Witness Name: GRO-B
Statement No.: WITN6213001
Exhibits: **Nil**
Dated: 12 May 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B
ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 09 May 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1966 and my address is GRO-B Liverpool GRO-B

2. I have been married to my husband, GRO-B for nearly GRO-B years. Together we have four children, with the two youngest still living with us.

3. I was born in Aden, now Yemen and I came to the UK in around 1976 aged about 10 years old. I have lived in the UK ever since.

4. I intend to speak about my infection with hepatitis C ("HCV"). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

5. In November 1987 at Rotherham General Hospital, I underwent an operation on my right thyroid nodule, which required a total lobectomy. During this surgery I received a blood transfusion. I remember waking up from the operation and finding a bag of blood attached to me next to the bed. I recall that at least one additional bag was administered. I was not pre-warned that I would or may receive a blood transfusion, though I didn't think anything of it at the time.

6. After the lobectomy procedure my voice was a bit weak, this was connected to the procedure itself. Otherwise, once I had recovered, I felt perfectly fine.

7. My husband and I moved from GRO-B to Liverpool in 1992. Our first child was born in 1993 and our second child was born in GRO-B 995.

8. Around 3 to 4 weeks after giving birth to my second child, I received a phone call from my GP, GRO-B at GRO-B in Liverpool. I struggled to understand what he was saying as he had a strong either Indian or Pakistani accident.

9. Dr GRO-B mentioned something about blood and that I was infected, which sent me into a panic. I immediately thought I had HIV. My husband GRO-B spoke to the doctor who explained that, in fact, I had HCV. GRO-B explained this to me after the phone call and we went to see the doctor that afternoon.

10. We discussed my HCV infection very briefly with the GP. We knew nothing about hepatitis and were understandably very worried. Dr

GRO-B appeared to have little understanding either and we received next to no information about what it meant for me.

11. I was referred to a specialist consultant in liver disease at Royal Liverpool Hospital. The consultant's name I believe was Martin Lombard, I remember that he was a prominent expert in the field. This was within 2 weeks of my initial diagnosis. We also saw Sir Ian Gilmour at times.

12. The consultant explained HCV to me and how it affects the liver. He said that it was contracted through the blood transfusion I received in 1987. There was some discussion about whether I drank or smoked. I do/did neither, we are Muslims.

13. After this appointment, I was seen by Helen Caldwell, the senior nurse in charge of the department. Helen explained infection management to me, including being especially careful with cuts and bleeds and avoiding sharing toothbrushes and razors.

14. Treatment was not offered to me at this time. The consultant said that there was no treatment available, although it was implied that they were working on one and it was getting closer to being authorised for use.

15. I had a number of blood tests at the hospital after my diagnosis. These showed my white blood cell count was low, which was causing me to feel fatigued. I believe that they measured my viral load but I cannot remember what it was.

16. Around 2 to 3 months after seeing the consultant at Royal Liverpool Hospital, I returned for a liver biopsy. This procedure was horrible. I was in unbearable pain. It is impossible to explain in words how it felt. After the biopsy I had to remain still on my side for a day afterwards. I remember feeling dizzy and sore.

17. I was offered a first course of treatment before 2001, though I am unable to say exactly when. I know it was pre-2001 because we were renting a flat at the time and were yet to the buy house the we still live in, in 2001.

18. This course of treatment consisted of interferon injections 3 times a week and was scheduled to last for a year. The nurses showed me how to inject it and I was then required to do so myself. I hated doing this but I managed to get through it.

19. I used to have to hide doing this from my kids. I remember having a 'sharps' box o dispose of the needles and then I had to take this box to a pharmacy to be disposed of safely.

20. During this treatment I was sick a lot and lost a lot of weight. My husband recalls that I looked gaunt. I was visibly ill and friends used to ask me if I was ok. I had not told anyone that I had HCV and so I had to make up what was causing this. The hospital was monitoring my viral load but this showed no signs of reducing. My white blood cell count was also dangerously low.

21. I felt extremely tired and struggled to get out of bed. It was worse than the flu and I had no energy whatsoever. During this period, I had two young children at home to care for whilst my husband was at work.

22. After persisting with the treatment for 2 months or so, the hospital decided to stop the course of medication. They were worried about the effects it was having on me and it had showed no signs of clearing the HCV infection.

23. Once I had stopped the treatment, I began to feel better. I did not display any noticeable symptoms of HCV. I regularly attended the hospital for check-ups every 6 months but I felt fine. I suppose they would say that I was 'non symptomatic'.

24. I was offered a second course of treatment around 2004. I remember that it was more than 2 years after the first treatment and my third child, born in 2001, was around 3 years old at the time. This treatment consisted of interferon injections self-administered once weekly and ribavirin tablets taken once daily.

25. I had regularly blood tests during this treatment but these showed very little reduction in the viral load. I lost a bit of weight during this course of treatment but the side-effects were not as severe as the first course. The symptoms were similar but not as profound.

26. I remember being told that the treatment was expensive. I think I was offered it because I was diligent in attending my appointments and was always on time. Nevertheless, this treatment was stopped after 6 months because it had failed to affect the HCV.

27. Over the next 10 years I experienced the odd bout of tiredness but no extreme symptoms. Helen Caldwell, my hepatology nurse, said that this was because of my healthy lifestyle and avoidance of alcohol throughout my life. I was anaemic and my white blood cell count remained low, which I attributed to the HCV.

28. I was then offered a third course of treatment in 2016. This was a tablet, the name of which I cannot remember, which was taken once daily over a number of months, I cannot remember how long. It was a new drug that they said cost £1000 per tablet. The hospital wanted to offer it to me because of how long I had been attending their clinic and owing to the two previously unsuccessful treatments. I was delighted to receive this.

29. Throughout the course of treatment I was monitored and it looked like it was working to clear the HCV. By the end of the course, the HCV was undetectable. I went back for further tests 3 months, 6 months and 12 months after completing the course and all these tests showed the HCV was undetectable.

30. At some stage I must have had a scan because I remember Helen Caldwell telling me that I had a very small shadow on my liver. This was obviously concerning at the time but my liver is thankfully fine now. I consider myself fortunate in this regard.

Section 3. Other Infections

31. I did not receive any other infections as a result of receiving an infected blood transfusion.

Section 4. Consent

32. I was told that I had HCV after the birth of my second child in GRO-B 1995. The only conclusion I can draw is that I was tested for HCV before, during or around the time of this childbirth. I was never informed that I was being tested for HCV and therefore did not consent to this. I also believe that I would probably have been tested for HIV at the same time, again without my consent.

33. I was not pre-warned or informed about the possibility of a blood transfusion being administered to me in 1987 during the lobectomy operation. I simply woke up and saw a bag of blood attached to me. I was never asked to consent to this, neither were my parents on my behalf (this was before I was married) .

Section 5. Impact

34. My infection with HCV changed my life. It was ever-present and always in the forefront of mine and my husband's minds. We lived a secret life, not even telling our families, except for my mother and my older sister. I had to make regular excuses about being unable to see people, which I used to blame on a thyroid problem.

35. This significantly affected my relationship with my husband GRO-B He was very worried for himself and our children and the risk of infection. I do not think that he really had things properly explained to him and so in some respects it was the fear of the unknown. This lasted over a long time and persisted until I was clear of HCV. After that things between us became easier again. I once broke down when talking to Nurse Helen Cauldwell about this aspect. She asked me if I would like her to speak

to GRO-B but I said not to because I didn't want to put him and that position and for him to know that I had been talking about him. We are fine now.

36. We later told our three eldest children that I had HCV. The two middle children were shocked and couldn't believe that I had such a serious illness. My eldest child had suspected something because of all the hospital appointments, but didn't know what. They all dealt with this well. We still have not told our fourth child because he is only 14.

37. I was constantly concerned about infecting others. I thought that I would be stigmatised if I told people about my infection, so I decided it would be easier not to. I knew that people would be uncomfortable around me and treat me differently if they knew I had HCV.

38. My husband and I were stressed and paranoid about cuts and bleeds. We became overprotective of the children and were fearful of them becoming infected.

39. After my diagnosis in 1995, my eldest child, who was born in 1993, had to be tested for HCV. My second child, who had just been born, then had to wait for 2 years before he could be tested for HCV. This was awful for us both. To hold a new born baby and constantly fear that you had infected him with this awful virus was traumatising. Thankfully neither child tested positive.

40. My husband GRO-B was also tested for HCV after my diagnosis, and tested negative. We had to ask doctors if it was ok for us to have more children after I had received treatment. The timing of our children was adversely affected by all of this. We decided to risk having two more children after my diagnosis and outside of any threat the treatment may have posed, they are thankfully negative. This was incredibly worrying nonetheless.

41. HCV to me was always associated with intravenous drug use and alcoholism. Whenever I was forced to tell people about my HCV infection, for example at medical appointments, I made sure to emphasise that it was contracted through a blood transfusion rather than through any lifestyle choices. I felt that I always had to do this when meeting 'new' medics or staff.

Section 6. Treatment/Care/Support

42. I have not faced any difficulties in obtaining treatment, care or support in consequence of my infection with HCV. I was concerned about having a bleed when I was at the dentist but they were understanding and did not treat me any differently.

43. I do recall that medics would put gloves on when they saw me but I had noticed that they hadn't worn gloves for the previous patient. I do understand why this was, having seen my file but I felt it nevertheless.

44. I have never been offered counselling or psychological support in relation to my HCV infection. The closest to this would be confiding in Helen Caldwell, who became a friend. I trusted her entirely and she was always very supportive. I am so grateful for all her help; she was brilliant.

Section 7. Financial Assistance

45. Helen Caldwell told me about the existence of the Skipton Fund in the mid 2000s. I applied with the support and endorsement of Helen, who filled in the relevant medical sections of the application form. I also believe that medical records were provided as evidence of my infection.

46. My application was accepted soon after and I receive a payment of £20,000 shortly afterwards. I currently receive £1,600 per month in financial support and a winter fuel allowance of around £500.

47. In around July 2021, I received a £30,000 payment because some people in Scotland had received £50,000 instead of £20,000 previously.

Section 8. Other Issues

48. I don't want anything like this to happen again.

49. I feel advantaged that, despite my ethnicity, I speak good English. Other ethnic minorities who can't speak English as well as I can, don't understand this fully and have been hindered as a result.

50. We never looked for anything, not least money. The money we received has helped but it has not changed the way HCV has affected my life.

Statement of Truth

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

Signed GRO-B

Dated 12/5/22