Witness Name: GRO-B
Statement No.: WITN2006001
Dated: 8 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B GRO-B My address is known to the Inquiry.

2. I am a retired GRO-B and live in GRO-B with my husband GRO-B:H GRO-B We were married in 1999. I have three children from a previous marriage and they all live overseas where they were born.

Section 2. How Affected

3. My husband H was infected with Hepatitis C ("HCV") and Hepatitis B ("HBV") in the 1970s from contaminated blood products.

4. My husband has moderate Haemophilia A. He was diagnosed as a child and received various treatments for this over the years.

5. GRO-B H was a patient at the Haemophilia Centre in Cardiff and was treated by Dr Arthur Bloom. He received Factor 8 blood products from Dr Bloom on at least three occasions during this period, the latest of which was during a tooth extraction in 1972. Please see my husband's statement for further details of this.

6. My husband was never warned of the risks of infection before receiving blood products.

7. Please see my husband's statement for details of how he was informed of his infections.

Section 3. Other Infections

8. My husband does not believe he has received any infections other than HBV and HCV.

Section 4. Consent

9. I do not know if my husband was ever treated without his consent or without being adequately informed.

Section 5. Impact

10. H suffers from extreme insomnia. Most nights he will finally get to sleep at 2 or 3 am if he is lucky. When I hear him snore it is sweet noise to me because I know he is a) finally asleep and b) still alive. He also suffers from exhaustion which is so severe that he is unable to work or participate in daily activities.

11. I was with H when he saw a liver doctor at hospital in the mid-1990s. This was when we lived overseas. When H left the room briefly to give a blood sample, the doctor informed me that he was sure H already had cirrhosis of the liver and would not last long enough for a cure to be found.

12. The doctor told me that there was no treatment for HCV (or Hepatitis Non-A Non-B as it was called at the time). He said that there were various drug being trialled in Taiwan but that by the time they were

approved for use and made available where we lived H would no longer be alive.

13. I was shocked when the doctor told me this. It was just before H and I got married and suddenly he was being given a death sentence.

14. I did not tell H what the doctor had said to me until much later. It was a great strain to keep this information to myself for years but I did not want to worry him or make him any more down in the dumps than he was at the time.

15. H had three courses of treatment to try and clear the HCV virus - one abroad in the mid-1990s and two in the UK in 2010/11 and 2012/13. All three treatments lasted for about one year and all of them made him very ill. The third treatment cleared the virus. Please see H statement for further details of these treatments.

16. The third course of treatment will always remain in my mind as the worst one as he was so ill for the full 12 months of the treatment. I remember begging him to stop the treatment but he was determined to continue to the end.

17. While on this last treatment H symptoms were very severe. He had non-stop symptoms of flu: body aches, severe headaches, nocturnal hallucinations, lack of appetite, insomnia and nightmares when he would often thrash about, depression, a hacking cough, loss of weight, loss of hair, fatigue, severe itching of legs and feet, loss of stamina and a loss of interest in life itself.

18. The treatment had a profound physical effect on H He lost so much weight and looked so ill that people in the road looked shocked

when they saw him out walking. He looked like he was suffering from the worst type of chemotherapy. I didn't think he would recover from it.

19. The treatment regimen required H to eat five fatty meals a day, but he had lost his appetite and was constantly nauseous. I struggled to find meals to cook for him that he would be able to eat. He lived for quite a while on liquid complan-type drinks from the hospital, which he hated.

20. About nine months into the last course of treatment the liver nurse asked for him to be referred to a dermatologist to try and get some relief from the continual itching. An appointment came back for 3 months later which would have been after his course of treatment had ended! I believe much better support for side effects should have been readily available from the NHS.

21. H coughing continued to persist even after the treatment ended. It was so bad that it would prevent him from speaking. Using the telephone became virtually impossible because he would start to cough as soon as he said a word and wouldn't be able to stop. Finally, he went to see a GP - after listening to me continually nagging him to - but the GP suggested he buy some cough sweets! What is worse - a wife that nags or a GP that doesn't listen? Or an NHS that doesn't want to know.

22. He is being treated for possible COPD or Asthma and finally finding some relief from his hacking persistent cough.

23. H was also informed he had high interocular eye pressures soon after he had his first course of treatment with interferon. This was eventually diagnosed as glaucoma a few years ago. He takes eye drops every morning and evening and has had two laser treatments within the last two years.

24. There are many published medical papers on the association between interferon/ribavirin and anti-virals – all of which my husband has had – and high interocular eye pressure. I believe that the courses of treatment for HCV have indeed caused these problems.

25. The treatment and its side effects also had a serious impact on H mental health. Apart from struggling to cope with the physical symptoms, he also became very depressed.

26. H was not usually treated differently by any medical professionals as a result of having HCV. We use a private dentist as there is no NHS dentist available locally, and the dentist is very informed and respectful. For years my husband has suffered from bleeding gums and has had extensive treatment for this. I believe HCV was also a factor involved in this illness.

27. There was also a nurse at the hospital in GRO-B who was wonderful. I knew she was always available on the end of the phone if we needed help. When H first started the treatment he was hallucinating in the night and got quite violent and she was a big help during those times.

28. The one occasion when I remember him being treated differently was when he went to have some physiotherapy, upon finding out that he had HCV the nurse left the room and went to put on rubber gloves. GRO-B GRO-B I find that totally unacceptable.

29. I remember being treated differently because of my association with H on one occasion. When I was working as a GRO-B in the late 1990s I can clearly remember going to donate blood at the hospital where I was employed. I stood in a line with at least 10 people I worked with. We handed over our completed forms. When the person behind

the desk read that my fiancé had HCV she held my form high up in front of her face and ripped it two. It was cruel, unkind and unnecessary.

30. Having HCV significantly changed H family life because his treating doctor told him that he would very likely infect his then wife and any children they might have. He therefore made a decision not to have any in case he put them at risk of infection. He is stepfather to my children and has a wonderful relationship with them, but it is very sad for him that he wasn't able to have his own.

31. My husband's only friends are those he made at university in the 1960s and 70s. More recently we have become friends with other infected blood campaigners and they have been a blessing and support to us and we have heard so very many heart breaking stories of lives ruined.

32. My husband is not quite a total recluse as he sees his old friends occasionally and family members. However, since we came to live here in 2004, when he retired, I can count on one hand the social occasions we have attended together.

33. He does not make new friends as he does not want people to know that he has haemophilia or HCV. Most people with HCV are very private and don't want to put themselves out there and mix with people they don't know because of the stigma around being infected.

34. There is also a stigma around having haemophilia. You don't tell people that you have haemophilia because they would automatically think that you have HIV and HCV. Sadly, ignorance is still very much rife around haemophilia, HIV and HCV. As a result, our family and old friends know but no one else. We have a doorbell that almost never rings.

35. We moved back to England from abroad in 2004, right after H became too ill to continue working. This has affected my family life as I am no longer living in the same country as my ex-husband and three children. I now only see my children about once a year if I am lucky. Although my children were adults when we moved, it is still hard to be so far away and not see them very often.

36. Seeing the effect of H treatment on him was very hard for me. It is hard to see someone you love be so ill and lose so much, and feel powerless to help him. When he was struggling with the side effects of his treatment and couldn't get a quicker referral to a dermatologist, it made me feel frustrated and angry and bitter that the NHS gave him this infection but they couldn't even help him cope with the side effects of the treatment.

37. The physical effects of H treatment also made it difficult to spend time with friends. I remember once we had some friends come round to our house, and one of them suddenly, before she had started drinking her coffee, announced that she had just remembered she had to leave and they left. I asked her when I saw her later that week what had happened and she said that H just looked so ill that she couldn't look at him.

38. In 2004, H was forced to retire from the business he had started due to ill health and his inability to keep up with the work load. The company he started is now a large and prosperous company of which he now has no part. I think he would still be working now if he could. The company is now a multinational conglomeration and two of the partners he started with are still there. I think it would have been nice if he could have carried on doing a little bit of work for them.

39. I retired from my job as a GRO-B in 2002. This was because I no longer wanted to do the job and was unrelated to H condition. I wasn't working when we moved back to the UK but then did take on some seasonal work for four summers making sandwiches. Along with our state pensions, that has been enough for us to live on.

Section 6. Treatment/Care/Support

40. H did not face any obstacles in obtaining treatment.

41. I believe the Skipton Fund may have offered H counselling but he did not take it.

42. I was never offered any counselling or other support. It would have been nice to have someone to talk to about it as I did not feel I could tell any of my friends about H health.

Section 7. Financial Assistance

43. Please see my husband's statement for information about the compensation he received.

44. I did not receive any financial assistance in relation to my husband's infection.

Section 8. Other Issues

45. H and I have been involved in some campaigning over the years. On one occasion about three years ago we went to protest outside the Houses of Parliament with a group campaigning for the rights of people affected by contaminated blood. I remember standing with about 40 or 50 people and a policeman saying that if one of the protesters didn't shut up he would be arrested. I thought this was strange because protests are

held outside of the Houses of Parliament all the time on various issues with much larger crowds and no one is arrested or told to be quiet.

46. We then went inside the Houses of Parliament to listen to a speech. The speech was scheduled to take place at 2pm, but it was eventually pushed back until about 4:30pm and some of the protesters had to leave before then to get their bus back to Wales. We were expecting there to be a statement saying there would be a public inquiry into the contaminated blood scandal and financial help for those affected, but there was nothing of the sort. It was a huge let down.

47. **GRO-B**

48. Through our campaigning I became aware that there are still many people who haven't heard of the scandal. In 2012, we went to Witney (it was then David Cameron's constituency) and I met a man in his 60s who said he hadn't heard about it. When I explained to him what had happened he was surprised and said it was terrible.

49. This is why I think the Inquiry needs to spread awareness of what actually happened. People need to know that many people who have HCV or HIV are nice people, it's not their fault, and you won't get infected just by touching them.

50. I hope the inquiry gets to the bottom of what happened and makes those involved admit what they have done. The government knew that they were importing contaminated blood products made from blood bought from drug addicts and prisoners and local manufacturers were also using huge pools of blood to make Factor 8 and similar blood products. They knew what they were doing and they didn't stop. The manufacturers were

greedy people and the civil servants and health ministers were simply trying to save money. Some of the ministers involved are still MPs or in the House of Lords. I see them on TV and it makes me feel ill. I think, how can you even live with yourself?

51. In my role as a GRO-B in the 1960s and 70s I administered countless number of blood transfusions to patients and I will often lie awake at night and wonder who I inadvertently infected just by giving them one unit of blood. It haunts me to think of how many people - families, older people, young babies - I will have infected GRO-B GRO-B

52. I would like someone to stand up and take responsibility for what happened. I would like them to give these men, women and children a big dollop of money to compensate them for it, if you can call it compensation.

53. To my knowledge no one has ever withheld information from my husband or me about infected blood.

Statement of Truth

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

Signed GRO-B ......

Dated ...08-04-2019...