

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1115001

Exhibits: WITN1115002-3

Dated: December 2018

## 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 GRO-B and I live at GRO-B
2. I met my husband, GRO-B: H in GRO-B and we married in GRO-B H died on GRO-B when he was just GRO-B as a result of being infected with HIV and Hepatitis C from contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my late husband's full medical records which I understand have been destroyed because of the passage of time.

### Section 2. How infected

4. H did not know that he was a haemophiliac when we first met. He had problems with his knee swelling up which was extremely painful for him. He

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was referred from the **GRO-B** to the **GRO-B** in 1976, where he was diagnosed as a mild haemophiliac.

5. **H** received treatment from **GRO-B** where his haematologist was **GRO-B** and his consultant was **GRO-B** **H** haemophilia database records are now shown to me marked **WITN1115002**.
6. After **H** first received Factor VIII in 1980 he was very pleased as he was told that he wouldn't have any more problems with his knees which was excellent news as they had been causing him so much pain.
7. In the summer of 1985 we received a letter from **GRO-B** at the haematology department at **GRO-B** It asked us both to attend a meeting regarding HIV. I remember asking **H** what 'H 1 V' was because I had never heard of it before.
8. When we went to the meeting **GRO-B** apologised to **H** and told him that he had been given tainted blood products and was HIV positive; he was told that he would die as a result of this infection.
9. As **GRO-B** was explaining this, I had an almost out-of-body experience. I was panicking about the prospect of losing my husband and having to raise 2 children without him. We had heard of the "gay plague" and HIV in the press but didn't know much about it.
10. **GRO-B** then asked us about our sexual partners and whether we had had relations outside of our marriage. **H** asked him why he wanted to know such personal things. He told us that the virus could be spread through sexual intercourse. We told him no, we had not had other partners, but it was upsetting being asked such questions.
11. **GRO-B** told us to use sheaths if we were to have sexual intercourse, but we were not given any other information at this stage, other than to not tell

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anybody about the infection. He did not tell me that I should be tested in case I had contracted the virus.

12. A short while after [H] diagnosis I went with him to his appointment with [GRO-B] and asked that I be tested because I was worried I might have caught HIV from [H]. Fortunately I was negative.

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

13. I am not aware that [H] was exposed to any other infections until 2017 when I received a payment from the Skipton Fund because the doctors believed [H] had been infected with Hepatitis C.

### **Section 4. Consent**

14. I do not believe that [H] had ever consented to be tested for HIV as when [GRO-B] told him about the diagnosis he was very surprised.

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

15. Before [H] infection he was the loveliest, most talkative man. He loved our family and we did everything together. If we wanted to go somewhere where we couldn't take the children then [H] would refuse to go.
16. [H] got very depressed immediately after his diagnosis. He was very closed off and he wouldn't speak about it to me at all. He went to his medical appointments alone and when he came back he just told me whether his blood count was up or down.
17. [H] started spending more and more time away from home. He went out in the evenings after work and avoided seeing as much of the family. When I asked him about this he said that he struggled to be around me because I

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was the only one who knew about his infection and I was therefore reminded him of it.

18. [H] health deteriorated rapidly in the last 3 years of his life. He suffered from severe headaches and had an inoperable tumour.

19. We had to tell [H] parents about his illness in late 1992 as we were not sure if he would make it until Christmas.

20. One evening the children were laying the table for dinner and accidentally put the knives and forks the wrong way round. When [H] saw this he stormed out of the house and didn't come back. It was situations like this that made me tell the children about their father's illness, as it was unfair to subject them to [H] increasingly erratic behaviour with no explanation. Having to tell my children that their father was dying was one of the most difficult things I have ever done.

21. [H] managed to continue [GRO-B] until October 1992, when he became too unwell to work. He had a massive stroke around Christmas and had to be kept in hospital.

22. When he was discharged home he had no mobility. I had to take him to the bathroom and back. We had occupational therapists who came in and helped but they were not there full time. [H] couldn't even sit on the toilet because he was in too much pain.

23. [H] hated hospitals. He felt that every time he went into hospital he lost a faculty. He also hated being catheterised. He was in constant pain and he was covered in lesions. He also lost a lot of weight, dropping from his normal weight of 13 stone down to just 8 stone.

24. [H] was extremely angry as he didn't even think he had needed the factor VIII treatment to begin with. He hated the doctors for what they had done to him.



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25. For the last 6 weeks of [H] life he was in the hospital on diamorphine. I had no one to look after the children so I had to take them to the hospital with me which was extremely difficult for them, especially my daughter. She wouldn't go to see him in the hospital and used to wait in the TV room. He was in the side bay of a general ward. He was kept separate because of his HIV status.
26. Due to the pain [H] was in, he was in a morphine induced coma for the last few weeks of his life and we were never able to say a proper goodbye.
27. It was fortunate that [H] death certificate did not state that he died as a result of AIDS, as despite the undertakers having to take precautions when handling his body, we didn't have too many problems when arranging his burial. There is now shown to me marked **WITN1115003** a copy of his death certificate.
28. This entire experience was extremely difficult for our children, who were just [GRO-B] when their father died.
29. Our daughter struggled with her father's deteriorating health and found it impossible to help care for him whilst he was still at home unlike her brother. There is still some resentment from her for not feeling included during that difficult time and my children barely talk to each other now as a result.
30. My daughter didn't attend school for 3 weeks before [H] death because she was scared that people would laugh at her if they found out about her father's illness. After he passed she refused to go to school for a very long time and wanted me to be sent to prison because she felt it wasn't fair that I was alive and her dad wasn't.
31. Despite being an extremely bright girl, our daughter initially failed her exams and had to go back to school to resit them. Our son also struggled with school and I have no doubt this is a result of what happened to his father as they were extremely close to him and [H] death hit him hard.

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32. They were left to grow up with no father figure in their lives and a mother who was constantly working to keep food on the table.
33. I had been working as a **GRO-B** in an office prior to **H** health deteriorating, however I had to give this up to look after **H**. The only time we ever received social security was for the 6 months prior to his death, when I was looking after him full time.
34. After **H** died I worked 3 part time jobs to ensure I could provide for my children. It was very difficult and everything I had went to my children; to this day I still don't have any savings and the only reason I don't have to work is because my current partner has provided me with some financial stability.
35. I didn't want to ask anyone for help because I didn't want to have to say that my husband died from AIDS. I worked so that I could pay my own was and avoid the inevitable questions as to where my husband was.
36. I didn't have anyone to talk to whilst **H** was alive as he refused to talk to me about the illness and I had been told by the doctors I shouldn't talk about it to anyone. I told my mum about it shortly after **H** diagnosis but she took that secret to her grave the following year. I could only really tell people when it was clear that he didn't have long left. It was very tough for me not being able to talk about **H** infection and everything that we were going through.
37. In the weeks prior to **H** death I discovered that the advice we had been given about using sheaths when **H** was diagnosed was incorrect. His HIV nurse, Maureen, was horrified to learn that we had never been accurately informed about the use of sheaths and no one had told us they had to be worn for the entirety of intercourse and not just for ejaculation. She quickly arranged for me to be re-tested because I had potentially been put at risk of HIV.

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38. The next day I received a call from Maureen telling me to come to the hospital immediately. She told me that she had the test results but that she couldn't tell me what they were over the phone. I was extremely worried and was sure that she was going to tell me that I was HIV positive. I left the children in the car as there was no waiting room for them and I didn't want them to be with me when Maureen gave me the bad news.

39. When I got to the room, Maureen told me that I had tested negative and that she wasn't allowed to tell me over the phone. This was all a lot of stress to go through the week before my husband's death.

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

40. My family were not offered any counselling.

41. I have no doubt that this would have been very beneficial for our children whilst they were growing up having lost their father.

42. I believe [H] was given ZCT for his HIV.

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

43. [H] was a party to the 1991 HIV litigation. He received a settlement of £60,000 via the MacFarlane Trust as he was married with 2 children. He told me that he had been made to sign a waiver to not take further action and that he was told if he didn't sign it he wouldn't receive anything.

44. I also received monthly payments from the Trust but the payments were reduced 6 months after his death.

45. I didn't ask for any financial help after [H] death as I felt that our children were now my responsibility.

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46. I was notified by the MacFarlane Trust in or about 2011 that I was eligible for a further ex-gratia payment.

47. I also received a payment from the Skipton Fund in 2017 as the doctors believe that [H] was also infected with Hepatitis C. I believe that I was referred to the Skipton Fund by the MacFarlane Trust as I had the same unique reference number on the letter I initially received from Skipton.

### Section 8. Other Issues

48. I was on my own for 17 years after [H] died. It was not the life that I imagined for myself or my children. Even today I find it difficult to say that [H] died of AIDS and it wasn't until April this year that I realised I wasn't alone –this had happened to other people. I've spent 25 years not talking about this and now I feel that the truth should come out.

### Anonymity, Disclosure and Redaction

49. I would like to apply for anonymity.

50. I do not wish to give oral evidence at the Inquiry.

### **Statement of Truth**

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

Signed

GRO-B

Dated

20<sup>th</sup> December 2018