ANONYMOUS

Witness Name: GRO-B
Statement No: WITN5717001
Exhibits: Nil
Dated: 10/1/22

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 September 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B I live in Yorkshire with my wife. I have one daughter, who lives nearby. I worked for 19 years and have recently retired.

2. I intend to speak about my infection with HIV and Hepatitis C through blood products. In particular, I intend to speak about the nature of my illnesses, how the illnesses affected me, the treatment I received and the impact it had on my family and our lives together.

3. I am not legally represented and I am happy for the Inquiry team investigators to assist me with my statement.

Section 2. How Infected

4. I was born in GRO-B North Yorkshire, and I grew up in GRO-B. I was diagnosed with haemophilia aged 2 or 3. My uncle from my mother's side had haemophilia and my mum found out she was a carrier.

5. Aged 2 or 3, I was taken to the Haematology Department at St James's Hospital in Leeds, as and when I needed blood products.

6. I have a brother and a sister. My sister was told she was a carrier at the age of 16. She was in the army for 25 years and never married. She's a retired postwoman. I also have a stepbrother who doesn't have haemophilia.

7. In my younger days, I was under the care of Dr Swinburne. Ever since then it's been a variety of doctors. Even though I was young, I could tell Dr Swinburne was a good doctor. She was South African.

8. There was a technician at the hospital who used to administer the blood products. I had cryoprecipitate when I was very young. Then at the age of about 11 or 12, I was treated with Factor 8. It came in small vials.

9. The local GP taught me to administer it myself. Before that I always had to go to St James's Hospital. You used to just turn up and say, "I need some Factor 8." It was as simple a process as that..

10. When I was younger, when my mates were playing football or jumping off of walls, I didn't really realise my limits. But from the age of 16 I

began to realise. That said, my haemophilia doctor went crazy when I got a motor bike. They definitely didn't like that.

11. When I was my twenties, I was under a consultant called Dr Mc Berry. That was when the world woke up to the HIV epidemic.

12. In around 1985 I was contacted by St James's Hospital, saying I had to go get tested for HIV. Unfortunately, I tested positive. I was about 23 years old at the time.

13. I can't specify when it would have happened, but I was told I could have had it for 2 or 3 years without knowing. It came out of the blue, it was like a bombshell. I knew some bits from the news but that was more about the gay community, not haemophiliacs.

14. Later on, I found out I had also been infected with Hepatitis C (HCV).

Section 3. Other Infections

15. I was tested for Hepatitis B and Hepatitis A, but I was not positive.

Section 4. Consent

16. In terms of blood products, I can't remember any risk being mentioned. But my father might have been told.

Section 5. Impact

17. When I found out I was HIV positive, I was shocked. It's like a time bomb, you don't know how long you have to live.

18. Mentally I just blocked it all out. It has made me very harsh. I keep everything closed in.

19. I didn't tell my parents. My mum had passed away when I was about 8.

20. I didn't tell anyone apart from my girlfriend, who is now my wife. I gave her the option to call it a day.

21. On the news they were saying that the gay community had donated blood, and HIV was then contracted by haemophiliacs through blood products.

22. At that point, I didn't have any physical symptoms of HIV. I'd go to the Hospital every 3 months. They'd take about 4 capsules of blood for tests. At that time I was under Doctor Minton at St James's Hospital.

23. I was given treatment and remember it was like a horse pill. It just got me very low. I sort of gave up in a way, I weighed just 7.2 stone.

24. Then there was the Hepatitis C. I can't remember exactly when, but I went through 6 months of Interferon injections and Ribavirin tablets to treat it. It didn't work, the platelet count hadn't dropped sufficiently for it to be deemed successful.

25. I was asked if I wanted to try again about 10 or 15 years ago. It was roughly 5 years between the two courses. I was offered Interferon again, and I was told that things had improved. This time it was Pegylated Interferon. I was more or less given assurances that it would work and, touch wood, it did.

26. My wife has always been very supportive, she understands it all. I met her because she was a nurse in hospital. She still is, she's spent the last thirty eight years as a nurse.

27. When we met, I was in hospital because I had had a serious bleed and needed to have a thigh operation. I was in hospital for 2 weeks. I was quite outspoken and I asked her if she wanted to get a beer on the Friday. She said she didn't get off work until Saturday. Then the head nurse kept me in until the Saturday. That's how our relationship started.

28. Eventually I got a bedsit near her mum and stepdad's. Then we bought a 2-bedroom house. It was a joke because I couldn't get insurance or a mortgage, due to the haemophilia and HIV. We bought the house in 1986, got married in 1987, and had our daughter in 1990. All this was somewhat of frowned upon… but, touch wood, everything was ok.

29. My wife's mum was diagnosed with liver cancer in 1991. We decided to tell her about my haemophilia and HIV. I remember she just cried and hugged me.

30. In 2009, I was, as mentioned, just 7.2 stone. I was going through a period of depression. I recall thinking, "Sod it. Is it worth it?"

31. I was still taking those tablets, this resulted in me getting oral thrush. I was extremely depressed. My wife was very supportive. I was put on a concoction of drugs for the HIV; Raltravagia (once a day), Trevader (once a day), and what I call the Yugoslavian football player - Marocovich (twice a day). I'm still on all of these.

32. I had a stroke 7 years ago. When that happened, I had to take Aspirin and continue to do so every day to thin my blood. I also have daily Factor 8 as prophylaxis.

33. I think it was a transient ischaemic attack (TIA). I've been on Atorvastatin ever since the stroke, as well as two other drugs.

34. I go through phases of depression. In 2015, I did try to kill myself. I'm not proud of that. It wasn't big and certainly wasn't clever.

35. It wasn't a call for help. My daughter and wife are very supportive. I'd basically hit rock bottom. But I know I'm not going to commit suicide or try again.

36. I do get depressed but I have more happy times than sad. I'm not going to go down the road of anti-depressants. I don't want to, although my wife wants me to. Ultimately she does care a lot. We both cope with it together.

37. In terms of the HIV, I've been alright with my CD4 count and levels. They have been really good.

38. I have bad knees due to the haemophilia, because I had excessive bleeds. And my left ankle is cell fused. It was an agricultural area where I used to live, and I don't think jumping in and out of a tractor helped. My legs seized up gradually. We now have a walk-in shower because I find it difficult with joint seizures in my legs and knees.

39. If I have a bad bleed, I get very down after 4 or 5 days. I don't get depressed, but down. It's not very often that I have bad bleeds.

40. I'm having trouble with my right elbow at the moment, because I push on my elbows when get up from a chair. I'm supposed to walk with a stick but I can't because it puts pressure on my elbows. I am unable to reach my collar to do up my shirts, and I can't wash the back of my neck. That's all because of the haemophilia.

41. My HIV was dealt with in the Haematology Department at St James's earlier on. Now, I go to two separate places; the Haematology Department at St James's, and the Brotherton Wing at Leeds General Infirmary. My dental health is dealt with at the Leeds General Infirmary too.

42. I used to see Dr Minton for both the HIV and HCV, but she retired last year. I don't know who the consultant is now. I just go and see a nurse

practitioner, either Tim or Karen, every 6 months. They check my blood pressure and CD4 count. I used to have liver biopsies, but now it's all done by blood tests. I've had ultrasound scans of my liver. Doctors haven't mentioned cirrhosis or fibroids.

43. I also see Dr Horn in the Haematology Department at St James's.

44. There has been a financial impact as a result of my infections. I couldn't get a mortgage, it's all in my wife's name. I don't take insurance when I travel. When I go on holiday, I just try to completely relax.

45. When younger, I used to be an adrenaline junkie but no longer. I used to jump off boats in Tunisia. I'm 59 now and my body says, "You can't stop growing old, but growing up is optional."

46. We regularly go on holiday with another couple and have a great time. But I'm always hoping I won't be stopped by customs, for fear the amount of medication I am carrying will be revealed and consequently generate questions from my friends.

47. It also affected me financially because of the mental impact. It's not underhand but knowing what I've got, and the baggage which comes with me, I've been more cautious with people. I've always been very aware. I kept myself away from people and stayed in my own bubble. That really has had an impact.

48. The haemophilia was limiting too. I kept it quiet but some days I might have twisted my elbow and needed a couple of days off, or a day off if my legs were bad.

49. In a way it was a bit of a culture shock moving from agriculture to the city life. My tractor licence was no use, and my legs were very bad. I was on crutches then, before I had a couple of operations. When I left school, I worked at GRO-B I later got a qualification from the GRO-B GRO-B

50. I never revealed anything about the haemophilia or HIV to my old workplace. The stigma has been more mental than anything else, because I haven't told people. I've always had this fear of it being exposed.

51. I think the haemophilia might have been automatically associated with HIV. Although it has quietened down a lot now. You only hear about this Inquiry every so often. It's not in your face all the time. I just keep it all in-house, in my own personal bubble.

52. I was stigmatised as a young child with haemophilia. People didn't understand it. I know a friend of a friend whose 12-year-old son is a haemophiliac. They don't know I've got it too. I know he's clear of everything that comes along with it. He's young and the treatment is now more scrutinised. I would be interested in hearing about whether people get stigmatised just for having haemophilia, because I certainly did.

53. My mum died when I was 8 or 9, and I can remember my dad was struggling looking after me and my sister. I remember him driving me to St James's Hospital once because I had a bleed, and I recall his words "I wish you'd never been born." That's why I never told him anything afterwards. But he recently passed away. I went to the chapel of rest and forgave him.

54. He died in GRO-B 2021. Last Christmas Eve, he was given 3 months to live. Then after my dad died, my wife was diagnosed with cancer. She had a big operation in July.

Section 6. Treatment/Care/Support

55. I think I had access to good treatment. I'm fairly easy going. If doctors have a lot on, they don't need people stamping their feet.

56. I haven't been offered psychological support and I wouldn't take it. We have a social worker but they say what they want to say. I don't take much from it.

57. I get my Factor 8 delivered now. On holiday I don't take any Factor 8 with me, I just don't do anything risky.

Section 7. Financial Assistance

58. I heard about the McFarlane Trust through the Haematology Department at St James's Hospital, in around 1995.

59. The hospital was supportive. The social worker pointed me in the direction of McFarlane and DHSS, who paid out a lump sum.

60. I don't think we ever claimed for what we could've done. We've always paid for it ourselves in a way. Not that we are proud, but we've always saved up and paid our way.

61. Financial support comes from EIBSS now. I don't know how much I get, I just go along with it. I'm easy going. I'm not driven by money but I've got family to think about. I've got nothing to pass on to my daughter.

62. Along with one of the payments, there was a disclaimer. I can't remember when that was, maybe 1998. The government said, "We are going to give you this and that's more or less the end of it." You had to sign it to say you wouldn't sue the government in the future.

63. There was some pushback from the McFarlane trust. I can't remember what it was. Once you get one knock back, you don't try again. I don't try to claim anymore. I've been kicked in the teeth that many times.

64. I tried to get my poll tax reduced by Leeds city council – they said no. I tried to get handles put in the bathroom – they said no. Eventually I stopped asking.

65. I also got a mobility car from the Department of Work and Pensions.

Section 8. Other Issues

66. I do feel bitter. I think they should have done more to prevent what happened. Not just to me, but to all the haemophiliacs. Now they are, in my view, trying to sweep it under the carpet.

67. It is just the mental health issues and financial problems I have gone through, probably unnecessarily. Plus, the impact on my family life. However that may be through my own doing asI keep everything in. But it's not something you really want to put on a placard and walk through Leeds with; "I'm a little bleeder with HIV."

68. It has changed me, mentally. It has made me more aware.

69. This Inquiry should have been held some time ago. The government have been dragging their feet. The majority of people have now passed away. Even for me, it's a time bomb.

Statement of Truth

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

Signed GRO-B

Dated 10/1/22