

Witness Name:

GRO-B

Statement No.: WITN5889001

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 4 August 2021.

I, GRO-B will say as follows: -

**Section 1. Introduction**

1. My name is GRO-B. My date of birth is GRO-B 1954 and my address is known to the Inquiry. I am a widow and have three sons and seven grandchildren. One of my sons still lives with at home with me. Before my children were born, I worked as a GPO telephonist for 7 years - operating, connecting, and redirecting calls.
2. 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 family's lives together.
3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. I wish to be anonymous.

**Section 2. How Infected**

4. In about 1981/1982, I had an ectopic pregnancy. I underwent surgery for this in Basildon Hospital and during the procedure I received transfusions of blood. As the ectopic pregnancy had ruptured, I lost a lot of blood internally, approximately 1 ½ litres, and I recall the doctors telling me that they were there to save my life. I am not aware of consenting to the blood transfusion, I just remember coming back from theatre with a blood bag attached to me.
5. As I was unable to get pregnant naturally, I had several rounds of IVF, about 12 in total. The first location was at GRO-B under Dr. Patrick Steptoe. I then moved to the Royal Free under Professor Ian Craft, then the GRO-B GRO-B again under Professor Ian Craft, and finally the Lister Hospital under Sam Abdalla.
6. Despite all the attempts at IVF with successful embryos, there were no pregnancies. A treatment was consequently suggested where I would receive white blood cells from my husband in order to conceive. I was not warned of any risks of this procedure. I had my husband's white blood cells given to me on at least seven occasions at St Mary's Hospital Paddington under the care of Professor Mowbray and Dr. Jenny Underwood. These all occurred in the 1980s.
7. This treatment did enable me to get pregnant. I went on to have another ectopic pregnancy in 1984/1985 which led me to pass out. I underwent surgery in GRO-B Hospital for this, and was given transfusions of blood before surgery. I later suffered 2 miscarriages, the first at 11 weeks where I required a dilation and curettage procedure (D&C) at GRO-B Hospital. Again, I received a blood transfusion. The second miscarriage happened at 20 weeks and again, I needed a D&C and blood transfusion, this time at Basildon Hospital. I finally went on to have three children.
8. My first child was born in 1989 with Biliary Atresia - a children's liver disease, which resulted in liver failure and a liver transplant. I question whether this

## ANONYMOUS

was a result of the HCV, as I definitely had contracted it by this stage, but I was not yet diagnosed.

9. In 2000, I was getting lots of indigestion pains and was constantly taking antacids. I was also experiencing extreme fatigue, aches and pains, itchiness, and was generally feeling run down. I went to my local GP practice (Dr GRO-B) and the locum GP there ran some blood tests. The liver function results were elevated so I was screened for all the hepatitis diseases, of which HCV came back positive. I was unaware at the time of how bad HCV could be. I was not provided with any advice regarding my infection at this point, and I remember the locum GP being quite reassuring that HCV was not that bad. My GP referred me to see a gastroenterologist at Basildon Hospital.
10. In January 2001, I attended the appointment at Basildon Hospital. I cannot begin to tell you how I felt. My eldest son, who was 12 at the time, came with me. The doctor did not carry out any examination, but stated "well by what you have told me that these transfusions took place in the early 80s, you have had HCV for about 17 years and people only usually live for about 20 years with the infection." My world fell apart. I was truly devastated. It was a living nightmare. I had 3 lovely children, what was going to happen?
11. The information given by this particular doctor was quite inadequate. I was given no prior warning as to who to take with me, and it made it worse having my 12-year old son present to hear the prognosis. Furthermore, I remember being given a form to take to the ultrasound department, but when I returned the next morning with my husband, I was told there was a waiting list of at least 6 months. We came home and abandoned all of the follow up with Basildon Hospital, and phoned my son's paediatrician, Dr. Gabby Jamieson, at Addenbrookes.
12. Dr. Jamieson kindly contacted Dr. Graham Alexander (HCV consultant at Addenbrookes) and told him about me. I was given an appointment to see him and nurse specialist, Tracey Woodhall.

## ANONYMOUS

13. On that appointment, my husband attended with me. Dr. Alexander reassured me that he did not agree with the 20-year prognosis and arranged for me to have a liver biopsy, endoscopy, and ultrasound scan.
14. At that visit, after explaining to Dr. Alexander about all the blood transfusions that I had received and about the white blood cells that were transfused from my husband, Dr. Alexander asked if I had ever taken intravenous drugs, to which I replied "no" (which truly I have not). I do not drink or smoke either. Dr. Alexander then asked my husband the same question. To my shock, he said that he had a couple of times as a teenager. This was never asked by St. Mary's Hospital before this treatment was done.
15. Dr. Alexander then arranged blood tests for my husband, which came back positive for HCV. I question whether he got the HCV from injecting heroin on 2 occasions or whether he got it from me because if I cut myself he would
  - always suck my cut. I cannot pinpoint whether my HCV came from the blood transfusions or the white blood cells from my husband. Either way, it was given to me by the NHS.
16. Not long after seeing Dr. Alexander, Dr. Jamieson arranged for our three children to get tested. Luckily, they were all negative.
17. I was at no time made aware that I was a risk to others or the risks of cross-contamination. However, I did my own research into HCV and made sure my children did not use my nail cutters, toothbrush etc. I may have picked up a leaflet on the virus when I was referred to Dr. Alexander.

### **Section 3. Other infections**

18. Apart from HCV, I do not believe that I received any other infection from infected blood. I was tested for HIV after my HCV diagnosis, and luckily this came back negative.



## ANONYMOUS

19. I did contract Hepatitis A "HAV" as a child (around the age of 7), but my immune system cleared the infection naturally. When I was screened again in 2000 the result was negative.

### **Section 4. Consent**

20. I did not consent to any blood transfusion I received.
21. My second ectopic pregnancy occurred during the HIV scandal period. I passed out in the ward and when I woke up ahead of surgery, a bag of blood was already attached to me. When I went down to theatre, I recall saying to the anaesthetist, "this is worrying me", to which he replied, "oh you've got nothing to worry about here, if you were in America it would be a different story." I was not warned by any medical professional that there was a risk of infection from receiving a blood transfusion, but from watching the news I was aware that HIV could be transmitted via blood.
22. I consented to receive the white blood cells from my husband and to be tested for HCV. I do not believe I was ever tested for research purposes.

### **Section 5. Impact**

23. Prior to my HCV diagnosis, I experienced pain across my stomach and horrendous pain in my liver on and off. I also suffered with constant heartburn and would often feel itchy.
24. When I found out I had HCV and the gastroenterologist at Basildon Hospital said that people die after 20 years of contracting it, I was devastated and my world fell apart. We had a family holiday to Lanzarote not long after my HCV diagnosis. I remember being on the beach with my husband and children thinking I probably would not be here this time next year. I wondered how my husband would cope with the children? We went through so much IVF, miscarriages, and ectopic pregnancies to get these babies. I wondered how he would manage with my eldest son's medication and his hospital

## ANONYMOUS

appointment. It traumatised me and the worry was so intense. Especially because as a mum you do not think anyone else can look after your children the way that you do, even your husband. I remember being very sad during this period.

25. Following the visit to Dr. Alexander at Addenbrookes in 2001, I had a liver biopsy, which confirmed my liver was scarred but in an "ok" condition. Fortunately, the ultrasound and endoscopy were good. I then went on to have 3 monthly check-ups. I was having a lot of nose bleeds and bleeding gums during this time.
26. The biopsy was terrible, and I found it hard to breathe. The doctors could not locate my liver during the first try and I was in excruciating pain as they kept on stabbing me. In the end, they had to leave it and arranged for me to have another one a few months later, guided under ultrasound. It took me a while to recover and I had pain in my shoulder and liver for a while afterwards.
27. My sadness eased somewhat after I saw Dr. Alexander at Addenbrookes, but I still worried all the time. I would say my nerves were shot to pieces.
28. In 2003, I became aware of a ringing in my left ear (tinnitus). I cannot tell you how badly this affected my life. I went to see endless doctors at **GRO-B** Hospital, Private Nuffield Health, and Addenbrookes. Dr. Grey, an Ear, Nose, and Throat consultant at Addenbrookes believes my tinnitus was due to my low platelet count, caused by the HCV infection.
29. At **GRO-B** Hospital, they made me a masking device to fit my ear, but I basically swapped one noise for another. At Addenbrookes, they arranged for me to see a counsellor, Dr. David Baguely, who gave me strategies to try that did work to an extent.
30. I went on to have horrendous panic and anxiety. I could not keep still and I was terrified to go out. I had head spins during which I felt as though I was in another dimension. Everything would feel as if it was going fast and I felt like I

## ANONYMOUS

was about to die. I could not sleep, could not eat and I was constantly on the toilet. I did something called the Linden method which helped me, but to this day I still have anxiety.

31. Two of my three children suffer from anxiety and they worry that they are always ill. I think this is learned behaviour from me, because of the trauma I have suffered.
32. In 2006, I had another liver biopsy which showed my liver had progressed to cirrhosis (stage 6). This was confirmed during a clinic appointment at Addenbrookes, where I saw a registrar. It was another one of those turnouts where the doctor had a terrible approach to things. His attitude was very insensitive. I asked him, "am I going to die", to which he replied in a not convincing voice, "not imminently". My husband was outside the hospital waiting for me in the car and because I had been so long he came to find out what was going on. I felt like I was having a breakdown. He took me to find Tracey Woodall, nurse specialist, who calmed me down. A few days later my blood results came back positive for Primary Biliary Cholangitis (PBC) – a chronic liver disease resulting from progressive destruction of the bile ducts. Addenbrookes explained that having two liver diseases had exacerbated my liver to become cirrhotic. HCV being the aggravating factor. To control the PBC, I was given a drug called ursodeoxycholic acid.
33. I do not know why I have PBC. There is no family history of this, but no one has ever confirmed whether it is genetic, autoimmune or whether it kicked in because of the HCV.
34. If the PBC was not caused by the HCV, I would have had this illness and kept it under control by the ursodeoxycholic acid. My liver would be fine, but the HCV was very aggressive, and now I have cirrhosis which has caused me lots of problems.
35. I continued to have 3-6 monthly check-ups, tests, ultrasounds, endoscopies yearly, MRI scans, DEXA scans, and blood tests.

## ANONYMOUS

36. I suffer from bleeding from my rectum from time to time. I had a colonoscopy which showed I have varices there. I have regular endoscopies because I have varices in the oesophagus caused by the liver.
37. I have also had ulcers in my gut that have needed treatment on 2 occasions. My digestive system is not good. I always have belly aches, diarrhoea, nausea, fatigue, itchiness, dry eyes and mouth, and suffer from anxiety and panic attacks.
38. Cirrhosis causes bone loss and I have osteopenia and osteoarthritis and have regular DEXA scans. I get lots of aches and pains. I broke my arm approximately 3 months ago and I was told during a telephone consultation with Dr. Mells that I am more susceptible to breaks and fractures as a result of the osteopenia and osteoarthritis, brought on by the cirrhosis. I have a DEXA scan booked for the 1 October in relation to this. The cirrhosis also causes a deficiency in iron and vitamin D. I receive a prescription for Iron tablets and Calci D from my GP and purchase additional vitamin D tablets.
39. I also suffer from brain fog as a result of liver cirrhosis and I do at times forget things, I am unable to focus, I cannot think of the correct words and get mixed up.
40. I have an enlarged spleen and portal hypertension.
41. I now have low white blood cells and recently had an appointment with Dr. GRO-B during which he referred for a bone marrow biopsy at Addenbrookes.
42. In April 2010, I had an accident with wire whilst feeding a horse. The wire lifted my eyelid and cut it, which required a stitch. Because of my low platelets caused by the HCV and my cirrhotic liver, I bled more than normal, but the hospital GRO-B did not give me a lateral cantholysis as they should have done and I have lost the vision because of this in my right eye.



## ANONYMOUS

43. Further to this, I had a tooth out in Southend Hospital as I needed a platelet transfusion before the procedure. After having the tooth extracted, I bled very badly. I was in excruciating pain but the doctor sent me home. I had to return immediately because I could not control the bleeding. They kept me in and had to send for a doctor from Basildon Hospital to put in stitches at about 1 am in the morning. Even after the stitching, I continued to bleed and I had to sleep for a week sitting up biting on something to stop the blood flow.
44. In 2012 I had one episode of atrial fibrillation. The consultant at Basildon Hospital told me it was down to stress. I was given a daily tablet to always take called Bisoprolol. But earlier this year Dr. Mells, my hepatologist at Addenbrookes, changed Bisoprolol to Carvidello twice daily as he said it helps with Portal Hypertension and more varices forming in my oesophagus.
45. There were very toxic treatments out when I was initially diagnosed (interferon), and even though I wanted it, I could not have it because of my PBC. I carried on getting worse until late 2015/ early 2016 when a new treatment was approved.
46. In response to being told that the medication to cure HCV was unsuitable for me to take, I bought many alternative treatments over the years in a hope of keeping my liver cirrhosis from progressing. I purchased milk thistle and Alpha Lipoic acid from the USA and used the Linden Method for my anxiety. I also purchased some frozen product from Lloyd Wright (in the USA), a natural alternative that was supposed to cure HCV. It was a huge scam and I spent a lot of money in the hope that it would cure my infection. I ended up throwing it away.
47. Coming up to the HCV cure I was grey and my liver function tests were not good. My platelets which should be at least 150 were down to 17. Now they hover around 30 - still bad but a bit better.
48. At the end of 2015, beginning of 2016, I underwent a 12-week oral treatment of Sofisburvir, Declatsavir, Ribavrin and was cured of HCV. I was monitored

## ANONYMOUS

after the first week, and then every two weeks during this period. To confirm, I experienced no side effects during the course of treatment. I continue to have 6-monthly check-ups, endoscopy, ultrasound, and DEXA scans under the care of Dr. Mells, within the PBC, and cirrhosis department.

49. Since 2001 I have suffered with severe anxiety ahead of an endoscopy appointment. The first time I had the procedure, the medical professional made me at ease and I felt it was not as bad as I'd thought it was going to be. However, on another occasion they did not have enough throat spray and my throat was not properly numb before they put the tube down. He shoved the tube down as if he was clearing a drain and I screamed for him to take it out. He was not very understanding and appeared annoyed that I'd asked him to take the tube out. After that incident, further ulcers were found and I had to take omeprazole for some time. I have been petrified since then and at times I have phoned up to rearrange my appointment because I have been so anxious. There is also a risk that varices on my oesophagus could rupture at any time and I could bleed to death, which in turn exacerbates my anxiety of the procedure.
50. Because of the bleeding from my rectum and the constant need to be near a toilet, I cannot just go out. I do not have a social life and live mainly in the bathroom. The illnesses I have developed as a result of the HCV infection get in the way of everyday activities, even shopping for groceries.
51. I feel like I am being held back with regards to what I can do, and the illness prevents me from spending quality time with my children and grandchildren. I find it difficult going out. I get terrible upset stomachs and aches - something to do with the liver and fat absorption.
52. Before my HCV diagnosis, I took part in many activities. However, the infection has now prevented all of that. I get terrible anxiety and feel like I am in a glass dome. The anxiety has had just as bad an effect on my social and personal life as the HCV infection itself did. Because of my infection, I withdrew from my social life, and as a result, I do not get asked out anymore.

## ANONYMOUS

53. I did not tell anyone in my family about my HCV diagnosis apart from my parents and the children. I never told friends, in-laws, etc. Because you have cirrhosis of the liver people automatically think you're a drinker or have taken drugs, even other patients in hospital.
54. As I stopped working when we had the children, my work life was not affected by the diagnosis, but I never felt as though I had the energy to return to work. I never had to tell employers about my infection and I was not stigmatised in the workplace because of this. My husband had to stop working in 2005 due to his HCV infection, at the age of 51. This had a huge impact on finances as a household, and also impacted our pensions. In turn, this impacted the children as we were unable to pay for school trips or extracurricular activities for them.
55. My infection greatly affected my sons. Two of my sons suffer terribly from anxiety and are hypochondriacs. The diagnosis also made my eldest son (who was present during the appointment with the gastroenterologist at Basildon Hospital) very nervous, and he had a constant worry that I was going to die when he was growing up. There was also a talk at his school about HIV and HCV which added to his panic and anxiety.
56. My diagnosis also devastated my husband. He worried as to whether I contracted HCV through the white blood cells I that received from him. It made him really anxious all the time, and he developed cirrhosis as well. My husband also had another circulatory illness and was constantly resting and taking morphine for the pain. Because of this, he was asleep most of the time and lost his fingers and toes as a result.
57. My husband sadly passed away in 2016 at the age of 62. I had to watch him struggle with his HCV infection and its health-related complications. He never received any medication to treat the infection. Although they treated him for sepsis and pneumonia, his death certificate states the causes of death as: 1) pulmonary edema 2) liver cirrhosis 3) HCV.



**Section 6. Treatment/Care/Support**

58. Because I had HCV, professionals saw me differently. When I was in the eye unit in Southend Hospital, I stepped outside the room and a nurse shouted up the corridor, "get back in your room, you should not be out of your room". I asked "why?", and she replied, "you have HCV". I was devastated enough of losing the vision in my right eye without being treated in this way.
59. Furthermore, when I went to a dentist about 14 years ago and I told him I had HCV he nearly crashed all his instruments as a result of jumping back so far. He said he could not deal with my tooth and that I should see someone else.
60. I was offered counselling through the Skipton Fund. I did not use it but it was available. No counselling was offered when I was initially diagnosed with HCV or liver cirrhosis.
61. No counselling was offered to my children or husband.

**Section 7. Financial Assistance**

62. I found out about the Skipton Fund from Nurse Specialist, Tracey Woodall, who gave me a form to fill in. I found the form easy to fill in, and a while after I was referred, I received a letter saying I qualified for payments. Dr Alexander completed a section on the application form and wrote a medical report as supporting evidence. I was later informed of the Caxton Foundation, by the Skipton Fund.
63. I received Stage 1 payment from Skipton in around 2003, and in around 2006, I received a Stage 2 payment from Skipton. I currently receive a monthly amount of £2,390 from EIBSS.
64. The Caxton Foundation has further supported me with one-off grants, some of which I used to purchase a washing machine, dishwasher, and to pay off a



## ANONYMOUS

couple of debts. Small grants were received quickly, but for larger sums of money I would have to wait for the decision of a panel before receiving the payment.

### **Section 8. Other Issues**

65. Having contracted HCV through a blood transfusion, it has totally ruined my life. I had so much trust in the NHS to take care of me, and that trust has now been broken. I feel totally betrayed. The system that I put my trust in just let me down tremendously and some NHS workers dehumanised me for having HCV. I was forced to isolate myself in a room at one of my darkest moments, having lost the vision in my right eye due to stigma and ignorance about HCV.
66. I'm angry at the fact that my life would have been so different if the NHS had not been so reckless. Not only have I had to suffer the consequences of what has happened, my children, my parents, and my husband have also suffered. It has impacted me emotionally, financially, and physically.
67. I would have liked to have given blood and helped others, especially since my son had a liver transplant, but now I cannot. The contaminated blood scandal has taken away that choice.
68. The scandal and my infection make me worried about the future and I do not know what is around the next corner. I still suffer enormously from ongoing problems and debilitating anxiety and mental health problems such as stress and depression. I have to live with ongoing appointments, and just before the first lockdown, I had a Fibroscan which detected very bad scarring.
69. If it had not been for this HCV, I would not have cirrhosis which has caused my low platelets, so I would not have lost sight in my right eye because of substantial bleeding. I was this told by an eye consultant at Southend Hospital.

## ANONYMOUS

70. My story began with me wanting a baby and because of my difficulties trying to conceive I have ended up a mental and physical health wreck whose body has been destroyed by HCV.
71. I feel that this blood scandal which has destroyed so many lives was covered up for years and it's very sad that it has taken so long to get this investigation. A lot of people will have suffered and died before seeing the outcome. I also do not understand why the blood was not screened at the time.
72. I am astounded that something, as described as the biggest and worst medical disaster that this country has ever faced, that has caused so much suffering and death, has taken decades to even begin an investigation such as this one. The Penrose Inquiry came to nothing, and year after year after year, it is not getting resolved. It is truly appalling that so many people's lives have been destroyed at the hand of such reckless decisions of those that we had put our faith in. Many people have tried to preserve our health to the best of our ability, but it has been a very hard struggle.
73. No amount of money will ever compensate for the fact that I have been given infected blood, but I do believe that those infected and affected by the scandal should be substantially compensated.
74. My current medication prescription includes: Artificial saliva spray, Calci-D, Carvedilol, Dihydrocodeine, Ferrous sulfate, Omeprazole, Systane eye drops and Ursodeoxycholic acid.

### **Statement of Truth**

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

Signed

GRO-B

ANONYMOUS

Dated 12<sup>th</sup> OCTOBER 2021