Witness Name: GRO-B
Statement No.: WITN0353001
Exhibits: **WITN0353002- WITN0353003**
Dated: 1st May 2019

# INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF GRO-B (ANONYMOUS)

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 February 2019.

I, GRO-B will say as follows: -

## Section 1. Introduction

1. My name is GRO-B My date of birth is the GRO-B 1944 and my address is known to the Inquiry. I am married with four children and I currently live with my husband and youngest son. I don't currently work, and I have not been able to as a result of looking after my son with HIV, and my younger son who has Downs Syndrome.

2. I intend to speak about my infection with Hepatitis B, which derived from my son GRO-B: S infection with Hepatitis B (HBV), Hepatitis C (HCV) and HIV. In particular, I will detail the nature of mine and my son's infections, how the infections affected us, the treatment received and the impact it had on myself and my family.

## Section 2. How Infected

3. There is a history of haemophilia in my family. My maternal grandfather was a severe haemophiliac who had nine children. The females are carriers, and males get haemophilia. My mother was a carrier, and I am also a carrier of haemophilia.

4. When I was pregnant with my first child in 1965 I told the doctor about my family history and whether I could have a haemophiliac child. He told me that I would not have a haemophiliac child because the haemophiliac line was too long ago. They didn't know much about it then.

5. Out of my children my two daughters are carriers, my youngest son has Down Syndrome but he is not a haemophiliac.

6. My other son, S is the only one of my children who has haemophilia. Through infected blood products, namely cryoprecipitate and then factor 8, he was infected with Hepatitis B, Hepatitis C and HIV.

7. S was born in GRO-B 1975 in Guy's Hospital, London, whilst we were living in GRO-B London. In the day or two after he was born, he developed a large lump on his head that turned out to be a haematoma.

8. When the hospital released S and myself, S still had the haematoma. We were home for about an hour before we received a phone call, asking for S to be brought back into the hospital straight away. The hospital had tested S for haemophilia and the results had come back positive.

9. In the beginning, S haemophilia was dealt with by using cryoprecipitate. Whenever we felt he needed it we would take him to the hospital for the cryoprecipitate to be administered, which was about once

a month in the beginning. We'd often end up there in the middle of the night, waiting in the hospital for hours for someone to come and treat him. My husband worked at Guy's hospital. Typically, my husband, would be there throughout the night then he would have to turn up there for work.

10. We were very careful with S to try to prevent bleeding. For example, we brought him a pram with very thick sides so that he wouldn't hurt himself. I remember one day I was in the shop with S and a lady asked me why a baby so young could have bruises. Things like this were always quite embarrassing, without having to deal with what was to come.

11. We were maybe a little bit too careful with him sometimes. You worry about your children anyway, so when they have a condition like haemophilia, you worry so much, especially once he had started to become mobile. As he got older and started crawling, we had to go to the hospital more. We near enough 'lived' at the hospital at this point.

12. I can't quite remember at what age S started taking Factor VIII rather than cryoprecipitate, it would have been before he was fifteen. I would mix the Factor VIII, and he would put the needle in his arm. For some reason I just couldn't insert the needle, but I would do everything else to assist him, including plunging the syringe. His Dad would also be fully involved in helping S

13. I was diagnosed with Hepatitis at the end of March or beginning of April 1976. I came over ill one day, it was a horrible time, my eyes looked yellow and my skin started itching. I called the doctor who thought I had Hepatitis A, it was quite embarrassing, I had the health service at the door asking where I had eaten recently.

14. After about three months my doctor thought it had gone on a bit too long for me to have Hepatitis A. My doctor knew a liver specialist at Kings,

and they thought that it was Hepatitis B, then known as the Australian Antigen, that I had.

15. It was decided to test my other family members and I. Myself, S and my daughter were positive for Hepatitis B. It was established at this time that S was the carrier and that he probably got Hepatitis B through contaminated blood products, through cryoprecipitate. I exhibit a page dated 1st June 1976, from Guy's Health District which indicates that it was from S infection that I got the Hepatitis B, as **WITN0353002.**

16. The doctors believed that I caught the Hepatitis B from dealing with S as an infant. It was thought that it was when he was going through teething. I couldn't have caught it before his teeth started falling out because he never had any outside bleeding. I could have easily touched his blood put my fingers in my mouth, without thinking or something.

17. It must have been known that there was an issue because the majority of the haemophiliac boys in the hospital had Hepatitis B. However, nobody mentioned to me that there could be a risk of S getting Hepatitis from cryoprecipitate.

18. S was diagnosed with Hepatitis C and HIV after his diagnosis with Hepatitis B. He was diagnosed with HIV roughly around in 1985 when he was eleven. I can't remember when he was diagnosed with Hepatitis C.

19. Among my papers I have found this single page from Guy's Hospital dated 28th November 1990, within which it is identified that S was diagnosed HIV positive in 1985. I exhibit this as **WITN0353003.**

20. We had taken S to the doctors because he kept on getting swollen glands, although it never crossed our minds that it might be HIV. They

subsequently tested for HIV, but we didn't know they had until the tests came back positive.

21. We found out that S had HIV only because my husband worked at Guy's Hospital at the time. He was at work in the lift with one of the doctors, and the doctor told him in passing that S had tested HIV positive. I can't remember having any follow-up letter to tell us about S HIV, nor do I remember having to go into hospital to discuss S diagnosis. It just seemed all so casual and without care or concern even.

## Section 3. Other Infections

22. I have not been infected with anything else other than Hepatitis B as a result of S infections.

23. I am not aware of S being infected with anything else apart from Hepatitis B, Hepatitis C and HIV.

## Section 4. Consent

24. As far as I am aware, I have always consented to any medical procedures I have had.

## Section 5. Impact

25. I was ill for about three months with my Hepatitis B, then I suddenly got well. I never had treatment for the Hepatitis, and I've never been offered treatment for it. It just kind of disappeared; I no longer feel that I am suffering from the symptoms.

26. I had to have appointments with the liver specialist, Dr. Eddelson at Kings College Hospital and for a long while after the main illness period I would get itchy skin, although I was told this could happen.

27. I still have to get blood tests now and again, and the Hepatitis still shows up. They were going to test me to see if I was still contagious, but that didn't happen.

28. I was not given any advice about how to deal with my infection, other than being informed about how to clean blood up. I just used my common sense, I knew it was contagious so I was extra careful.

29. Having Hepatitis B changed the way I dealt with things. I was always cleaning, and I was very particular with S which is very difficult with a baby. Looking after S wasn't easy and I was worrying all the time. For example, I would worry if he cut himself in case the other children caught the infection, especially because my eldest daughter caught aspects of Hepatitis B and became a carrier.

30. It was very difficult when S was first diagnosed with HIV. It was very frightening and we were scared. Every time he got a little bit ill I was worrying about how bad it was going to get. I'm one to read everything up and I thought that I'd been so careful with Hepatitis B, I'll make sure no one ever picks this up. No one else in my family have been infected with HIV.

31. S came out of mainstream school around the age of thirteen or fourteen and was home tutored because he was too ill to go to school. This was partly as a result of the HIV, and partly because of his haemophilia.

32. Looking after S when he and the other children were young it was difficult. We would have to watch our youngest all the time, particularly because he has Downs Syndrome, especially with toilets and so forth.

33. S didn't go on drugs for the HIV initially. After 1989, he started on AZT and started getting ill from the drugs.

34. There was a period when S was in his late teens when he was very, very ill. His weight was down to five stone because he had a long while where he couldn't eat, due to sores and thrush all in his mouth and throat, a condition caused by the HIV. I don't think he'd have cared if he didn't eat.

35. S lost loads of weight and became so thin, like what a we came to recognise as someone with AIDS.

36. I can't remember how, but I found out about some drinks that could act as meal replacement, with so many vitamins in. He took these drinks for a few years and they built him up, helping him put on weight as a result.

37. Had I not intervened and made him drink these drinks, it makes me wonder if he would still be around.

38. The only information we got from the doctors was to be careful of S blood, and even that was quite a while after he had been diagnosed. I was not informed of ways to deal with S HIV.

39. In 2013 S had an enhanced liver fibrosis test and it showed that he a score of 10.15, which puts him in the "severe fibrosis/cirrhosis" category. The top score is 12.00 which is onset cirrhosis. This is due to his infection with HCV.

40. Since he has moved to GRO-B S has to go to a sexual health (STI) clinic to see a liver doctor and get check-ups. He detests the place, and it's not very nice to put him in the same category as that. He was not responsible for this condition.

41. S also has Haemochromatosis, a condition in which he has too much iron in his system and he has to get blood removed to take away some of the iron It seems like an odd thing to do to a haemophiliac. The doctors say it is hereditary, but no one in our family has ever suffered from Haemochromatosis so I don't know how they can say that.

However, secondary Haemochromatosis can be caused by chronic liver diseases, such as Hepatitis C, and I believe that is how he has developed it.

42. S is not like other fellas his age, they're married and he's not. He's not had the same opportunities as other men his age. He's not really had any personal relationships and some of his good friends, all haemophiliacs have died as a result of contracting HIV through infected blood products.

43. S didn't move from the family home until about fifteen years ago, not long after I had moved to GRO-B He moved to GRO-B for a few weeks then moved back to London. He stayed there for a while, before he moved to another area of GRO-B about six years ago to be closer to my husband and myself, because we would regularly still have to help him. For example, at times he hasn't had a car and we'd have to go up to help him; he had a time where he couldn't breathe one day and we had to go up and take him to the hospital, things like that.

44. More recently, although S has a car, he had an operation to his left foot/ankle due to the haemophilia and has not been able to drive since January.

45. S doesn't want anyone to know about his HIV. Everyone knows he is a haemophiliac, but not even all the family know about his HIV infection. People might have guessed because he has looked ill in the past, such as when he weighed five stone. However, we never told anybody because he didn't want to them to know and because of concern of the stigma HIV has. In that regard I suppose the stigma has been kept to a minimum because he and we just didn't tell anyone and in any case he hasn't worked and doesn't really mix with other people socially.

## Section 6. Treatment/Care/Support

46. I have not had any difficulties or obstacles in obtaining treatment. I couldn't fault any of the doctors, I had a fantastic GP at the time of my infection.

47. With regards to the dentist, they have never given me a special appointment. I've had no experience different to what I would expect from a dentist. S has gone and still goes to the hospital for any dental treatment because he is a haemophiliac and has always been treated well.

48. I think that the doctors were fantastic with S although I think he may say something different.

49. I have never been offered counselling, but I wouldn't have taken it anyway, I'm just not that sort of person. 'Old school' I suppose.

## Section 7. Financial Assistance

50. I did not apply for any financial assistance from the Skipton Fund because I did not think they would give me anything for Hepatitis B.

51. S received the £20,000 stage one payment from the Skipton Fund around ten years ago. However, although we made other applications for the stage two payment of around £50,000 it was deemed that S liver wasn't sufficiently damaged to receive stage two payment despite being at 10.15.

52. S receives an annual amount from the Macfarlane Trust, around £18,000 a year.

53. From memory, I recall us being in contact with a law firm, Pannone,Napier, who acted on S and others' behalf in litigation. As a result, S received £20,000. I don't know where that money came from.

## Section 8. Other Issues

54. It was horrible when I watched the Panorama documentary in the 1970s, which outlined the contaminated blood issue, especially because we had been infected with Hepatitis B by the time it came out. It showed people giving blood in the US; filthy, dirty people queueing to give blood for money. We were never informed by the NHS that this was how the blood S came to have was infected. It makes me feel horrible that S has had the blood from these people and nothing was done about it.

55. Living with haemophilia is bad enough but that is something that nobody could have prevented. Even being a haemophiliac, I believe that S could have lived a relatively normal adult life and would have had a career and family but to have this 'given' to him as well, HIV in particular, has completely wrecked any chance of that.

## Statement of Truth

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

Signed GRO-B

Dated 01/05/2019