Witness Name: GRO-B
Statement No.: WITN2317001
Exhibits: WITN2317002 -008
Dated: 8th January 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My name GRO-B GRO-B. My date of birth is the GRO-B GRO-B, 1967 and my address is known to the Inquiry. I was medically retired when I was thirty years old, due to ill health. I intend to speak about being infected with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my wife.

2. I can confirm that I have appointed Thompsons Solicitors to be my legal representative. I confirm that the Inquiry should send all correspondence regarding me to Thompsons.

Section 2. How Infected

3. I am the youngest of GRO-B children. I had GRO-B. I am diagnosed with moderate haemophilia. My other brothers are diagnosed with mild haemophilia.

4. I was born in GRO-B Royal infirmary and lived in GRO-B with my family until I was two years old when in 1969 we moved to GRO-B GRO-B Scotland.

5. My first memory regarding my haemophilia was when I was about five or six years old and I was in Edinburgh Royal Infirmary. I must have had a bleed and received cryoprecipitate intravenously. It was a big bag and it took a long time to complete this treatment. This would have been in 1974 or 1975. As a young boy growing up I had a lot of nose bleeds and knocks playing football. I would always go to Edinburgh Royal Infirmary for treatment where I was under the care of Dr Davies. He was my doctor until I was about eight or nine years old. At the beginning of the 1980s Dr Davies left and Dr Ludlam took over my care.

6. When I was about thirteen years old in 1981/1982 I damaged my knee and as I usually did, I attended the Haemophilia ward at Edinburgh Royal Infirmary. Dr Ludlam advised me that I needed complete bed rest and lots of Factor VIII. I was admitted for four weeks where I indeed receive a large amount of Factor VIII.

7. In April 1986 when I was seventeen, I was involved in a car accident where I suffered an injury to my spleen. I went to the Edinburgh Royal Infirmary and was admitted onto the Haemophilia ward and treated by Dr Ludlam. During this time I remember a nurse came to my bed with a big bag of blood. I had never been given blood in my life, it had always been Factor VIII. I asked the nurse what it was for and I remember she

said it was just a precaution. I remember this well because I was on the phone to a friend at the time and I told him I had to go because I was being hooked up to be given blood. I later made an insurance claim regarding the accident GRO-B GRO-B GRO-B The solicitors wrote to the Haemophilia Department to confirm my treatment following the accident. The solicitor then advised me that the hospital letter that they had received which I refer to as **WITN2317002** stated that I had not received a blood transfusion. I could not understand at the time why they would lie about this. I clearly did receive a blood transfusion, I remember it so well. Reviewing the medical records now, the situation is complicated further as immediately after the letter which I have exhibited, there are a number of pages that have been blacked out.

8. My mother and I were not given any information or advice regarding the risk of being exposed to infection from blood products. I do remember around the time that it had been on the media, that some haemophiliacs had been given contaminated blood and had developed AIDS, my mother asked enquired with the hospital about it, I was with her when she did. I remember Dr Ludlam said there were no risks, as the blood was being heat-treated.

9. I was given large quantities of Factor VIII from thirteen years old and also a blood transfusion in 1986 following the road accident as discussed above. As a result I contracted hepatitis C.

10. I believe it was around 1993 when my brother GRO-B: B contacted me saying that I needed to go to the Haemophilia ward. He told me that he had been diagnosed with hepatitis C through being given contaminated blood. He said I needed to go and get checked out.

11. I cannot remember who told me I had hepatitis C. I assume someone attached to the Haemophilia ward. Shortly after my diagnosis, I became

very unwell. I was suffering with extreme fatigue and I had horrendous sweats. The sweat would just pour out of me. It may be because I was so ill then that I cannot recall who diagnosed me. I have no recollection of being given any information or advice on how to manage the condition. I cannot remember if I was given any information about hepatitis C or the risks of others being infected as a result of my infection.

12. What I have established from reviewing my medical records now is that non-A, non-B hepatitis was suggested in my medical records in 1984. I exhibit this letter as **WITN2317003**. I also exhibit a letter that was written in 1994 that confirms that my suspected date of infection was February 1984 as **WITN2317004**. I was not aware of this. I have also located a laboratory result confirming that I tested positive for hepatitis C in 1992. I was not aware until 1993. I exhibit this as **WITN2317005**. Some of my records have been damaged through the course of time which presents a problem now in piecing together what has happened.

Section 3. Other infections

13. As well as hepatitis C I know I have been exposed to VCJD as a result of being given contaminated blood. I refer to the exposure assessment form as **WITN2317006**. In 1995 it was on the national news that a man who had died recently from vCJD had been a blood donor. I remember going to see a female Doctor by the name of Dr Horne. Eventually, it was confirmed that I had indeed received an implicated batch in 1997. I was completely devastated. She told me there was no test for vCJD. She said they would know if symptoms started to develop or it would be discovered after my death at the post mortem. I have to live with this knowledge every day.

Section 4. Consent

14. I remember in 1985 on a routine appointment at the Haemophilia ward, I saw a nurse there, her name was Sister Philips. I was with my mother at the time. She handed me a big brown bag. I looked in it to discover it was full of condoms. I asked why I was getting these. She just said that it was routine for my sexual health. I look back now and believe they knew then that I had hepatitis C. I remember it well because my mother asked me what was in the bag. I was only 17 and I remember feeling really embarrassed. GRO-B GRO-B.

15. In the early 1990s when I began to feel unwell with fatigue and extreme sweating I attended the haemophilia unit all the time. They gave me weekly appointments which was unusual. They always took my bloods. They didn't say why they needed to take my bloods so regularly. I assumed they were trying to find out what was wrong with me. I was under the care of Dr Ludlam at this time. I remember wondering why Dr Ludlam and the nurses were being very sympathetic with me as that was unusual. I look back now and believe they knew I had hepatitis C and were using my blood on a weekly basis for research. This was under the instructions of Dr Ludlam.

16. I believe Dr Ludlam intended to use my blood for the purposes of research. I cannot recall any conversation about being included in any sort of study, given what happened to me. Again this is difficult to establish with my records being damaged over time.

17. I remember on one occasion when I was about 16 years old. I was at the Haemophilia Department with my mother. This was a routine check-up. My mother and I were sat in the waiting room. A man I knew called GRO-B came out of Dr Ludlam's room and approached us. He was always there when I attended for my appointments. He said to my mother and I, "if he asks you to sign something, don't sign it". He then walked off. My mother and I went in to see Dr Ludlam. During the appointment he had a piece of paper in his hand. He put it on the desk

turned it toward us and asked my mother and I to sign it. I remember my mother asked what it was for and he said it was just routine. My mother said she wouldn't sign for something that she didn't know what she was signing for. I assume she said this because of what GRO-B GRO-B had said. Dr Ludlum appeared to get angry and I distinctly remember him saying, "Well if you don't sign it, you will get the American factor and catch something". He was very arrogant and talked down to my mother and I. We stood up and both walked out. Neither my mother nor I knew what American Factor meant but I remember we were both quite upset with him saying I would be given blood products and catch something.

Section 5. Impact

18. The impact of contracting hepatitis C was enormous for me physically and mentally. Physically I suffered from extreme fatigue. I was exhausted all the time. I also suffered with extreme sweats. I felt just generally unwell. When the physical symptoms appeared it was horrendous because by this time I was a full-time carer for my mother as she had terminal cancer. Mentally, I was very low. I do not know if this was solely because of the interferon, as I was severely depressed at the prognosis for my terminally ill mother.

19. I have cirrhosis of the liver as a result of having hepatitis C. I recall that my liver results were as such in the early 1990s that I was advised that I had cirrhosis in 1993. I exhibit a reference to this as **WITN2317007**. I cannot locate the record that this list refers to though and there are no other entries in my medical records that refer to cirrhosis until 2012. I was officially told by a Registrar at Edinburgh Royal Infirmary in 2012. I exhibit a letter dated the 6th September 2012 as **WITN2317008**. My health has deteriorated recently very rapidly so every day is a constant worry. My gallbladder has been removed now and I believe this is as a result of the cirrhosis caused by the hepatitis C.

20. After I was diagnosed with hepatitis C, I was referred to Professor Peter Hayes, the liver specialist, at Edinburgh Royal Infirmary. I remember I told him that I felt very unwell. I told him about my sweats and constant fatigue. He said he did not know what was causing them then but did offer me treatment for hepatitis C.

21. I was given a course of treatment. This treatment was three injections of interferon a week this was by way of self-injection. After six months on the treatment I was also given tablets to take that were called ribavirin. I lasted the course for the 12 months but I was told after it finished that it had been unsuccessful. Professor Hayes told me there were no other treatments available.

22. In 2015 I was offered a new treatment that had become available. This consisted of taking two tablets a day for three months. I cannot remember the name of the tablets. This treatment was successful and my hepatitis C was non-detectable. As I was going through this treatment I would see the liver nurse Kim Macbeth.

23. The second course of treatment in 2015 caused me to have severe physical and mental effects. I had severe flu like symptoms. I remember feeling really terrible. I had the shivers and terrible sweats. It was a long and horrendous three months. Mentally, I became extremely depressed. I practically locked myself away. I didn't want to see or speak to anyone. I developed brain fog and could no longer calculate maths. I was always the one responsible for the family finances but I could no longer do them. I couldn't do numbers and became confused. GRO-B, my wife, says I became a different person. She says I was very irritable and agitated.

24. My infected status did not have much impact on my treatment, medical or dental other than people were more cautious around me. After I'd

been diagnosed with hepatitis C I remember the nurses at the haemophilia ward would always gown up and put gloves on when they dealt with me. I remember feeling dirty, although it's not like that anymore.

25. The impact of contracting hepatitis C has totally destroyed my life. I now have severe cirrhosis of the liver and do not have a long life expectancy. My wife and I have tried desperately to have a child for the past 10 years. We have since discovered that having hepatitis C affects the sperm and as such there was very little chance of my wife conceiving. I started getting the symptoms of hepatitis C in my early 20s. I should have been told then and perhaps had some sperm frozen for a later date. By not telling me until many years later, GRO-B and I have been robbed of the opportunity for our own family. This was my dearest wish.

26. My wife and I live in constant fear of my imminent death. I'm constantly ill and can do very little for myself. I have no social life.

27. I am aware of the stigma associated with hepatitis C. It is associated with HIV and AIDS and homosexuality. It is also associated with drug users who share needles.

28. I remember in 1985 when I was 18 years of age I was at home with some of my friends. We were just relaxing watching the television when World in Action came on. The program was about haemophiliacs who had been given factor VIII blood products from drug users and homeless people from America. These people needed money and were getting paid to sell their blood. The haemophiliacs who had been given this blood had contracted HIV and developed AIDS. I remember feeling really embarrassed. They all knew I was a haemophiliac and they started asking me lots of questions. I remember I lied to them and said that I wouldn't get AIDS because I didn't get factor VIII blood products. From this moment I began to be treated very differently by people. I

remember people shouting on the street, 'stay away from him he has got AIDS'. It was a horrible time for me.

29. Some of my 'friends' distanced themselves from me. I felt ostracised and was very unhappy. I started getting into fights and was deeply troubled. I remember I got into a fight with another boy who had said that I had AIDS. I ended up in hospital with severe facial injuries.

30. I avoided relationships with the opposite sex as I was led to believe that I could pass the infection on to others through sexual intercourse. It wasn't until 2008 when Dr Horne said that it couldn't be passed on that way that I decided I would have sexual intercourse. Fortunately I had met my wife by then.

31. My mother decided because of the way I had been treated and the trouble I was getting into that we would relocate. GRO-B GRO-B I decided when I moved I would not tell anyone that I had haemophilia because of the stigma.

32. There were no educational effects on me from contracting hepatitis C.

33. I have been constantly ill since my early 20s as a result of having hepatitis C. My physical symptoms mainly are extreme fatigue this has meant that full-time work has been impossible. I was a full-time carer for my mother for a number of years. I found this to be hard work as I myself was often fatigued, even though it was a labour of love. My mother died in 1994. GRO-B At the age of 30 I was physically unable to work and I have been medically retired ever since

34. Having had hepatitis C and developing cirrhosis of the liver has cost me a career. Also, financial decisions my wife and I have made have been around my life shortening illness. Around the time of the Penrose

Inquiry people who had been infected were told they would receive substantial compensation.

35. I met my wife GRO-B. She has also suffered and still does because of my illness. GRO-B wanted a child with me and I asked Dr Horne if I could pass on hepatitis C to her through sexual intercourse. Dr Horne told me I wouldn't pass it on to her. She encouraged me to go for it. We spent 10 years trying for a baby not knowing that the hepatitis C infection affects the sperm count and the chances of GRO-B getting pregnant were practically nil. She was heartbroken and so disappointed not to find herself pregnant.

Section 6. Treatment/Care/Support

36. I have never been offered counselling or psychological support throughout this whole process. Not only have I not been supported by the NHS I believe I have been lied to and deceived.

37. After the incident with Professor Ludlam when he said if my mother didn't sign a form I would get American factor blood products and catch something. I decided to change Doctors and went with Dr Parker at Western General in Edinburgh. This is how badly I felt I was treated.

38. In 2012 I went to my own local GP. He was called GRO-B GRO-B told him I felt really unwell and he took my bloods. I went back to see him the next day and he told me my condition was very serious and it could be liver failure. I went straight to see Dr Horne at Edinburgh haemophilia centre. I had my bloods taken again. I remember a female Doctor came to me and said she had examined my bloods and my liver function tests were, “not that bad”. She said she would refer me back to Dr GRO-D. I do not know the name of this female Doctor. She was lying to me, my own Doctor had told me how bad my results were.

39. I went to the appointment to see Dr GRO-D. I was sent for a fibro scan on my liver. I remember the nurse that did the scan tried six times but was unable to get a reading. She said she would try one more time and on this occasion it was successful. I remember she said, “Oh my god I'm shocked your reading is 38.8 and even people with cirrhosis are sometimes between 16 and 18”. I was then taken back to the ward. Prof GRO-D came to see me. I remember it was a Friday night and my wife was waiting for me at the bedside. Prof GRO-D said to me that he was keeping me in over the weekend and he would speak to me on Monday. I remember GRO-B asked him directly if I had cirrhosis and he did confirm that yes I did. On the Monday I was taken to see Prof GRO-D also present was Dr Woolsey Dennis and a nurse I do not remember the name of the nurse. My wife was also with me. I asked Prof GRO-D how bad I was and he said I was middle of the range. I knew this to be a lie because of my reading. I told him that my reading was 33.8 and he appeared shocked that I knew the result. His reply was simply, “Well it could go higher”

40. So in terms of support and psychological help I received quite the opposite all I have experienced is deception. I have been lied to for years.

Section 7. Financial Assistance.

41. I believe it was GRO-B brother B that told me that financial assistance was available. He told me to speak to Dr Horne regarding the Skipton fund. I did this and I filled an application form in I believe Dr Horne sent off to the Skipton fund.

42. In 2005 I received a lump sum of £20,000 from the Skipton fund.

43. In 2011 I remember Dr Horne said to me that there was a second payment from the Skipton fund that I would be entitled to and that I

should apply for it. She then left and was replaced by Dr Anderson who told me that I wouldn't be entitled to it.

44. In October 2012 when I was told I had cirrhosis of the liver the hospital applied directly to the Skipton fund on my behalf and within two weeks I received a lump sum of £50,000. I also now receive £2200 every month from the Scottish government.

45. Although I was thankful for the money I have received, it in no way compensates me for my experience of contracting hepatitis C and now having been left with life-threatening cirrhosis of the liver.

Section 8. Other issues

46. I do wish to remain anonymous in this Inquiry.

Statement of Truth

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

Signed GRO-B

Dated 23/05/2022

Signature: GRO-B May 23, 2022 13:57 GMT+1)

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