnosed.
7. I believe his mother, who passed away in [GRO-B], took him to hospital when he had a bleed; his father did not really know how to deal with the treatment [H] needed. I believe this is why he was in the hospital so much when he was young.
8. I have known [H] since I was [GRO-B] and I believe he was using Factor VIII concentrate (Factor VIII) from when he was [GRO-B] or [GRO-B] years old. I am sure he used other blood products prior to the introduction of Factor VIII but I do not recall what they were. [H] was led to believe that without Factor VIII he would have died.
9. [H] was also treated at the [GRO-B] in [GRO-B] and received blood products from the time he was diagnosed until he died. He received treatment from [GRO-B].
10. [H] suffered a [GRO-B] in or about [GRO-B] and I believe that was when he was infected with HIV.
11. I do not know what information or advice, if any, was provided to [H] or his family beforehand about the risk of being exposed to infection from blood products.

12. As a result of being treated with blood products [H] was infected with HIV and HCV.
13. I believe it was in [GRO-B] when he received a letter through the post stating he had tested positive for HIV.
14. [H] was not told that he had been infected with HCV until much later on, probably around [GRO-B] I remember he was told during a hospital appointment, because when he told me he had been infected he said that he was told not to worry about HCV as people at the time were dying from HIV and nobody was really worried about HCV.
15. We were in a relationship at the time. We had always been good friends, but our relationship started in [GRO-B] We married in [GRO-B] after he had been quite ill.
16. I was also diagnosed with HCV in [GRO-B] shortly after [H] I had to request to be tested. We were not told the results of our tests until we went back and asked for them.
17. I am not sure when I was infected with HIV; It could have been anytime before [GRO-B]
18. I was told I had been infected with HIV shortly after a blood test. [H] and I had a burst condom and we were told that I should be tested. However, I do believe I had been infected a long time before this happened.

### Section 3. Other Infections

19. I do not believe [H] and I have received any other infections as a result of [H] being treated with blood products.
20. However, both [H] and I have received letters saying we might have been exposed to vCJD. I would have thought when [H] died he would have had a

post mortem, but this didn't happen. I do not know if they ever took any samples from him, but I gave no consent for a post mortem.

21. I have tried to blank out everything that has happened; it was a horrific time in both our lives.

#### **Section 4. Consent**

22. I do not know if [H] was ever tested or treated without his knowledge or whether he was treated or tested without his consent, adequate information or for the purposes of research.

#### **Section 5. Impact of the Infection**

23. I do not know how [H] coped mentally with HIV in [GRO-B]. However, he was a very strong character and I imagine he handled it with the same bravado he carried throughout his life.

24. In the mid [GRO-B] very little was known about HIV

25. Physically I do not believe HIV affected him at all, even up until his death he had few symptoms. He seemed to be one of those who were long term survivors with HIV.

26. I received AZT treatment before [H] did as my T cells had fallen quite dramatically. At the time viral loads were not tested, [H] had few complications relating to the HIV.

27. In [GRO-B] I believe [H] went onto a cocktail of treatment and he did very well on this. I can not really remember clearly as I had been on treatment for a long time. I do believe his HIV was controlled. I do know that [H] had no side effects whilst receiving treatment for HIV.

28. We had no difficulties or obstacles receiving treatment for HIV. The [GRO-B] was very good. However, HIV treatment was kept very quiet; no one really wanted to talk about it. Our records were kept separately to others, and when we had clinic appointments we would be taken off to the side; separated from everyone else.
29. Both [H] and I saw the same dentist who was a bit detached but I think we were very lucky as it was extremely hard to get treatment from a dentist with our infections. At the time they would not want to touch us due to HIV.
30. After [H] was told of his diagnosis with HCV, he had few symptoms. HIV was viewed as the 'big one', and he was made to feel that he should not worry about having HCV.
31. I felt totally devastated after finding out about HIV; I felt really sorry for [H] because he felt it was his fault. I thought I would not see my children grow up. I thought I was going to die and went downhill quite rapidly after that and had to start treatment far earlier than [H] did. But I am still standing. His CD4 cells were always up and mine went down very quickly and I thought I was going to start developing AIDs.
32. By [GRO-B] [H] was showing signs that something was wrong with his liver. I remember that he was in hospital at [GRO-B], he was very unwell and he was told that his liver function was not good and that he had [GRO-B]. I started to feel very panicked, I recall thinking that this could be something. He was told not to drink; so he didn't.
33. [H] and I were being seen by the same liver specialist; I had a liver biopsy.. [H] was told he could not have a biopsy because of the haemophilia and the high chance of his liver bleeding. [H] received no treatment for his HCV. It was mentioned that they were going to put him on Interferon but it never materialised.



34. I cleared HCV following a course of Harvoni **GRO-B** About **GRO-B** years ago, I had a course of Interferon and Ribavirin treatment which did not work. It was a really horrible treatment and it changed my life. I was a mess and eventually I had to tell my children, who were **GRO-B** and **GRO-B** years old. The Interferon was a very potent drug and it had side effects. My white blood cell count was so low and I had to keep injecting myself. I had to do this everyday; it was horrible. It made me feel awful. It sticks in my mind more now.

35. It was a nightmare. I had lots of side effects from treatment for HCV. I do not know the names of all the treatment I was taking, there were so many different mixtures that I just can't remember them all.

36. I have had so many side effects; I am tired all the time. I had a **GRO-B**

**GRO-B**

37. We had to get in touch with the Dr **GRO-B** who was the head of the clinic in **GRO-B** for HIV. He changed my treatment and since then my viral load has been

undetectable. I go to the clinic at [GRO-B] every [GRO-B] for monitoring, if there was anything strange with my results I am told by Dr [GRO-B] at an appointment.

38. I am a fit woman, and I have fought these illnesses to the hilt. I am not saying that my husband didn't fight, but I think sometimes it became too much for him.

39. [H] was flown over by air ambulance to England for a liver transplant, in about [GRO-B] I remember he was still working at time. I told him to stop by the clinic on his way to work, and they told him he needed a transplant. Within three weeks he was flown over to Kings College Hospital. It all seemed to happen so fast, the last time the doctors had talked to him they were talking about his treatment, and he never got it. I found out he had taken to sleeping at work, and in the car; so I didn't know how lacking in energy he was. He never got the transplant. When we were in the hospital he was told that he would not be getting the liver as he was HIV positive. My heart broke; they knew that he was HIV positive before flying him over to the hospital. I think he just gave up after this. I remember one of his surgeons said that they could have operated on him, and I just thought why they are saying this to me when they could have saved him.

40. I considered taking [H] to [GRO-B] but I probably would not have had enough money to do that. I guess it is all based on the emotions I had at the time.

41. [H] fell [GRO-B] and died [GRO-B] later. I had to take him off life support, to give him as much dignity as he deserved. It was a horrible decision to have had to make but I know that that is what he would have wanted. It was the most horrific time of my life. The smell of blood sticks with me.

42. [H] was so good to my kids and he always worked hard to make their lives better. To have gone the way he did was heartbreaking. At the time it was

probably quick enough for him that he never really knew what hit him, but it hit me incredibly hard.

43. After **H** passed away the **GRO-B** trust wouldn't **GRO-B**  
**GRO-B**  
**H** home. I only had my joint bank account with **H** and no money of my own.

44. **H** was always so strong and so good. The only way I have been able to deal with it all is to put it to the back of my mind and not think of it all. I cannot bear to think of anything sentimental, as it is just too hard.

45. I have always kept my infections to myself. I didn't want people to know as they can be so judgmental. I think it would have been too hard. My children were **GRO-B**  
**GRO-B**, **GRO-B**. My **GRO-B** and my **GRO-B** have had **GRO-B** throughout their lives, which I think is linked to what has happened. My **GRO-B** and **GRO-B** do not know about my HIV but do about my HCV. I told my **GRO-B** that I was infected with HIV a couple of years ago. I didn't tell my **GRO-B** about having been infected with HIV until I finished with my Interferon treatment.

46. I lost a lot of weight when I was taking Interferon; I am quite a small person anyway. My second batch of treatment was Harvoni and there were far fewer side effects. I still keep an eye on my liver function as some people have ended up with cancer. I felt a lot better once I stopped coughing; it felt as though I was constantly coughing all the time.

47. All of this has had a massive impact on my **GRO-B** it is very hard to deal with. They have had **GRO-B** and I have had **GRO-B** myself. I just can not help but think that I should not be in this situation. You try to live away from all this but it is very hard. I am always on medication and it's



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awful. My life has become so regulated; I am always conscious that I can not forget to take it. I always have to be mentally alert.

48. I have found it too hard to move on from all of this; I couldn't find someone else.

It is too much to have to tell people about what has happened to both me and my husband and that he is dead. I do not really have much of a social life. Luckily have some very good friends who have stuck by me through the years.

49. It has also ruined any chance of a career. I gave up work when I was given

**GRO-B** in **GRO-B** when I had my **GRO-B** I had **GRO-B**, and gave up work to **GRO-B** I always intended to go back but it just never worked out. A career has been impossible because I have not been very well for over **GRO-B** years and have had to bring up my children by myself. Once I was diagnosed then **H** said that he would work while I looked after the kids and we would sort something out later. By the time he died, I couldn't pursue anything else. **H** was **GRO-B** in a **GRO-B** firm. He kept that job until he died. He did very well supporting all of us.

50. We had no income after **H**'s death; basically I have been living on **GRO-B**

and **GRO-B** The MacFarlane Trust used to give me enough to pay my mortgage every month. I managed to pay my mortgage off **GRO-B** in **GRO-B** **GRO-B**

51. I was careful with any money I did receive as I had **GRO-B** children to support.

52. My daughter went to **GRO-B** in **GRO-B** but she **GRO-B** **GRO-B**

53. My **GRO-B** got a **GRO-B** in **GRO-B** at **GRO-B** after completing his Bachelors in **GRO-B** and **GRO-B**

54. My **GRO-B** didn't go to **GRO-B** he works for **GRO-B**. He has done very well for himself. **GRO-B** who are absolute delights. They all live in a **GRO-B**

55. It's a shame because I am so tired all the time and have no energy after some of the treatment I have been on. I would like to be able to spend time with my **GRO-B**. I never thought I would still be here **GRO-B** years later; after 2 very bad blood borne virus's and to still be alive.

56. I really thought that the HCV would have killed me a long time ago, after watching what happened to **H**. I thought at the most I would have **GRO-B** years after **H** died but it has been **GRO-B**.

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

57. I personally have received really good care. The consultant I see for my HIV in the **GRO-B** department in **GRO-B** is very helpful. It almost feels like I can treat them as friends rather than doctors and I can always go to them with my problems. I try not to unload my problems on them but they are very helpful; especially when I have any adverse reactions to my medication.

58. I was offered **GRO-B** after **GRO-B** as I found it very difficult to accept that I had **GRO-B**. It was just another kick in the teeth.

59. There has been further counselling organized since the inquiry has started and I see a **GRO-B**. I believe that she is the **GRO-B** for most people in **GRO-B** who have been affected by contaminated blood. She has helped me to get rid of a lot of the anger I have been holding onto for a long time. I think finally there is some positivity coming back into my life; it is hard when you think of all the setbacks you have had. I think it is a trauma that you never get over.

**Section 7. Financial Assistance**

60. I signed a waiver with the HIV litigation which ended in 1991, but that was regarding my own infection; I received [GRO-B] I do remember that I was told that if I did not sign it then I would receive nothing.

61. [H] got [GRO-B] from the Skipton Fund which was paid to me after he passed away. [H] also received about [GRO-B] from the Macfarlane Trust in around 1991.

62. I received [GRO-B] from the Skipton Fund; I received this when it was first out there, perhaps around [GRO-B] I did apply for the second stage payment but was denied. We never applied for anything from the Skipton Fund again. I gave [GRO-B] each to my children to help them with their futures out of the money I received around [GRO-B] years ago. This was from the Skipton Fund money I received for [H].

63. In the beginning I found the applications for the MacFarlane Trust really straightforward; they had a lovely Director at the time, I think she was called Anne Hithersay. She was lovely and would always help in whatever way she could. I never had to write; I could just call and never had to show how much was in my bank account.

64. All of the new support schemes are so means tested I just can not bring myself to suffer through that process. The money is given out each month. In [GRO-B] [GRO-B], we get [GRO-B] I think in the beginning I got [GRO-B] per [GRO-B] per month.

65. I now get a monthly means tested payment of [GRO-B] and I get another payment every [GRO-B] months of [GRO-B]. I have recently been successful with my application for [GRO-B] and [GRO-B] payments. I find, however, that going through all these applications is incredibly stressful and very intrusive.

66. The lump sum 'widows payment' of [GRO-B] was received from the MacFarlane Trust. Every widow of those who died of infection from contaminated blood in the [GRO-B] got [GRO-B] apart from [GRO-B] who got [GRO-B] per year.

67. I did also get a funeral grant from the MacFarlane Trust as I had to arrange for [H] s [GRO-B] and it was all paid for me. I was so grateful not to have to think about it all. However, I think that once Anne left, people were made to beg and it was awful. It got to a point where it became too hard to ask for anything, and I stopped trying.

68. I fitted a new bathroom and I did get a contribution to that, but they couldn't send more as I had money in the bank. That was the way that the MacFarlane Trust functioned towards the end. It is almost like being punished for being sensible with money, it was held against you because you saved.

69. People have never really been compensated. If [H] had been alive today we would have been in a far better position financially; instead I have had to scrimp and scrape.

70. I had to hang onto my house so that my kids will have something when I go. I want them to have something from their mum and their stepdad.

71. I have taken my kids on holidays whenever I have had the chance.

## Section 8. Other Issues

72. It is very important to me that the loss of [H] and the ramifications of this loss on our family, is recognised by this inquiry. Obviously, I was infected as a result and I have endured hardships, stigma and the alienation that comes with living with HIV and HCV. I feel there are also knock-on effects for my [GRO-B] children,



who have also lost [H] and have also endured several hardships over the last [GRO-B] decades as a result of the Contaminated Blood Scandal.

73. If they knew what they were doing, and it all comes out, someone needs to pay for it all. Such a small minority has been picked on and it is so contained that it is so obvious that something must have happened. I think that by the time they found out about the ramifications of the contaminated blood, it was too late. They continued to give people products that weren't heat treated when they knew that they should not have done.

74. [H]'s treatment in [GRO-B] was great but the treatment he received at KCH was shocking and he should never have been flown over to England just to be told that he could not have his liver transplant. It left us completely in the lurch. It was horrific having to organize how to bring his body back home. It still makes me feel horrible thinking about the way he was brought home.

75. We returned [H]'s [GRO-B] to our house and had [GRO-B] as it is what he would have liked. We were not [GRO-B] but had been born into [GRO-B]

76. I had to make decisions that I should never have had to. I was left alone at the age of [GRO-B]. He was a great guy. He could not have made anyone as happy as he made me.

### Section 9. Anonymity, disclosure and redaction


77. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.


78. I do not want to be called 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** .....

 **GRO-B**

Dated... 10-3-2020 .....