

ANONYMOUS

Witness Name:

GRO-B

Statement No.: WITN6220001

Exhibits: WITN6220002 - 004

Dated: 21 July 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 June 2022.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1962 and my address is GRO-B Leeds GRO-B
2. I am divorced and live alone. I have three grown-up daughters and seven grandchildren.
3. I intend to speak about my infection with hepatitis C ("HCV") and the resultant liver damage. In particular, the history of my illness, how the illness has affected me, the treatment received and the impact it has had on me and those around me.

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4. The anonymity option has been explained to me by the Inquiry investigator. I do wish to be anonymous.

Section 2. How Infected

5. I am the youngest child of six. The brother next to me was diagnosed with Von Willebrand's disease ("VWD") when I was young, before I can remember.
6. My brother and I always played together. We did crazy things such as climbing up trees and such like. As a result of my brother's VWD disease, he was sent to GRO-B in Leeds. This was a special school for physically disabled children. I can remember a minibus used to collect my brother each morning.
7. I went to a normal school like everyone else. It never affected him and we were, and remain, good mates.
8. I have no idea how my brother was diagnosed with VWD. My diagnosis was when I was aged 9 or 10 and had a tooth removed. Afterwards I was bleeding mildly for 2 weeks. I eventually went to hospital where I was then diagnosed with VWD.
9. I can remember my brother and I going on days out organised by the Haemophilia Society. One particular occasion I remember was a visit to a safari park. These all stopped quite suddenly, although I have no clue why.
10. VWD didn't affect my life at all. I am a trained electrician. At work I used to cut myself from time to time on sites. These would bleed but they would stop eventually. I have never had bleeds in my joints. On this basis I believe that I have a mild blood disorder.
11. I may have received factor products when I was a child prior to or after dental procedures, but I cannot say for certain. I have never heard of

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cryoprecipitate, as mentioned to me by the inquiry investigator. My brother and I were told that we had 'plasma'. We never took any factor products to self-administer at home.

12. In March 1984 I went into hospital to have my appendix removed. The hospital knew I had VWD so took my arm and fitted it to a splint with an intravenous drip attached. I was kept like this and administered a constant supply of factor VIII through this drip over my stay in hospital.

13. I had the appendectomy operation when I was 21, and GRO-B I married aged GRO-B in GRO-B. We had 3 daughters together, and did the usual family things i.e. moving house, buying cars and going on holidays. I also used to play football for a local team every week and I did lots of running and cycling. I was like a racing snake, always on the go, and I worked on construction sites as an electrician.

14. My ex-wife and I divorced in the late 1990s. Other than this my life was happy and largely uneventful. I appeared fit and healthy and was working all the time, seven days a week, to pay for two homes and child support.

15. In July 2013 I was on holiday with my then girlfriend. In the 6 months prior to this I had started to notice a few health problems, such as a swollen foot and general fatigue. I put this down to me overworking and just battled on through it.

16. Whilst on holiday I slipped in the pool and developed what was later diagnosed as an inguinal hernia. When I got back from holiday I went to see the doctor and he said there was an 18 week waiting list for the hernia operation. He asked if I was by any chance with Bupa, to which I replied yes, as I was a member of the electrician's union.

17. I went to the Bupa hospital the very next day for the hernia procedure. Prior to the operation, I told the doctor about the recent issues I had experienced with my legs and body aches and pains. He asked me a few other questions and then told me to come back for tests two days

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later. I later discovered that he referred me for tests because he noticed that the whites of my eyes appeared jaundiced.

18. I duly returned to the Bupa hospital two days later and was seen by Dr Mark Aldersley. Dr Mark Aldersley is the consultant hepatologist at St James' Hospital, Leeds, who I presume also undertook private referrals through Bupa.
19. I had a CT scan and 30 minutes later was seen by Dr Aldersley for the results. The doctor said that I had especially bad cirrhosis of the liver. I do not believe that I was tested for HCV at this time, although I used to have regular check-ups with Bupa, including blood tests, every couple of years. At one of my Bupa check-ups I recall being told that my liver function tests were poor, but again I had no idea that I had HCV when I was informed I had cirrhosis.
20. I used to like a drink but I was far from a heavy drinker. I knew that there was no way in the world that the cirrhosis could have been caused by my alcohol intake. I think the doctor probably thought that drinking had caused it.
21. From this point onwards, the 'wheels fell off the bus' and everything started to go wrong. I began to feel really ill and weak but I couldn't afford not to work because of all the bills and child support I had to pay.
22. My company, GRO-B sent me to work at RAF Aldermaston in Berkshire, over 3 hours drive from my home in Leeds. At the same time I had to attend an appointment at St James' Hospital every Wednesday re my liver. I asked the firm if I could be moved to a site closer to Leeds but instead they said that I could get the train there and back the same day.
23. I could hardly walk by this time and I had no appetite. Despite barely eating, I was putting on weight. From the waist down I looked like a balloon but from the waist up I was a skeleton.

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24. Whilst working at RAF Aldermaston, my health declined drastically. I phoned my girlfriend one Friday, when I was due to be returning to Leeds, and said that she had to get me a doctor's appointment for that evening.
25. I was so weak that day that all my work mates had to help me pack my stuff and even assist me getting into the car. I somehow managed to drive home I was also having blackouts during this period.
26. My girlfriend drove me to the doctors that night. It was in December 2013, around two weeks before Christmas. I was seen by a new doctor, a Sikh man, who opened up my file and said he knew exactly what was wrong with me and then said that I had HCV.
27. I didn't know exactly what hepatitis C was. I had heard of it but didn't know much else. I thought at first that it couldn't be too bad because surely hepatitis A and B are worse than HCV. Which just goes to show how much I knew! The doctor corrected my thinking and told me that, on the contrary, HCV was far worse.
28. My impression from this appointment was that the doctors had known that I had had HCV for a while, a long time before I was properly informed of my diagnosis. The GP read my file and knew straight away, which suggests that it had been recorded but I had never been informed or consulted about it.
29. My girlfriend drove me from the GP surgery straight to St James' Hospital that evening. I was laid out on in a ward on a trolley like a beached whale. The doctor came round and asked me how long I had had HCV. I flippantly replied "for about 10 minutes"! When she asked what I meant, I explained that I had just been told I had HCV 10 minutes ago by my GP.
30. The doctor at St James' couldn't believe this. She was staggered that I was just being told of my diagnosis, most probably because of the condition I was in by that stage.

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31. The same doctor then said that she needed to test the fluid in my stomach to see if it was infected. She pulled a long needle out, over 6 inches, followed by a large syringe. The needle was stuck into me and caused me incredible pain. She removed half a pint and found that the fluid wasn't infected.
32. About a week later, having remained in hospital, I was told to lay on one side. I was attended to by the doctor, her assistant and a nurse. The doctor then cut a hole in my side using a scalpel and the assistant pushed a pipe into the hole she had created. This was attached to what appeared to be a deflated football within a cube frame, which collected the fluid that was drawn from my body. The nurse was there to mop up the blood and to help with bleeding.
33. It took 30 seconds for the football to fill up before it was replaced the first time. It then took 5 minutes to fill up again and this repeated again and again for 12 hours. It took 10-12 fill ups the size of a standard football before I was fully drained.
34. The fluid itself resembled urine, which I understand was due to my kidneys failing as a result of my severely damaged liver. I was in a room on my own to reduce the risk of infecting others. I had this draining procedure on 5 or 6 further occasions, over the following months at about 4 week intervals, during which I gradually filled up gain.
35. After I had the fluid drained on the first occasion, I asked the nurse if I could have a shower, there being an ensuite attached to my room. When I came out of the shower I saw myself in a full-length mirror, the first time I had bothered to look at myself. I looked like a skeleton, similar to the poor jews who were kept in concentration camps during world war two. I resembled a 100 year old man and you could see all the ribs in my front and back. You could've hung a coat on my hip bone.
36. I had ignored my declining health up to this point. After seeing the condition I was in, I thought I had months to live at best.

37. At some point around this time, in early 2014, I was put on the liver transplant list. I underwent a full check-up over a two day period to determine whether I was fit enough for a transplant, both physically and mentally.
38. I was assessed by a panel of medics regularly over these two days and they asked all sorts of questions about my lifestyle. I think they were weighing up whether I was well enough to undergo a major operation such as a liver transplant and survive it, ie not wasting a good liver. Thankfully I was deemed to be fit enough.
39. Over this 6 month period in 2013/14 I began to feel like I was going insane. All the poisons in my body caused by my failing organs were beginning to affect my brain. The medical term for this is encephalopathy, as described in **WITN6220002**, a letter from the hepatology department at St.James Hospital to my GP dated 1 May 2014.
40. I started to behave completely out of character. For example, one time at St James' Hospital I got a ticket from the parking machine and was walking to my car to display it. I then blacked out and the next thing I knew I was on the ward in bed. One of the nurses had seen me and took me there but I could not remember a thing.
41. On another occasion, I kicked my girlfriend in the chest. This is unforgivable and is totally alien behaviour for me. I am ashamed of it. I was shouting at her telling her to get me out of hospital, and when she said that she would take me home tomorrow morning I snapped and started shouting and eventually kicked her. I feel awful about this episode but it shows how badly I was affected. I was going crazy, convinced that I was going to die.
42. I was called for a liver transplant three times before I was finally admitted. On the first occasion, around October 2013, I had not yet been

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diagnosed with HCV. Someone phoned me at home around 3pm and we drove to the hospital and went straight to the hepatology department. When we arrived, no-one seemed to know about it. I said that I had come for my transplant but they didn't know anything about it. They said it was a misunderstanding and I just went home.

43. The second time I was called, I was in hospital. A nurse came to see me and said they had a suitable donor and I should not eat or drink. They then found something wrong with the 'new' liver so the operation was aborted.
44. On the third occasion, I was in hospital again and the nurse came to me in the middle of the night and told me to go nil by mouth. In the morning I was given a bottle of shampoo with disinfectant in it. I was told to thoroughly clean every part of my body.
45. When I came out of the shower my girlfriend was crying her eyes out. She told me they had cancelled the transplant. I had my gown on all ready to go. I was resigned to dying.
46. Around 2 or 3 weeks after that on 05 August 2014, I finally had the liver transplant operation. The same thing happened and I was called in for the operation. I was warned that I shouldn't be surprised if I woke up and discovered that they hadn't been able to change the liver for whatever reason, obviously to manage my expectations.
47. When I woke up, I felt like I had been cut in half. It was as if the lower half of my body was disconnected from the top half. I was probably still under the effects of the morphine. The nurse was at the end of my bed and told me they had transplanted the 'new' liver and it had been successful, as far as they could say at that point. I was beyond relieved.
48. Two days or so later, a social worker came to see me. She explained that I would probably get depressed and also warned me that I would feel guilty. I asked why and she said that it just happens. Thankfully I have never experienced depression although I have felt guilty that I am

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still here when others much younger than me have died. I lost a cousin and this had a profound effect upon me. I had been resigned to an early death and I felt guilty in some ways that I had survived.

49. Another event gave me a serious scare around 6 weeks prior to receiving the liver transplant. I had recently had an endoscopy that showed my stomach lining had eroded because of my liver failure. It was explained to me that liver damage turns my stomach lining from sponge into varicose veins, which bleed and thus causes internal bleeds.
50. One night I had a mouthful of food, which was the first food I had consumed in ages. I was violently sick in the night and vomiting blood. I was also passing blood through diarrhoea.
51. In the morning my girlfriend went to work from my house. She later returned home to check on me. I was on the sofa under the duvet because I was always cold. She woke me up and said we needed to go to the hospital. I lost my temper and as I was on the way to the stairs to collect my overnight bag I collapsed.
52. An ambulance was called and a paramedic used adrenaline to wake me up. I was taken to the ambulance. When I looked round to the bottom of the stairs where I had collapsed I saw a pool of blood.
53. When I got to hospital I was pumped with blood for 5 to 6 days. A doctor came to see me after 6 days and asked if I could remember him. I couldn't, and he said that he had been the first to attend to me when I was admitted to hospital. He then said that if I had stayed at home for another hour I would have died as a result of blood loss. I was so lucky that my girlfriend had called in on me.
54. Dr Aldersley discussed HCV treatment with me prior to the liver transplant but they simply ran out of time. I was so ill that the liver transplant was the main priority, so they decided to wait until after the operation. I understand that it is very unusual to do this, as they normally want to clear the HCV infection before inserting a new liver. However, I

was so close to death that they were forced to wait until after the transplant.

55. I began HCV treatment almost immediately after the liver transplant, whilst I was still in hospital. This consisted of 2 tablets, Sofosbuvir and a combination of Daclatasvir & Ribavirin, both taken once daily every morning for 12 weeks. The tablets were effective and by the end of the 12 week course I was cleared of HCV. I am unable to say whether I experienced any side-effects because I was still recovering from the liver transplant, so it is difficult to distinguish between the side-effects of the treatment, getting used to a new liver 'bedding in' and recovery from a major operation.

56. I believe that the medication I received was a clinical trial. I have a letter dated 13 January 2015 (enclosed as exhibit **WITN6220003**). This is a letter sent to me by Mevish Hussain, Clinical Trials Assistant at St. James' Hospital, thanking me on behalf of the Department of Hepatology for my participation in a 'Clinical Trials Programme'. I also recall that one of the nurses told me that the medication was expensive, in the region of £15,000. I treated them like bars of gold after learning this.

57. It took me a while to get over the liver transplant but I feel much healthier now. I have always strived to positive and continue to do so.

Section 3. Other Infections

58. I do not believe that I received any other infections as a result of receiving infected blood products.

Section 4. Consent

59. I believe that I have consented to all treatment I have received in respect of my HCV infection.

60. I believe that my doctors knew I had HCV long before I was informed of my diagnosis, and so I believe I must have been tested for HCV without my knowledge or consent. This really annoys me to this day.

Section 5. Impact

61. Without my then-girlfriend, I have no doubt that I would be dead. She saved my life more than once. We are no longer together because I was forced to self-isolate during the Covid-19 lockdowns for over 10 months. This was a result of my weak immune system following my liver transplant and the treatment I have received in consequence of my infection with HCV. This subsequently meant I was unable to see my girlfriend and eventually distance made us grow apart and we separated amicably. I saw very few people during this period.

62. Immediately after the liver transplant I was taking up to 100 tablets a day. This led all my bodily hair to fall out, though I kept the hair on my head. I was given a list of tablets to take with a strict regime of how and when to take them. This included my HCV treatment.

63. I currently have to take 10 tablets everyday and I cannot afford to miss out the anti-rejection ones. I had my spleen removed at the same time as my liver and have to take tablets to balance things out in that regard.

64. I have a list of food that I cannot eat. Seafood in particular is hard for me because I spent a lot of time in my childhood on the Irish coast where we were always eating fresh shellfish. I cannot eat rare steak, soft eggs, or rice from take away restaurants. There are more banned foods but these are the main ones that I remember because they affect me the most.

65. I have to stay out of the sun as I am told that I am susceptible to skin cancer because of my medication.

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66. I cannot risk drinking water at work from the tap because it is tank stored. I have to get water from a dedicated drinking station because I cannot risk infection.
67. I have lost all strength and ability to perform my previous work duties as a result of my illness. Although my body has accepted the new liver, my physical strength will never be the same again. I used to be an electrician at the top of my game, working all over the country and making lots of money. Now I work as a building facilitator in a local college, helping out in workshops, for which in truth, I am well over qualified. The days of me working as a contractor are long gone and I physically could not do the job.
68. Prior to being informed of my HCV diagnosis when my health was declining rapidly, I was sent to work in Stockport by my company. I couldn't work properly, I couldn't focus and I knew I was a liability. I would have sacked myself to be honest.
69. After being diagnosed with HCV, I informed my employer [GRO-B] who then sent me to see a specialist doctor. The doctor said that I was not fit to work and I had some time off. When I returned and went back to work in Stockport, the contracts manager came up to me and said he was sending me home.
70. When I asked the contracts manager why, he said that I had having nose bleeds in the canteen. I denied this categorically and everyone else I was working with also denied it. He was insistent however and I was sent home. I have no doubt that this was in relation to my HCV status and was the start of them pushing me out.
71. Not long after this, the company were having redundancies and I was forced to take involuntary redundancy. I have no doubt my name was at the top of the list and that this was because I had HCV. I later took [GRO-B] to a tribunal for constructive dismissal and won, receiving £5,000 in damages. In retrospect I should have held out for more money but I was

desperately struggling financially at the time and was forced to accept the offer.

72. I had no choice but to borrow money from my family owing to the loss of earnings incurred throughout my illness. I nearly lost my house, I had children to support, I had mountains of debt and bills all whilst I was ill and unable to work. The Child Support Agency were like the gestapo and I had bailiffs knocking on the door. Thankfully my sister was able to bail me out.

73. I didn't tell many people that I had HCV because there wasn't much time between my diagnosis and receiving treatment. Whenever I told people that I had cirrhosis, they would put 2 and 2 together and make 5. They all assumed that I was a heavy drinker and the cirrhosis was caused by alcohol abuse. In all honesty I probably would have thought the same as them back then.

74. I used to always tell people that drink was never the cause of my cirrhosis, so when I was diagnosed with HCV I felt vindicated. It was by no means a relief, but it made me feel better knowing that I was right all along. How perverse is it that I was happy to say I had HCV rather than people thinking I was an alcoholic?

75. I feel extremely fortunate to be alive. I did not think I was going to make it. This wasn't just thoughts that I had. I have become aware that my then girlfriend had visited Dr Aldersley and was told that I had about 3-4 months to live. This would have been about February/March 2014. I had the liver transplant in August. I had been placed on the top of the transplant list nationally. This is how seriously ill I was.

Section 6. Treatment/Care/Support

76. The only issues I have had with treatment have been in relation my bleeding disorder, rather than my HCV infection, to my knowledge. This also applies to dental treatment. It took me 6 or 7 years to finally have

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my hernia operation, which was the original reason I went to the Bupa hospital back in 2013 in the first place. This caused me discomfort but was nothing compared to my HCV, liver failure and transplant.

77. I have never been offered counselling by the NHS in consequence of my HCV infection or in relation to my liver failure and transplant.

78. Only in the last couple of years have I been offered counselling by the English Infected Blood Support Scheme ("EIBSS"). I did not take up the offer and have never felt the need for counselling. What is there to talk about? I am grateful and fortunate to still be alive.

Section 7. Financial Assistance

79. Dr Aldersley advised me about the Skipton Fund after my liver transplant operation. I think that I filled in the forms and sent them to Dr Aldersley, who then completed the application and submitted it to the Skipton Fund.

80. I enclose as exhibit **WITN6220004** a letter sent to me by Dr Aldersley on 08 January 2015. Dr Aldersley writes that one of his liver transplant coordinators, Katie McGoohan, was able to 'obtain some documentation showing that [I] did indeed receive clotting factors which are likely to have been contaminated in March 1984.' Dr Aldersley added that he completed the form and sent it the Skipton Fund and said that I would be entitled to additional payments having undergone a liver transplant. He also wrote that Katie McGoohan 'spent a considerable time trying to obtain documentation for' me. I have nothing but praise for Dr Aldersley and his staff.

81. Also within this letter (**WITN6220004**) is a record of the factor product I received. I was administered with 'a coagulation product called Lister, with a batch no.: HLA3135' over the period 16 March to 20 March 1984, prior to, during and after my appendectomy.

82. I was accepted by the Skipton Fund and received a stage 1 payment of £20,000 followed by a stage 2 payment of £50,000 owing to my liver transplant. I was awarded monthly payments as well, which are now paid by EIBSS and amount to £2,460 a month. I also receive a winter fuel allowance of approximately £560.

83. The money that I receive helps me enormously. I took a major financial hit as a result of my illness and this financial support has helped me to survive.

Section 8. Other Issues

84. I am of the opinion that I can either hide or get on with it, and I have chosen to get on with it. It is this attitude that has kept me going throughout my illness.

85. The NHS has been absolutely amazing with my treatment from start to finish. The amount of people within the NHS who have apologised to me is incredible. When I first attended the hepatology department at St James' Hospital, the doctors and nurses were apologising to me all the time. I said that it wasn't their fault. I could never blame an individual doctor for infecting me whilst trying to save me.

86. I believe that blood was imported from US prisoners and dodgy donors to save money for the Government. It was all a money-saving exercise and I suffered as a result of this.

87. I feel very strongly about the fact that I was not informed of my HCV when the doctors clearly knew long beforehand. They must've known I had HCV, it only took my GP 10 seconds to look at my file and tell me. I don't know who to blame but I know it isn't right.

88. I often think why is it that I was allowed to get HCV in the first place. Why was my HCV status withheld from me?

Statement of Truth

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

Signed

GRO-B

Dated 21st JULY 2022