Witness Name GRO-B
Statement No: WITN6618001
Exhibits: None
Dated: X 5/9/2022

ANONYMOUS

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 20 January 2022.

GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1947 and my address is known to the Inquiry.
2. I am a retired self-employed accountant having effectively finished working when I had a brain haemorrhage in 1994. I am a widower and have three adult children.
3. I intend to speak about my infection with HCV. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact on my life, and the impact it had on my family.
4. I can confirm that I am not legally represented and that I am aware of the provision for anonymity and I request that I be granted anonymity to protect my privacy and that of my family who are not fully aware of my involvement in the Inquiry.

Section 2. How Infected

5. Sometime in January 1991, when I was 43, I attended an outpatient appointment as I was having problems with marks on my chest apparently caused by blood being slow, following circulation, to return to the heart.

6. Sometime in early 1991 I had a CT scan and was prescribed Warfarin, in a very high dose to improve blood flow.

7. I was diagnosed with a blockage of some sort, and on 24/25th June 1991 I had surgery for Superior Vena Cava (SVC) syndrome to bypass the blockage at Hillingdon Hospital.

8. Following surgery, I was kept in an induced coma for 8 days. The hospital did two operations - one to fix the blockage, which was in a vein, via the bypass, and later another to repair some internal bleeding that had occurred. I did not even know I had the second surgery, and I do not know how much blood I was given. There must be a record of a blood transfusion on my notes because as I will explain later, I was the subject of a look-back contact. In any case such serious surgery would require the use of blood.

9. I believe I suffered a considerable amount of blood loss during these surgeries. Furthermore, the second operation had to be done because I was still bleeding.

10. I was discharged from the hospital following these surgeries in mid-July 1991. I was in the hospital for I think around 3 weeks in total, however, I cannot quite remember exactly how long I was there. I was under pressure from my business partner to return, as a senior business partner was retiring in September, along with the added stresses of raising a young family at the same time. Things were fine for a while after this.

11. In March 1994 I was found to have a bleed on the left side of my brain after a short history of headaches. I underwent a CT scan and it showed a large void, which indicates blood, in my brain but they didn't initially know what it was. Later, I was diagnosed with a brain haemorrhage. I had private medical insurance and through that I had an operation at GRO-B Hospital to correct this. To prevent any further bursting of blood vessels I was kept on Warfarin but the dosage was decreased after the operation.

12. In October/November 1995 I was diagnosed with HCV by a GP. I was called in as my GP, who's name I can't recall, had received a notification regarding a look back exercise in respect of the use of infected blood. It had been sent out by a Doctor in October/November 1995. The letter stated that I had received a unit of blood from a donor who subsequently tested positive for Hepatitis C. I subsequently had a blood test. When I returned for the results, I was told that I was HCV positive. I was assessed as genotype 2. I hadn't really given it much thought up until then but now I was shocked. What did it mean for me going forward? I did not receive any information about HCV at that time and I wasn't even sure what it really was.

13. I remember later, after I had received my results and it had sunk in, saying to a doctor that something must be able to be done about my infection, and that I wanted to sue the NHS for giving me contaminated blood. I was that angry at that stage. I thought the doctor was quite dismissive and I think I was told to learn to live with it, which made me even more annoyed and angry. I asked about a cure, and I think I was told there was not anything available.

14. I had no idea what HCV really was or what it could mean for my life. Luckily my wife GRO-B was a health visitor and knew quite a lot about medical things. The first thing she did was get a book on HCV.

15. Up until my operation in 1991 the only blood transfusion I had was in 1956 at GRO-B hospital where I was treated for a kidney abscess – I believe it was known then as a 'carbuncle'. Even though I was a child I remember it clearly and having the blood bottle hanging by my bed. I have never been an intravenous drug user nor do I have any tattoos or piercings. I have never been medically treated overseas. My only risk factors are the blood transfusions.

16. I do not remember if I got any information later about HCV from the doctor GRO-B took care of it all.

17. I am unaware i GRO-B was tested after I was diagnosed. However, I believe during her five years of treatment for cancer prior to her passing, it is highly likely the numerous blood tests she underwent would have shown anything up.

18. GRO-B nd I made a conscious decision not to have our children tested as we did not want to alarm them. They were at home at the time but were only young.

Section 3. Other Infections

19. I do not believe that I was infected with any other infections apart from HCV as a result of being given infected blood products.

20. I do not remember ever being tested for HIV and if I was, I do not recall being given any result.

Section 4. Consent

21. I cannot remember if I knew that I was being tested for HCV. Rather, I just knew that there was a possible problem, and consented to having my blood taken for general testing by my GP. I did not know what HCV was before I was diagnosed.

22. I did consent to all the treatment I received for the condition.

23. Following initial diagnosis, I was so angry because as I said earlier, I thought the GP told me just to learn to live with HCV, that GRO-B and I went to St Mary's Hospital in Paddington for a second diagnosis to make sure the GP surgery had not made a mistake. I was fully aware of the purpose of those tests.

Section 5. Impact

24. Before my diagnosis GRO-B would always complain that I would say that I was fatigued. It became a feature of our lives that I was always tired, more so than ever before but apart from the constant tiredness, I do not remember any other symptoms prior to diagnosis.

25. We led a busy life, with mortgages on the house and office for the accountancy firm, as well as young children and a son with learning disabilities. It was a busy, and stressful time, and I believe the brain haemorrhage could have been caused by that.

26. Following diagnosis, I did not notice many symptoms. I had just suffered from a brain haemorrhage the year before and was focusing on that.

27. At the time I was diagnosed with HCV and was still dealing with the after effects of my brain haemorrhage and the previous crash in the economy, and my business partner and I were under an enormous pressure from our clients. I do not think having HCV in my system affected me particularly then, but who knows - there was a lot going on at that time.

28. Any disruption to my work caused by the HCV was trodden on totally by economy issues and the fall out from my major brain operation.

29. The brain haemorrhage caused me to lose part of my vision, approximately 2/3rds of my right field, short term memory and driving licence.

30. The day after the HCV diagnosis as I've said, GRO-B and I went to St Mary's Hospital for a confirmation

31. Eventually, I was put under the care of a Professor in the liver department. At some stage I had a biopsy, in actual fact I had two, one private and one on the NHS, which noted that the amount of liver scarring I had was consistent with HCV. I think I had a necro-inflammatory score of 4 out of 18, as well as a fibrosis score of 3 out of 6 (Stage 1 fibrosis).

32. I was told that my liver scarring was not too serious and I was not going to die immediately! I was relieved but I don't think you realise the serious nature of this infection early on.

33. The Professor further advised me that he was able to offer me treatment, however, as I recall, he also advised me to wait as the treatment was probably going to get so much better. There was also the risk the treatment – interferon, would interfere and react badly with the drugs, such as the warfarin I was taking as a result of my brain surgery, I was made aware that there could be some nasty side effects to Interferon which may be difficult to handle in my weakened state.

34. From then on, I had regular six-monthly outpatient visits at the liver department, and would have to visit the hospital a week before to get my bloods done too.

35. Despite having private medical health care, after a year, BUPA said that as my infection was chronic, they would no longer fund my care. I informed my treating Professor and fortunately this did not affect my treatment, and I was transferred onto the NHS treatment list.

36. The HCV infection diagnosis was devastating for us as a couple. From the information GRO-B had gathered I read that I needed to be careful with daily activities such as shaving, as well as sexual transmission. Despite this, GRO-B and I decided it did not matter as I had been infected for four or five years prior to diagnosis.

37. In February 1999, I was diagnosed with stage 2 fibrosis, and I believe with a necro-inflammatory score that made me grade 1. The biopsies were extremely painful, and I had to lie still for 12 hours afterwards. Because of my Superior Vena Cava bypass operation in 1994 I was on warfarin, and so I had to stay overnight in hospital both times to make sure I was not bleeding internally.

38. My liver score results remained fairly level for a while, and so I did not need any further biopsies as these were replaced by fibro-scans which were far less intrusive.

39. In 2005 GRO-B ost her long battle with breast cancer. Afte GRO-B died my whole life changed. Our eldest son moved into independent supported living accommodation, and our other children had already moved out.

40. I do not know if the stress of my HCV diagnosis was contributary to GRO-B s cancer although it can't have helped her state of mind in those latter years. GRO-B was a children's nurse for a couple of years when she was younger, and was the one to hold the baby whilst x-rays were taken. I hope it would never happen now but back then no one knew.

41. Once the new treatment was made available, it took three years of being told that there was a new treatment before it was made available to me. I found that wait frustrating. I was told the treatment was very expensive, and I think they said that they could only pay for 6 individuals every six months to be treated. Each time I attended the clinic I was shown where I was in the queue for treatment.

42. I remember getting fed up, and worried that as I was getting older the treatment would not be offered to me. I had never in almost 20 years had a treatment and I felt my wait warranted it.

43. Around July 2018/2019, I was called by the nurse who I was under asking me whether I could come in next week to start on the new treatment. I was told that there were new drugs available that were still expensive but much cheaper than before, and as a result the hospital could be much more generous with it.

44. I was not allowed to have the drugs all at once due to the costs, and so I had to make two visits, with four weeks of treatments provided each time. The drug was called Mavyret.

45. The treatment lasted two months, and I had to take three tablets a day. I am fortunate that the treatment was successful. I was elated to find that I had cleared the virus but I wish that my wife had been there to see that.

46. I did not experience any side effects from the treatment.

47. I had ongoing fibro-scans to monitor my liver. I had a scan five years ago which showed an increase in readings. After that I completely stopped drinking wine, and limit my alcohol consumption now to one beer a day. A fibro-scan in the past 12 months showed my reading to be within the normal bandwidth.

48. This has affected me to an extent socially. I limit myself to one drink. I will never have a glass or two of wine, like I used to. It can be difficult but there is a good reason.

49. As far as I am aware, I do not believe my infection with HCV caused any of our family friends to pull away. However, it is hard to tell. It is not the sort of thing you broadcast so only a few people were aware.

50. I do not know if I mentioned my HCV infection to my business partner but I probably did - there was so much pressure on the business with the economy dropping, and the other stuff that was going on health wise with my wife, in the greater scheme was worse than this diagnosis.

51. With the children GRO-B and I did not want to make a big deal out of my diagnosis. The children were very young - GRO-B was 14, GRO-B was 12, and GRO-B has a learning disability so would not understand anyway. They were too young to be burdened with that sort of worry. None of the children as I've said were ever tested as we had no worries that they may have been infected. They are aware of my condition now and my daughter recently gave birth and I am sure would have been tested during pregnancy.

52. I was overly cautious about shaving and cuts, and making sure that no blood went near them or that they drank from the same cup. It didn't interfere with physical contact but just made you more aware.

53. After GRO-B died, a divorced woman asked me out. When it came to a situation where sex became involved, I did not want to risk infecting her.

This cost me that relationship, and made me realise the difficulties for any further relationships that I may develop. I have recently been in touch with her again and I appraised her of my reasons back then and she understands why I did it.

54. I came to realise that, in order to not risk infecting any person I become close to, I cannot have relationships. Despite this, at the time I was in my late 50s / early 60s and I felt a pressure from women who were interested in asking me out. It was a difficult decision to make but one that I felt was for the best.

55. I have had no issues with my mortgage, life or travel insurance because of my HCV infection.

56. The brain haemorrhage had a far greater impact on my work than the infection. After the haemorrhage occurred, I realised that I was not going to get back into employment. I was unable to work in 1994, and I dropped part of my share in the practice. My income plummeted as I was not able to do anything. I ticked along with holding some share until 2000/2001, when the partner decided to sell on retirement.

57. I did try to go back to work once the business was sold in 2000/2001. I accepted an offer from one of the new partners to go and work at my old company so clients could see my face and I could do a bit of work. For two or three years I did two or three days a week. However, I could not hack working for people who previously had worked as my employees.

Section 6. Treatment/Care/Support

58. As mentioned, I received little support from my GP with regard to my diagnosis. I thought he was very off-hand. It was a case of 'get on with it' I was never offered any psychological counselling at that stage nor later when receiving treatment.

59. With my previous dentist, I had to have check-ups as the last patient of the day. I found it humiliating but understood it to a degree. However, it did not stay like that forever, and when my current dentist took over the practice, he informed me that he was not too worried about my infection.

60. Apart from the two above mentioned incidents, I am happy with the treatment, care and support that was given to me although it did take a

long time before treatment was available and I feel I was lucky that my liver damage was limited.

Section 7. Financial Assistance

61. I found out about the Skipton Fund from my Solicitor. I applied in June 2004, and on the 01 September 2004, my claim was accepted by the Skipton Fund. There were no difficulties and the form was straightforward to complete. I received a lump sum of £20,000 but no on-going payments at the time. I don't think there were any conditions attached to the payment. That was it until I began to receive regular payments from November 2016 of £3,500 per year.

62. I should mention that I was part of a group action run by a solicitor's firm in Nottingham in the early 2000's. There were 70-100 of us involved and it was against the Department of Health. We were successful and I received a pay-out which totalled around £13,000 but by the time the costs had been met through the insurance cover we had, I think I received about £600 at the end! This did initially affect my Skipton entitlement as there was a ruling that those involved in litigation were not eligible. However, this was later reversed and I received the payment mentioned above.

63. I was just relieved to get it all finished and allow me to get on with my day-to-day life and looking after my wife who had by this time been diagnosed with cancer.

64. In 2017, I received a letter from the Skipton Fund notifying me that I would be moving to EIBSS. After this I received a top up payment of £30,000 in 2021 which I believe was to bring us into line with the rest of the UK countries.

65. I now receive £1625 per month which is a significant increase.

Section 8. Other Issues

66. I would like to know who it was who made the decision not to test the blood I received in June 1991 when I believe the rest of the Western world was testing their blood supplies. If the decision to test the blood before June 1991 was in place, then I would probably not have been infected with HCV.

67 I am grateful for the look back exercise and the fact it identified my infection but why did it take until 1995 when they were aware of possible consequences and started screening blood in late 1991?

68. I always wonder as well what impact the virus being in my system may have had on the brain haemorrhage that I later suffered. No one I am sure will ever express an opinion on whether there was a link but questions remain.

69. Despite receiving a regular payment, it does not make up for the fact that I have been infected with HCV. For 20 years I felt like a lepper. It still affects my thought patterns now. If they did not pay me a penny and told me I never had HCV, I would be much happier.

70. On the train journeys to Paddington for my 6 monthly appointments, I used to joke with GRO-B that going to these was like a person on death row waiting to see if his lawyer had managed to get a stay of execution. Pity she didn't ever get to know that I eventually got a free pardon via the treatment

71. The stigma of being infected is still present although I am cured. Being infected has made me feel dirty, and has affected so many aspects of my life. It was worse than losing a limb or limbs. The whole of your being and body is contaminated. This has been life changing for me I will always regret that my wife was unable to know that treatment occurred and I cleared the infection. Going through all of this has hurt me mentally and is very damaging.

72. My feelings are that the Blood Transfusion Service caused this by choosing not to screen blood until September 1991.

Statement of Truth

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

Signed X GRO-B

Dated X 5/9/2022