Witness Name: GRO-B
Statement No: WITN5191001
Exhibits: Nil.
Dated:

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 11 January 2021

I, will say as follows: -

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1944. I reside in the West Midlands, the full details of my address are known to the Inquiry.

2. I've been married to GRO-B for 52 years and we have a son, GRO-B and a daughter, GRO-B They both live close by and I was brought up approximately three miles away from my current home. I am lucky to have five grandchildren and I look after them regularly.

3. I can confirm I am not legally represented and I am happy for the Inquiry Team to assist with my statement.

Section 2. How Infected

4. I suffered from bowel problems in my late 20s which was later diagnosed as ulcerative colitis. For many years, I dealt with the condition through various medications, including salazapyrine, but it stopped working and I slowly deteriorated. My quality of life was poor and I was steadily going downhill as well as losing weight quickly. This made it difficult to look after my two young children.

5. In October 1988, I was referred by my consultant Dr Montgomery, at Heartlands hospital in Birmingham, to a surgeon Mark Goldman to discuss the course of action for my bowel problem. I was informed there were some options, though in reality there weren't really any options, so I had to undergo an ileostomy operation to remove part of my bowel. The surgeon undertook my initial operation in October 1988 at Heartlands to remove my ulcerated bowel.

6. I was hospitalised for three weeks prior to my first operation and led to believe that four pints of blood were administered, to prepare me for the surgery. I have no idea if this is true, although, I do remember seeing the blood bags. My parents, husband, and even I, remember the bags hanging there. I can visualise this now. Post operation I spent around three weeks in hospital, which was a long time to be away from young children.

7. Following the first operation, I had two stomas fitted and had to deal with this for approximately three months until I was due for my second operation. This operation was performed by the same surgeon at Heartlands and he re-joined my bowel. Unfortunately, I am still left with one stoma, unable to escape the lifelong implications of two ileostomy operations.

8. In 2014, I made an appointment at my local GP surgery. I don't remember exactly why I needed to see a doctor, but I must have been feeling under the weather. I didn't see my usual GP, Dr GRO-B instead I saw a locum Doctor whom I was not familiar with.

9. In the consultation I was asked if I had ever had a test for hepatitis C, or any tests on my liver. I thought this was strange as this was the first-time hepatitis had ever been mentioned by a doctor. The locum Doctor stated hepatitis C was very prevalent in Europe, but that it is not commonly tested for here. He suggested I went for a test and it came back positive.

Section 3. Other Infections

10. To my knowledge I was never infected with any other viruses, or diseases as a result of my blood transfusion in 1988.

Section 4. Consent

11. In 1988, and by the time I was hospitalised, I had reached such a low point. My health was on the edge and the bowel operation was the last resort. I don't remember being asked for consent to either the blood transfusion or the operation, but it was lifesaving, so I had to go ahead with it.

12. I was not in a position to question the blood given to me, especially as the consultants at the end of my bed told me what to do. You have to trust the medical professionals and put faith in the people at the end of the bed.

Section 5. Impact

13. I was diagnosed with hepatitis C in 2014, despite having been infected over 26 years ago in 1988. The biggest shock is that I was in hospital numerous times during that period; once in 2000 following a head on car accident; and again in 2014 with kidney failure. They tested my blood for lots of things, however nobody knew I had hepatitis C.

14. Approximately seven years ago, I was diagnosed with kidney failure. I think I caught a bug from my grandson, as I was experiencing severe sickness and diarrhoea. I was so terribly ill: unable to keep any liquids down, and was on the edge of unconsciousness. I cannot remember the ambulance journey, nor arriving at hospital.

15. I was admitted to Heartlands hospital and placed in an intensive care ward. At one point I stopped breathing completely and my son remembers the doctors asking him, and the rest of my family to leave the hospital room.

16. To my mind it seems logical that when a patient is presenting with serious kidney failure, it would make sense to do tests across the board. I don't understand why they didn't test comprehensively to help determine what the root of the problem was. There could have been other causes. If you are as ill as I was it would seem reasonable to test for everything.

17. Currently, I know from periodic scans that I have a cyst on one kidney and something on the other one. However, I am assured it isn't dangerous as it develops naturally with age. There is no medication for this.

18. I cannot comprehend that I was in hospital twice in 1988, once in 2000, and again in 2014, and nobody knew I had hepatitis C. I had numerous tests and they still had no idea.

19. I suppose finding out about hepatitis C is like finding out about cancer, particularly because I led a completely blameless life; I do not drink, I've never taken drugs, I'm teetotal; and I don't have any tattoos; nor have I been

in multiple sexual relationships. I led a clean and healthy life, so it was a massive shock to me.

20. When I was on treatment for hepatitis C it was very difficult to get out of bed in the morning, as I felt so unwell. During this time I didn't feel myself; I struggled living in a big house with a big garden, as I could no longer enjoy them; and the side-effects of the treatment were horrible. This really knocked the stuffing out of me.

21. As discussed in the section above, I was relieved I was chosen to receive the expensive hepatitis C trial treatment. I was told that a significant amount of hepatitis C sufferers wouldn't receive the new drug.

22. I used to wonder how many of the other patients had been given the opportunity to have the treatment as I know it cost a lot of money. However I felt I was entitled to be given the drug. I fitted the criteria of someone who deserved it.

23. The treatment was tough and it made me feel awful, but knew I had to tolerate it as I had no choice. The approach I took was: 'you have to grin and bear it'. The sooner I finished the treatment, the better.

24. At the time I began my treatment, I continued to look after my grandchild as my daughter needed help.My grandson is a boisterous chap which made it difficult to look after him. Fortunately, my husband was here to help, nevertheless, I found it much harder to look after small children. It was also terrible knowing I had to complete six months of interferon and ribavirin treatment.

25. I am very privileged because I am still in contact with school friends and I speak with them most days. During my treatment and when I was in the mood they came to visit me. It truly does affect you as a person. There were times when I really didn't feel myself, so I didn't want to go out. Everyone was understanding, but I am not one to broadcast personal information. I

was grateful for friends stopping by or calling to check in, but it gets to a point when you don't want to talk about it anymore.

26. It's my character to keep things to myself and being infected with hepatitis C is a personal thing. People are afraid of hepatitis C and worry it's contagious. I only discussed my infection with close friends: those in my intimate circle.

27. I cannot emphasise how shocking it was to find out, 20 odd years later, that I had hepatitis C. I regularly visited the hospital and was critically ill at one point. They tested my blood for everything, yet hepatitis C was not considered. Taking into consideration the locum Doctors' comment, they should have tested for hepatitis C much earlier. How could they not have known I was infected?

28. There is no question that I now have liver damage, even though I have cleared hepatitis C.

29. There were no financial implications for myself or my husband. I never worked. We sold our property in Spain and now we visit Cornwall two to three times a year as a family. As such, I haven't needed holiday insurance. We are well travelled.

30. My husband often says that 'I cope'. I had a very tough father; he was in the army for six years; and we were taught to get on with it. It may be wrong to say, but I am a tough cookie. I am intolerant of weak people.

31. My tough disposition does not lessen how I felt or how my infection affected my life, or the mental trauma it caused me. It's constantly at the back of your mind, which is why I won't read articles about it. I won't look at newspapers that discuss the blood scandal, because it's too painful. This has been going on for many years and it's still not sorted. When the Investigator rang me, my initial response was 'oh god'. I find it difficult to continue living, whilst knowing about what happened to me through no fault of my own. It is so deeply buried in you.

32. I found it very painful to write the notes I prepared for the Inquiry.

33. My daughter was particularly concerned and worried about me. I'm close to both my children and they were worried. My daughter is a lovely girl, so I only have to pick up the phone and she will be here.

34. I wasn't reliant on others. At one point, I hired a gardener to help me, but he didn't come up to standard and I let him go. I live in a conservation area on a private road and I have lots of trees in my garden, perhaps it was too much for him.

35. I am a member of the RHS and go to Chelsea every year. I go the day after the royals with my daughter, as we both do a lot of gardening. I really enjoy this event.

36. I have never been offered any psychological or counselling support by the NHS. I have my own support mechanisms: one friend acts as my confidant. We are on the same wavelength as she's experienced health problems too.

Section 6. Treatment/Care/Support

37. Following my diagnosis in 2014, I attended a research unit at Heartlands Hospital. I remember a Doctor whom I was unfamiliar with, asked if I would give permission for the unit to use my blood in their research. I recollect the Doctor saying it would be sent around the world. I didn't question it, so I agreed.

38. I was referred to the liver consultant, Dr Daley. My first consultation was very difficult, as I found it hard to absorb what she told me. I was in such shock; I could have fallen out of my chair. It was very difficult, because many doctors had seen me and had no idea I was infected with hepatitis C.

39. I remember the conversations with Dr Daley; she simply gave me the plain facts.

40. In terms of advice, I was never provided with any information on how to manage the infection, but I was told to inform my dentist and not to have sexual relations outside of my marriage. I was asked about sexual partners, drug use, drinking habits, sharing anything including toothbrushes, and whether I had any tattoos.

41. I have a letter from Dr Daley which I find very painful to read, but in it she states: "Mr GRO-B attended the clinic 10 march 2014 and saw Dr A Daley. She has genotype 3 cirrhosis, and we talked about potential treatments. I have explained she can start treatments immediately, interferon injections twice a week, ribavirin tables for 6 months, but chances of cure are in the order of 50%. I informed Mrs GRO-B hat there are new treatments, although they are not yet available for use in the UK. We hope they will be available by the end of the year, however, since you have cirrhosis, you will need interferon with these new drugs, still only 65% chance of cure".

42. Dr Daley told me the side effects of treatment were very unpleasant. I was also informed about an on-going hepatitis C trial being undertaken at Queen Elizabeth Hospital in Birmingham. She led me to believe that the trial was very expensive and I seem to remember a figure of £35,000 being mentioned. There were only a select group of people chosen for the trial and Dr Daley gave me the green light. Supposedly, the trial drug was revolutionary and I was under the impression it was something they had been waiting for.

43. Dr Daley never elaborated on how I might have contracted hepatitis C, but delved into my lifestyle and whether there could be anything suspect in that regard. She asked if I had ever received a blood transfusion, to which I answered '*yes*'. In fact, it was the only question I answered '*yes*', so I felt it was obvious.

44. I must have told Dr Daley about my child care commitments and how I worried about feeling unwell whilst looking after my grandchildren, because

she used to say, 'you're the lady that likes children'. She knows I have an affinity with children.

45. In terms of on-going treatment and care, I have routine liver tests and screening. In the event that a tumour develops, Dr Daley would say, 'we can catch it early'. From that point onwards, she took my blood every time I went to the clinic and screened my liver.

46. I started with interferon and ribavirin for approximately six months from March 2014, tablets every day and weekly injections. In and around September 2014, my husband remembers I was given Sovaldi. Once it was approved it was called sofosbuvir. Each time I took a tablet, I then had a blood test. The sheet of paper that came with the new drugs was three foot by three foot and there was a number to ring, 24 hours a day, because of the severity of the side effects.

47. Ultimately, the NHS is responsible. Dr Daley always spoke about hepatitis C in a matter of fact way. I've met her a few times now, I like her, she is cool, calm, and collected.

48. Over the course of 2014/2015, I saw a sister at the research unit in Heartlands hospital. She was very understanding, sympathetic, and emphasised I could always get in touch. She told me the treatment for hepatitis C was very similar to chemotherapy. It truly was awful but worth it.

49. In more recent times I don't see Dr Daley. I see a younger man, a gastroenterologist. He usually asks me how I feel and tells me what the scans and blood tests show. This is the extent of the conversation I have with him.

Section 7. Financial Assistance

50. I became aware of the Skipton fund through Dr Daley. She advised me to obtain my medical records, as I had a blood transfusion in 1988. In 2014 I

rang my GP to enquire about accessing my medical records, however I was told they don't retain medical records beyond 2000. I also rang Heartlands hospital where I similarly hit a brick wall.

51. I also spoke to my GP's son who practises at the same surgery. He hadn't dealt with anything like this before and he didn't know how to obtain my records. At this point, I came to a dead end.

52. I was rejected by Skipton and the letter read, 'we received your completed application form, unfortunately that there are no medical records available which show you received NHS blood or blood product'. I find this totally laughable, as they clearly hadn't researched the questions that they put to me. I believe the onus should be on Skipton to find the records. How can I be expected to do the research? The hospital where I received blood products destroyed my records and my GP couldn't help.

53. The letter provided some information regarding the appeal process, but where could I go with that? I have no records and I exhausted all avenues to find them. I had no further information to provide, so I've decided to lock this away in my mind.

54. It is incredible when you think about it. I have to prove something that happened to me. It is ridiculous, because they tell you it didn't happen and I have no power to prove that it did. I gave up as there was nothing more I could do.

Section 8. Other Issues

55. I told my dentist about my infection in 2015 and within six months I was cleared of the virus. I don't have to disclose this now, as I don't have it. In fact I'm not on any medication across the board.

56. This whole thing is a very sad state of affairs; people have been through hell
and the same people have to continue their journey through hell to prove
57. innocence. It doesn't end. I find it hard to believe this happened and is
happening in a civilised country.

58. I want this to be put to bed and the NHS to acknowledge their part in this whole thing. All these people were innocent and simply did what the experts told them to do. They purchased infected blood products and gave it to innocent patients. It was malpractice. After all this time, I have to fight to prove that's where it came from.

59. This has not disappeared. It has only opened up old wounds. I trusted the NHS and something they gave me, changed my life.

Statement of Truth

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

Signe GRO-B

Dated 1st March 2021.