ANONYMOUS

Witness Name: GRO-B

Statement No: WITN4884001

Exhibits: **WITN4884002 - 04**

Dated: 1/2/23

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 27 September 2021.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1951. I live in GRO-B, Essex and my full address is known to the Inquiry. I am retired but I used to run an off licence for many years. I now volunteer at a charity shop one afternoon a week as I am too unwell to work anymore than this.

2. I have a son who lives in Canada and 2 daughters GRO-B. I also have 11 grandchildren that I enjoy spending time with. I live alone in

GRO-B, Essex, but one of my GRO-B comes to stay with me regularly.

3. 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 I received and the impact it had on me and my loved ones.

4. I am not legally represented and I am happy for the Inquiry Team to assist me with providing a statement to the Infected Blood Inquiry. I would like to be an anonymous witness as I am well known in my community and very few people know about my infection with HCV.

5. My daughters GRO-B, have accompanied me to provide this statement to the Infected Blood Inquiry and have assisted me in recalling certain dates and facts in relation to my HCV diagnosis and treatment.

Section 2. How Infected

6. In 1979, I had an emergency appendectomy operation as my appendix was close to rupturing. When they opened me up, they realised I also had ovarian cysts which they decided to remove. The operation was done overnight and when I came around from the anaesthetic, I recall the surgeon saying, "Oh you gave us a bit of a panic and we had to give you a blood transfusion". This was done at GRO-B Hospital, which no longer exists.

7. On 02 August 1990, I had a hysterectomy at Elizabeth Garrett Anderson Hospital, which now comes under University College London Hospital (UCL). This was done because I had suffered long term bleeding and I was found to have abnormal cervical cells following a cone biopsy, which put me at risk for cervical cancer. I had been seen at a number of local hospitals but finally was treated at Elizabeth Garrett Anderson as they were specialists in the field. I had a blood transfusion following this operation.

8. A few years later, I started to suffer from liver pain but I put it down to the underwiring of my bra digging into me and ignored it. I also was feeling tired but I put this down to working long hours and bringing up my daughters. Their father had left me a few years prior to my diagnosis, so I was having to manage things at home independently. I had my son when I was just 16 years old from a different relationship, so by then he was no longer living with me.

9. In 1998, I decided to donate blood as there was going to be a centre in GRO-B accepting donations. I had donated blood in my early twenties, but I had not done it for some time and thought it was a good thing to do. I remember the girls being with me in their school uniforms, so they were still very young.

10. At the end of my donation, one of the nurses pulled me aside and told me that unfortunately my donation could not be used as they had found an infection in my blood. She did not give me any further explanation as to what this infection was, but I was told that they would refer the issue to my GP and to contact them in a couple of days. The girls recall me coming out of the centre with a look of panic and confusion on my face. I had no idea what was wrong.

11. When I saw my GP at GRO-B, they told me that I had tested positive for HCV. I didn't really understand the distinctions between the different types of hepatitis, but I was shocked and distressed by the news as I knew hepatitis was a scary thing. There was a complete lack of information and support provided at this point, and I was just told that I would be referred to Addenbrookes Hospital in Cambridge for further tests.

12. At the time of my diagnosis, I was not given any information as to how I would have become infected with HCV. I think it was through a leaflet I was given at Addenbrookes Hospital or my own research online that I learned that I could have become infected through a blood transfusion. I believe I became infected with HCV when I received blood in 1979 during the appendectomy or in 1990 during the hysterectomy.

13. I have no tattoos and I have never been an intravenous drug user or engaged in any high-risk activities for HCV. A doctor at the Royal London Hospital later confirmed to me that he believed I was infected with HCV through a blood transfusion.

14. On 28 January 2021, I received a letter from the University of Nottingham in relation to Hepatitis C research UK and the IBI. Although I don't recall participating in this research project, I may have signed up to it when receiving treatment. They told me that my details had been supplied to the IBI, as I was someone who might have acquired HCV through blood transfusion or blood products. This confirms that I have always known that a blood transfusion was the source of my HCV. (**WITN4884002)**

Section 3. Other Infections

15. I do not believe I was infected with any other infections apart from HCV through the blood transfusions I received. When I started my care at the Royal London Hospital, I had a number of general blood tests and I believe I would have been tested for HIV at this stage.

Section 4. Consent

16. As the appendectomy I had in 1979 was an emergency operation, they would have not had time to get me to sign consent forms for this. When I had the hysterectomy in 1990, I signed a consent form prior to this operation. I assume this covered consent in relation to receiving a blood transfusion if it was necessary.

17. I consented to the HCV treatment that I received at the Royal London Hospital.

Section 5. Impact

18. After I learned about my HCV diagnosis, I was left confused and worried as I had been given so little information about HCV or what this meant. I was just expected to wait until I received an appointment at Addenbrookes Hospital for any further information.

19. At the time, I didn't question this referral to Addenbrookes Hospital as I thought this was the only hospital that could deal with HCV. However, I do not understand why I was not referred to a hospital in London which would have been more accessible for me. Due to suffering from heart arrhythmia, I was not driving at the time and Addenbrookes was really not accessible. When I got an appointment a few months later, I had to get a lift both ways which was not easy as it was a 2 hour drive each way.

20. During my first appointment at Addenbrookes Hospital, I was given a leaflet about HCV (**WITN4884003**). This was very basic and really didn't address everything I wanted to know. There was no mention of treatment and I felt like some of the advice was quite conflicting. This was all the information about HCV that was provided, and I really felt this was inadequate. There was no counselling or support offered. I was told that I could live well into my 80s with HCV if I looked after myself, and this was the approach I decided to take at the time.

21. After reading this leaflet about HCV and doing some of my own research, I became very paranoid about making sure the kids were not put at risk. I would be very worried if someone shared a towel with me and I made sure they knew not to use my razors, flannels or toothbrush. The girls now say that they knew how obvious I was about my concerns about HCV, but at the time they didn't want to make it more stressful for me.

22. While at Addenbrookes, they suggested that I should have a liver biopsy and they arranged an appointment for this. This was the most horrendous, painful procedure I have ever experienced in my whole life. It was also a completely wasted procedure as they did not take a big enough piece of my liver and could not analyse it effectively.

23. After this procedure, I decided I did not want to go to Addenbrookes Hospital anymore. It was so difficult to get there and I had been told I could manage the condition myself with a healthy lifestyle. No treatment had ever been mentioned so I did not feel like I was missing out by not attending future appointments. I think they sent me 2 further appointments before taking me off their books. I decided to be as healthy as I could and manage the HCV myself.

24. After my diagnosis, I didn't want to tell too many people about the HCV due to the stigma involved. I had to inform my ex-partner, the girls' father, due to the risk to him. He said he had undergone a series of blood tests and tested negative for HCV but he was quite off-handed about the whole thing.

25. I also told my elder daughter GRO-B but decided not to tell GRO-B from the beginning. She definitely knew something was wrong, but didn't know what was happening. Unfortunately, she learned about my HCV diagnosis when she got into a fight with her sister about not doing enough around the house, and it came out that way, which was not ideal. There was never any advice that the girls should be tested, but they have been tested for HCV while pregnant and were all clear.

26. I have decided not to tell my son about my HCV diagnosis. He moved to Canada many years ago and although we visited him in 2003, we are not very close anymore. Sadly, my daughter in law is a very judgemental person and I did not feel comfortable sharing this news with them. She is the type of person who wouldn't talk to you if she knew you were gay, so I am sure they would not have spoken to me again if they knew I had HCV. I wanted to tell people I trusted. If not for her, I may have told my son.

27. I continued to work and live as normal a life as possible over the next few years. I kept it a secret from my work, where I ran an off licence. I was initially so paranoid and if I was eating something and someone wanted to have a bit of my food, I would make any excuse to prevent them from having it. I remember being so worried if I cut myself and wanted to make sure no one touched my

blood. When I split my head open after banging it, I was bleeding significantly but I was more worried about anyone touching my blood than my injury. I think over time I became a bit more accepting of my diagnosis, but it was always in the back of my mind.

28. The girls have told me that they could feel how worried and paranoid I was. They felt like I was less worried when I was working more, as when I wasn't at home, I wasn't putting them at risk. We had an au-pair for a period while I was working, as this allowed me to leave the girls more. They say they only recall me being calm when we did things like trips into London or Kew gardens and when we went on holiday to Canada, as I was more relaxed.

29. I had been an outgoing, lively party person which all changed after my diagnosis. I put up a wall and even if someone would chat me up, I would shut them out. Even if we went to a party, I would always have that worry in the back of my mind about things like someone drinking out of my glass or eating off my plate, and I could never fully enjoy myself. It really did have a big impact on my life.

30. Although I wanted to meet a new partner and have someone in my life to settle down with, having HCV meant I was scared to start new relationships. I did date a man for a few months who I had known in the past and I did tell him about my HCV. He was understanding of it as his father in law had also had HCV through infected blood products, as he was a haemophiliac. However, after we split up I didn't feel like I could tell new people and I ended up staying alone, which is not what I wanted.

31. Around 2007, the pain in my liver got far worse and I felt more and more tired. I went to see my GP about this and explained that Addenbrookes Hospital was just too far away for me to attend. This time, I was referred to the Royal London Hospital and they were just fantastic. I told them straight away that I did not want another biopsy, and they told me I didn't need one. I did have an ultrasound-like test while there, and they told me that I had 5 cysts on my liver.

The doctor also confirmed that he believed my infection was through a blood transfusion.

32. The doctors at the Royal London Hospital told me that I could start a treatment trial for HCV and I was shocked as Addenbrookes Hospital had just never mentioned a treatment for HCV. I thought that HCV was something I would live with forever. I think they also gave me some more information about HCV and told me to generally avoid alcohol, although an occasional drink for a special occasion would be okay. They also warned me about the stigma related to HCV that I might face when sharing the news.

33. Not long after I started to be seen at the Royal London, I started a treatment trial of Interferon and Ribavirin for 48 weeks. This involved Interferon injections and Ribavirin tablets. I had to inject myself in the stomach once a week and take tablets daily. I was also asked to start taking the antidepressant Mirtazapine, as there was a high likelihood of becoming depressed on the treatment.

34. I had weekly monitoring and blood tests at the Royal London during this time and they would take about 8 vials of blood each week, although I don't know what they were testing me for. I saw a specialist HCV nurse, Tracy, who was great and very supportive throughout this process.

35. Being on the HCV treatment was like being on cancer treatment and I constantly felt like I had the flu. I looked so unwell and could barely eat. I had headaches and fever and just felt awful. My mental health deteriorated and I felt a bit suicidal at times, although I would never have done it because of my children. I felt like a walking zombie.

36. I remember bumping into a local hairdresser I had known since I was young, and she thought I was dying. I looked so grey and frail. My friends worried about me but I didn't want to tell them what was going on as I was convinced they wouldn't want to know me. They would call GRO-B to ask what was wrong with me, and she would have to lie on my behalf.

37. My daughter GRO-B had to accompany me to my hospital appointments, as I couldn't manage the journey into London myself. She had to make arrangements for her 2 children which meant her partner would often have to take time off work, which involved financial loss.

38. Finding the train fare for both of us to get to the hospital every week wasn't easy. I had stopped working when I started the treatment due to the impact it had on my health, so I was managing on disability living allowance. At one point, DWP cut my money and I was living on just over £50 a week which was very difficult. When they eventually adjusted it, GRO-B said I could claim back the difference but I couldn't deal with the stress of it.

39. I felt very alone during the treatment, although my daughter GRO-B called me every day. Sadly, GRO-B was in a relationship at that time that involved domestic abuse and she was not allowed to see me. We would only see each other every 6 months or so, which was awful. She only came to one hospital appointment when GRO-B couldn't make it, and she had to beg her partner to allow her to do this. It was a horrible time.

40. One day GRO-B and I were at the hospital, queuing up at the pharmacy to get a prescription. Tracy saw me and said that I didn't look well at all, and decided to take my sugar levels which were very low. She told me that I should try and eat whatever I could manage and said to eat little and often. GRO-B stocked my fridge with rice pudding and fruit jelly, as this was all I could eat. Eating was often making me sick, which I hated, so I was afraid to eat.

41. I recall having a dizzy spell in the bathroom during the treatment, and GRO-B got one of her close friends to come and sit with me. She was very worried about me in general and said that I looked like I was on death's doorstep. She is still haunted by this time as she just saw me deteriorate and was worried I wouldn't get better. She just wanted me to be her old mum again.

42. I completed the 48 weeks of treatment and Tracy told me that I had cleared the HCV infection. She said that I was actually showing to be clear of HCV after about 3 months on the treatment, but they didn't tell me this at the time as they wanted to make sure I would complete the treatment. Since completing the treatment, I have had no check-ups whatsoever on my liver.

43. My diagnosis with HCV and my treatment has emotionally impacted myself and the girls. I think it was hard for them to know their mum was living with this thing. GRO-B did rebel and she feels that she made bad decisions because of this. GRO-B as the eldest daughter took on a more adult role in our household and became very protective of me. I think she lashed out at GRO-B for how she was acting and it took them a long time to build a relationship and to start talking again.

44. After the treatment and being so ill for almost a year, I felt like I lost confidence in myself that I have never gained back. I find it difficult to deal with things like sorting out bills and speaking to people, which was something I was strong at before. Even when I received a letter from the Infected Blood Inquiry, I asked my daughters to help me deal with it as I just don't know how to handle things anymore. I fret over things even though in the past I would have taken it in my stride. I was worried about this witness statement meeting as I didn't know what to expect and I felt worried that I might not remember everything.

45. After completing the treatment, I worked for a company called GRO-B GRO-B that started out as a cleaning business but then went into the field of providing care. I worked as a carer there for a number of years and did not disclose that I had undergone HCV treatment, as I was now clear. I also took all the necessary safety precautions and always provided care to patients in a safe way, so I would never be a risk to anyone and equally would never be put at risk if a patient had an infection.

46. After this caring job, I worked in Sainsburys for a year, which was very boring and tedious. I then decided to stop working as I just became too weak and

unwell. I do volunteer at a charity shop one afternoon a week, but I can't do any more than this due to my poor health.

47. More recently, I told my best friend about my HCV and the treatment I went through. She was more shocked and angry at the fact that I kept it from her for so long, as she would have wanted to support me through the process. I just did not think that anyone would want to be there for me if they knew about the HCV, although my daughters said this wouldn't be the case.

48. Since the HCV diagnosis and treatment, I have had a number of health problems. As I mentioned above, I have arrhythmia which is caused by a congenital heart defect that was diagnosed in 2010. This meant I had an extra heart passage. I had to have a surgery called ablation where they pass a wire up through my groin to cauterize this extra passage.

49. In 2013, I went into Whipps Cross Hospital due to unstable angina. I was in hospital for 2 weeks and was transferred to Barts Hospital where I had 3 stents placed. This has left me breathless and I feel like I wouldn't survive Covid if I caught it. I'm not sure if the HCV or any problems with my liver have affected this.

50. Around 5 years ago, I went on a group holiday to Weymouth with my friend and one night I thought I had bad indigestion. It became really bad through the night and I had to wake up my friend. I ended up in Hospital in Weymouth and was diagnosed with a gallbladder problem and I had lots of gallstones. No one mentions that gall bladder problems can be linked to HCV, but I do believe that it could be linked.

51. The doctor at this hospital also said that I had 3 cysts on my liver and I told them this was good, as I had previously had 5! I have actually felt when cysts have burst in the past, as there is a pop and an uncomfortable burning sensation.

52. The Hospital in Weymouth wanted to operate on me then and there to remove my gallbladder, but I said absolutely not as I wanted to finish my holiday and only stayed in hospital for 24 hours. When I came home from the holiday, I got in touch with my doctors and I was referred to Whipps Cross Hospital. GRO-B recalls the doctor saying that people with the 3 F's are more likely to have gallbladder problems – 'fat, female and fertile', which isn't very tactful. I had my gallbladder removed not long after this.

53. I also discovered about 3 years ago that my body does not produce B12. This means that I have to have painful injections every 2 months at my GP surgery. I'm not sure if this is related to HCV but it was discovered during a routine blood test. I think I had this for quite a while as I was suffering from debilitating tiredness, even after clearing the HCV. I have also suffered from a mini stroke.

54. Even though I have cleared HCV, it still feels like I have it. When I am in hospital, the first thing on my notes in the folder at the end of my bed is that I have HCV. Knowing that a doctor or nurse can pick up these notes at any time and find out about my HCV makes me feel very uncomfortable and worried.

55. Even on my hospital discharge sheet it said I had HCV, which makes me angry as I am clear. When I have a blood test it says on the form that I have HCV and I have seen a yellow sticker on my notes to show I am an infection risk. This has an ongoing effect on my mental health and I feel angry that I have to feel like this even after going through the treatment.

Section 6. Treatment/Care/Support

56. All the doctors and nurses I have dealt with have been okay in relation to my HCV. Tracy, my specialist HCV nurse, was great and very supportive. The Royal London was a fantastic hospital and I really cannot fault them. If I had stayed at Addenbrookes Hospital, I wonder if I would have ever been offered treatment.

57. When I went to the Royal London clinic for my HCV treatment and monitoring, there were lots of posters and signs in the clinic about various STDs and I felt a bit conscious about people watching me go into the clinic, as they would make assumptions about why I was there.

58. Due to the mental impact the treatment was likely to have, I saw a therapist at the Royal London, although I barely recall this. GRO-B attended these appointments with me and remembers this in more detail, and she felt it was very helpful for me. Apparently, I had to dredge up quite a lot from the past but I was so out of it while on the treatment I just can't remember this.

59. I was made to feel like a leper when I was refused treatment by a dentist due to my HCV. I had read somewhere that I should inform my dentist about the HCV, and wanted to make sure I did this. He told me he could not treat me which was very embarrassing and upsetting. I had to go to the Royal London dental hospital whenever I needed dental care. When I explained that I had been refused treatment, they were brilliant and said they would treat me with no issues. Now I go to a normal, local dentist and they have been fine.

Section 7. Financial Assistance

60. During my first visit to the Royal London, the doctor treating me asked Tracy to give me information about the Skipton Fund, as he believed I had been infected with HCV through a blood transfusion. If he had not mentioned this, I would never have known about the Skipton Fund. I had to contact them and get the relevant forms sent to me.

61. I made my application to the Skipton Fund on 24 February 2007 and my doctor filled out the form. (**WITN4884004**) The Skipton Fund rejected my application and said that I needed to provide medical records showing my blood transfusion, as there was not enough evidence to support my claim.

62. By then, GRO-B Hospital had closed and I could not get records from them. I rang Elizabeth Garrett Anderson Hospital and I said that I wanted to speak to

someone about a blood transfusion I received in 1990 and finding records in relation to this. The woman I spoke to was very defensive and when I told her why I was looking for this information, she said, “there was nothing wrong with our blood supply” and put the phone down. I was so stunned by this I didn’t even call back or follow this up. It was shocking.

63. I have also requested medical records from my GP, but there are huge gaps in my records. There are a few very early records from the late 1970s and then nothing until 2018. I’m not sure if this is because they had not copied over the paper records. I tried to speak to someone at the Skipton Fund in relation to my struggles trying to get these records, but he was not helpful. I was not told I could try and appeal this decision or reapply, so I just left it.

64. My friend’s father in law did receive £10,000 from the Skipton Fund for becoming infected with HCV. I think the Skipton Fund payment was meant to be £20,000 so I'm not sure why he only got half of this. Sadly, my friend has since passed away so I cannot ask him about this.

65. When I received the Skipton Fund rejection, it did create self-doubt in my mind about whether I had been infected through a blood transfusion. Although I had never engaged in any high risk activities for HCV, I worried that I had caught it through sex, but I now know this is extremely unlikely. It felt like there was a complete lack of support through this stressful process and they were doubting the people who applied.

66. I am now aware that the English Infected Blood Support Scheme (EIBSS) has taken over the role of the Skipton Fund. I am considering making an application to them, as any financial support will make a huge difference to my quality of life. I get very upset about money and often speak to my daughter GRO-B about this. I was even worried about paying for public transport to attend the meeting with the Infected Blood Inquiry, as I was expecting my pension money the following day. Money is always tight and I have money worries on a daily basis, which is upsetting given I have worked my whole life.

67. I feel like the government made these financial assistance funds to make it look like they were helping those infected due to contaminated blood, but then made it impossible to meet the criteria to get this money. There should be more support and understanding for people in my position who are struggling to access their medical records.

Section 8. Other Issues

68. I feel that people in a similar position to myself who have become infected with HCV through no fault of their own should get more support. I feel that people with HIV do get a great deal more support than those living with HCV. The only information I received following my diagnosis with HCV was a tiny and vague leaflet, and this was just inadequate in terms of providing information. I would like the Inquiry to advise that more support and information should be provided to those in my position.

69. I was actually very pleased and relieved to get a letter from the Infected Blood Inquiry asking whether I would like to make a statement, as it felt like someone actually cared about my experience and wanted to listen to my story. I hope the Inquiry will investigate the Skipton Fund and make it easier for people to claim financial assistance when they are struggling to obtain medical records that have been destroyed or lost.

Statement of Truth

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

Signed GRO-B

Dated 1/2/23.

Exhibits:

Exhibit number	Description	Date
WITN4884002	Letter to GRO-B from The University of Nottingham – regarding Hepatitis C Research UK and the Infected Blood Inquiry	28 January 2021
WITN4884003	Addenbrooke's Hospital – Hepatology Hepatitis C information leaflet	Undated
WITN4884004	Skipton Fund application form	24 February 2007