Witness Name: Mr. GRO-B
Statement No.: WITN1880001
Exhibits: WITN1880002
Dated: 13 March 2019

WITNESS STATEMENT OF MR. GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B and my date of birth is GRO-B 1957. My address is known to the Inquiry.

2. I live at home with my wife GRO-B We have been married 32 years this year. I gave up work on 27 July 2018 as my condition was preventing me from carrying out my job effectively. GRO-B retired the week afterwards; on the 3 August 2018, to support me. Our approach is to spend as much time together as possible. I have been sick for quite some time and the realisation of the seriousness of the condition made us both evaluate the importance of our time left together, however long that might be.

Section 2: How Infected

3. My Christmas disease; Haemophilia B, was not picked up until I was boy. I cannot recall exactly when it was diagnosed but I know that from early 1968, it

was known to the medical profession.

4. From the medical records that I have seen from the Royal Hallamshire Hospital in Sheffield I understand that I may have received blood product treatment in 1973 from the Royal Infirmary in Sheffield; the records do not tell me what I had the treatment for but it would appear that I received both Factor VIII and Factor IX products at that time. In any event, it is my understanding that I was not given the contaminated blood product(s) until 1979 because I was told by the Haemophilia Centre in Sheffield when I approached them for advice about requesting my medical records for the first time in around September 2018, that I should contact the records department at the Royal Hallamshire Hospital to request my records and specifically to request the information relating to the blood product(s) that I was given on Christmas Day 1979, which they could see from their log. The records eventually arrived and I can see from them that I was given Factor IX on 25 December 1979, post tooth extraction. I assume therefore that this is how I came to be infected with hepatitis C. I copy below the information that is contained on that record for the Inquiry's reference:

25/12/79	GRO-B	GRO-B	Xmas	IX x 4	GRO-B	Post tooth extraction	GRO-B

5. I believe that the sixth column refers to the batch number but I cannot say for sure because the document does not contain titles for the columns. This document was accompanied by another which looks peculiar in that it contains what looks like braille. It has the following information on it "*quality tested supplies, Printed in England*"; "*5-84*"; ' GRO-B *57*". The CC number is my hospital number and the GRO-B 57 number is my date of birth. I do not know that the "*5-84*" stands for. A copy of the braille document is provided to the Inquiry **[WITN1880002]**. I can provide a copy of the blood product record should the Inquiry deem it helpful to do so.

6. The care I have received for my Haemophilia B has been provided mainly by

two specialists. The majority of the care was provided by a Professor Preston and more recently has been provided by a Mr. Makris. Professor Preston was the Head of the Haemophilia Centre at the Department of Haematology, Royal Hallamshire Hospital in Sheffield. I know that I also received care from a Professor Blackburn at the Haematology Department, Royal Infirmary in Sheffield and from a Dr. J.G Tetley Consultant Haematologist at the King's Mill Hospital in Mansfield because there are records from the early 1970s relating to tooth extraction which indicate that I did receive care from Professor Blackburn and from Dr. J.G Tetley. I have not been able to recover many records from around the time of my infection; it appears that there is a gap in my hospital medical records from 1979 to 1983 (there being only 20 pages in total made available to me during this time) however, the significant record relating to the tooth extraction that indicates that I was given Factor IX on 25 December 1979 (as included above) does include the name of a medic which is not legible to me. I have called the Haemophilia Centre to check the name of the medic and they are unable to confirm the signature.

7. As far as I am aware I was given blood products for the first time on 12 September 1973. My records show that I had carious teeth removed in 1970 without any haemostatic problems and that there was a plan for further teeth extraction; without any special cover other than liquid plasma, for September 1973. The records are confusing but it seems that I may have been given Factor VIII (100%) and Factor IX (18%) in 1973, but they do not say what it was given for. As far as I am aware I was given infected blood products only once and on the 25 December 1979 because this is what I have been told by the Haemophilia Centre in Sheffield. As my Haemophilia B is so mild, I do not need blood products for the condition. I only require blood products when I sustain an injury and I believe I have required them only five times during my lifetime, the last occasion being in 2010. The records that I refer to above can be provided to the Inquiry if required.

8. I was not infected as a result of my relationship with another person.

9. I was a child when I was given the Factor IX and Factor VIII in 1973 and Factor IX 1979. My father attended the appointments with me and he has now passed away. I do not believe he was ever informed that there was a risk of infection from the receipt of blood products. I was never aware of it, neither then or as an adult in 1979 when I was given the infected Factor IX blood product.

10. I have been infected with hepatitis C.

11. I was told that I was carrying hepatitis C in 1991 during an annual appointment at the Haemophilia Centre. I have no recollection of being told how I had become infected. I believe that this diagnosis came from a blood test that I provided to the Haemophilia Centre on my previous appointment the year before. I was expecting just a normal check over which included taking bloods; I was asked if I was ok in myself. I said that I was. I cannot remember specifically what they said but I believe they said something like, I had been infected with hepatitis C and that was it. I knew nothing about the seriousness of it and left the appointment feeling like I did not understand it. The medical records that I received in October 2018 indicate that in September 1991 the hepatitis C antibody was detected and that there was evidence of past infection with hepatitis C.

12. Looking back I think I assumed that I was infected as a resulted of receiving a contaminated blood product but I was never told specifically that this was the case. Over the years my assumption was supported by various articles and documentaries. I think that it was finally confirmed for me when I requested my records in September 2018 and the Haemophilia Centre told me to focus my attention on the treatment I received in December 1979 and to specifically request the blood product information related to that.

13. My recollection is that I was not given adequate information to help me understand the Infection or to manage it. I had no idea how serious it was.

14. I do not understand why I was diagnosed in 1991 and not before or after that date. What changed in 1991 so that I found out that I had been infected? There was no change in my physical condition, I was not presenting with symptoms but I had been providing blood tests on a regular basis. I was infected in 1979 and the Haemophilia Centre told me they had a log which shows that they knew about what carried the Infection to me as soon as I asked for my records.

15. I think that I should have been told about the serious implications of carrying the virus and what it might mean for me and my wife. I do not know what the medical profession knew at the time about hepatitis C, but hepatitis as a virus has been around for many years and will have been known to the profession and so based on that alone I do not understand why I was not told anything about it beforehand, a period of 12 years elapsed between infection and diagnosis.

16. I was given limited information about the ways the Infection could be transmitted. I was told it could be transmitted sexually and if someone came into contact with my blood. The detail was not explained. Again I did not realise the seriousness of it.

Section 3: Other infections

17. I believe I have been infected with hepatitis C only.

Section 4: Consent

18. In 1979 when I received the blood products, I was 21. I do not recall being told about the need for me to have blood products or about the risk that might attach to me receiving them. So yes, I believe that I was treated without my knowledge, consent and without being given adequate or full information.

19. I knew the Haemophilia Centre was taking blood for tests but not specifically

what they were taking the blood for. It is interesting to me now when I look back, given I have a mild case of Haemophilia B, why I was going to the Centre and giving blood as regularly as I did. I just presumed this was the norm. I have since checked with my mother who has informed me that I was not receiving regular blood tests prior to 1979!

20. I do not know if I was treated or tested for the purposes of research, I thought I was giving blood as a matter of course.

Section 5: Impact

21. Hepatitis C (HCV) has had a massive impact not only on my life but on my wife's life too. In 1991 when I was diagnosed with the Infection, I did not attribute any symptoms that I had been experiencing; most particularly those related to tiredness, to it. Looking back now I can see that the tiredness was related to it as opposed to my job and the stresses I thought it brought to my health.

22. My physical condition has worsened in the last five years in particular. I suffer from chronic fatigue which means that I can no longer do the physical work that I used to. For example, I cannot tend to my garden anymore; it got too much for me. What used to take me 10 minutes years ago, takes me 30 minutes now. In the end, this led me to the decision initially to reduce my working week by one day; however, after only two or three months, I realised I had no alternative but to take early retirement which I did in 2018. I could no longer fulfil what was required of my job both physically and mentally.

23. I constantly feel tired, a lack of energy, I cannot do long periods of manual work, and I struggle to carry out normal daily activities such as helping my wife with the cleaning and working in my workshop on odd jobs.

24. I have aching joints throughout the whole of my body. I have been referred by

the hospital for physiotherapy but I am still awaiting the appointment. I struggle to see what benefit this might deliver but I remain hopeful.

25. Occasionally, I experience pain in the abdomen, I have itchy eyes, irritable bowel and a loss of appetite which I understand can be the consequence of HCV.

26. I suffer from anxiety and I worry about the condition and my health most of the time. This leads to me feeling depressed. The condition is ever-present in my mind; I cannot escape it because it is with me physically.

27. At this present time, I am not aware of any further complications that have resulted from the Infection.

28. I deferred treatment for almost 20 years as I was told that it had serious side effects together with a low success rate. I therefore do not think that I have faced difficulties or obstacles in accessing the treatment. I decided to go ahead with treatment in 2013 because I was told there was a new treatment available that was not as severe as what was available previously which had better prospects of success, but, I understood that it still carried some significant side effects. In the end I postponed it because my father became seriously ill and I felt I could not cope with it at the time especially when I needed to be there to help and support the whole family through my father's illness. Sadly my father passed away in 2013.

29. My consultation for part of the treatment in September 2016 was with Dr. C Durojaiye at the Royal Hallamshire Hospital. Dr. Durojaiye's emphasis during whole consultation was on alcoholism and my alcohol intake to the point where he implied that this was the reason for my liver condition; he even offered counselling for it. It wasn't until my wife and I left the hospital and we sat and thought about how the consultation had progressed that I realised how dreadfully he had dealt with me and my situation. It became clear to us that he

could not have read the medical records prior to the meeting otherwise he would have known about the blood product infection in 1979, my diagnosis in 1991 and my condition from that point. It surprised me that in 2016 in the absence of understanding my condition how quickly he jumped to this conclusion about the cause of the Infection. The following day my Wife rang the hospital to air her concerns. Looking back now, I am still shocked that he dealt with me this way. I do not understand it.

30. I started the treatment in October 2016; it consisted of a 12 week course of Ombitasvir, Paritaprevir, Dasabuvir, Ribavirin and Ritonavir. The side effects were not that severe until the final week when I developed nausea and vomiting but I did have to deal with pruritus from midway through the treatment. I completed the treatment in January 2017 and after six months I was told, thankfully, that I had cleared the hepatitis C virus.

31. From the early diagnosis and the stigma attached to blood-borne viruses at the time, I felt only able to tell my Wife and immediate family about my infection as I was concerned people would treat me differently and so I kept this from everyone including my friends and my work colleagues until I decided go ahead with the treatment in 2016. My strategy to cope with the information that I had contracted a serious and potentially life limiting liver infection was complete avoidance and I tried to distract myself with work.

32. My condition has had an impact on the hospital treatment I have received; when I damaged my hand and had to have surgery, the slot I was given was the afternoon slot so that a deep clean of the theatre could be undertaken afterwards.

33. I have explained that I had to reduce my hours and then retire as a result of the symptoms from the Infection and my Wife decided to take early retirement in 2018 to help and assist as necessary; this obviously has had a financial impact on our lives as we both now heavily rely on the funding from EIBSS as our main source of income. Additionally, I was unable to obtain life insurance against my

mortgage which caused a lot of additional financial stress to our lives.

34. Other than my Wife, the Infection has not had an effect on anyone else in my family. I have not discussed it in any great detail with anyone other than close members of my family. My mental and physical condition upsets GRO-B She tries to be strong for me so that she can be as supportive as possible. GRO-B has not yet been tested; although the risks of infection are low, I expect this is a way in which my infection has affected her. As a couple we would like to do more, we would like to travel more. I am still being charged an insurance premium because I was infected, even though I have cleared the virus. We are reluctant to go abroad in case I get sick and when we do we worry while we are away. There is also a financial impact of doing so now given we are both not working.

Section 6: Treatment/Care/Support

35. As far as I am aware, no difficulties have been faced in obtaining treatment or care. The nursing staff and my haematology consultant at the Sheffield Hallamshire Hospital have been very supportive and offered counselling when I was having the treatment. This was offered to us both.

Section 7: Financial Assistance

36. I was told about the financial assistance offered by the Skipton Fund by the Haemophilia Centre at the Royal Hallamshire Hospital in around 2005. The Centre processed my application which led to a payment shortly thereafter of £20,000.

37. I did not receive annualised, regular payments until 2016. I received £3,000 pro-rata per year and an annual winter fuel allowance of £500 from around November 2016 from the Skipton Fund.

38. More recently these monthly payments and the winter fuel allowance have

been transferred to EIBSS.

39. I applied to EIBSS for the Special Category Mechanism (SCM) payment on 18 February 2018. I had to get reports from nurses and my haematology consultant at the Royal Hallamshire Hospital to apply for this. It led to an approval to pay £1,262.50 per month from March 2018; this was increased to £1,500 per month or £18,000 per year beginning April 2018. I received a back payment of £6,060 because the SCM began in October 2017 and I did not receive it until 27 March 2018. This replaced the original Skipton Fund payments. We get the winter fuel allowance payment on top of this.

40. I reapplied to EIBSS in July 2018 following my retirement, for the top up as the payments are means tested now. The payments increased to £1,564 per month from July 2018, with a back payment made to account for the short fall from when it was due. I reapplied again on 6 September 2018 when GRO-B finished work. We were not allowed to amalgamate the applications. We were granted an increase to £1,979 per month. Even though the payments have increased, our level of income has dropped significantly from around £60,000 combined per year down to approximately £24,000.

Section 8: Other Issues

41. I feel that I want to know who was responsible for all of this. I want to know why I was not advised of the risks. I want to know why infected products were used and why they continued to be used when it was known that there was a significant risk attached to doing so.

42. I hope that this Inquiry will bring closure. I hope that there will be a financial structure put in place for all of those that have been infected and affected. I would like compensation to account for the impact that this has had on my life. I want treatment to be available to everyone.

Statement of Truth

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

GRO-B

Signed:

Full Name: GRO-B

Date: 13/03/2019