Witness Name: GRO-B
Statement No.: WITN2112001
Exhibits:
Dated: 2nd August 2022

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 15 December 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1956. I reside in the UK and full details of my address are known to the Inquiry.

2. I live by myself and have one daughter. I intend to speak about my infection with Hepatitis C ("HCV") following a blood transfusion when I was 18. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my life.

Section 2. How Infected

3. I was born with a genetic condition called Ehlers Danlos syndrome (EDS). EDS is a muscular-skeletal disorder that causes a defect of the collagen. Collagen makes up 90% of the body. The symptoms of EDS for me include extremely fragile skin, hair and bones, deformed feet, and hyper flexibility.

4. When I was five I started school. The school doctor and nurse picked up that there was something wrong with me due to my deformed feet, difficulty learning to tie shoelaces and getting dressed and undressed for P.E. I was subsequently diagnosed with dyspraxia and I later discovered that I had EDS. I believe the orthopaedic consultant who I saw when I was aged 13 knew that I had a Connective Tissue Disorder, namely EDS, but withheld it from me. I was not formally diagnosed with EDS and dyspraxia until aged 54.

5. I was involuntarily admitted to a psychiatric hospital after an incident on my 18th birthday where it was presumed incorrectly I had mixed prescription pain pills and alcohol. I specifically told the psychiatrist that I didn't need psychological help as my symptoms were physical. He did not believe that I had undergone 12 operations on my feet because my GP had failed to inform him. He presumed that everything was psychological and threatened to section me if I didn't agree to be admitted to the psychiatric hospital voluntarily.

6. Whilst in hospital, I was denied all pain medication which meant that I was in very severe pain due to the 10th operation on my foot when they damaged the root nerves in my right foot. I had to self-medicate by self-harming through cutting my arms to release endorphins, a natural painkiller produced by your body.

7. I was only released from the hospital when I told the psychiatrist to dial GRO-D GRO-D Hospital and obtain a copy of my medical notes, and ask about the pain I was feeling. When he received my medical notes, he then realised he had made a gross error and tried to conceal it. A fortnight later, I was suddenly discharged.

8. On 24 September 1974, I started to experience symptoms of severe anaemia. I experienced an episode of flashing lights and the feeling of the walls moving in and out. The cause of my anaemia was, in my view, because I was self-harming.

9. As it was out of hours, I managed to cycle myself to GRO-D Hospital and described my symptoms to the medical staff. I later discovered that they had interpreted my description of symptoms to be analogous to someone who may have taken street drugs. This was despite answering "no" when they had asked if I had taken any drugs to cause the symptoms I was experiencing.

10. The doctors suspected that I was severely anaemic and undertook a blood test. I was then transfused with six units of blood to treat the anaemia. I was kept in the hospital for three days whilst I had the transfusions. I do not understand why I was given a six-unit blood transfusion as the first point of action. Why did they not give me iron tablets or an iron injection? They did not need to subject me to the risks of having a blood transfusion.

11. Two weeks after this incident, I became itchy all over. It was continuous throughout the day and became much worse at night. It became so bad that I went to see my GP a few months later. I also became extremely fatigued and started to really struggle to do basic things such as, walking to the bus stop, getting up for work on time or getting through the work day, etc.

12. I was always very knowledgeable regarding medical conditions, as from the age of 10 I wanted to be a doctor and would spend my time after school in the library reading medical journals and textbooks. As such, I was aware of the possibility of being infected with hepatitis via a blood transfusion and asked my GP to test me for hepatitis. I felt my knowledge of hepatitis was at that stage superior to that of the doctors. I was able to explain to the GP that the symptoms I was experiencing mirrored my knowledge of hepatitis and liver disease and that the symptoms were as a result of the blood transfusion.

13. I remember the doctor stating that I could not have been infected with HCV as my eyes were not yellow and the blood was all tested. However, the test for HCV was not available at the time and they could only test me for HBV.

14. I am unaware of the actual results of the tests but the GP told me that I was negative for HBV and HAV. I told the doctor that they needed to notify the blood transfusion service that I received the infected blood. I also informed them that they needed to diagnose me with non-A non-B hepatitis, and notify the blood transfusion service as non-A non-B hepatitis was a notifiable disease at that time.

15. I've always felt extremely guilty that I didn't pursue this more vigorously directly with the relative department in light of the fact of those who were subsequently infected.

16. I wasn't told that I also had the antibodies for HBV. It is my belief that they did not want to admit this because the doctors did not want to close down the practice and deep clean or burn anything.

17. In 1994, at the age of 38, I was sitting in my doctor's surgery waiting to be called in for an appointment. I picked up a magazine and saw an article saying that there was now a test available for non-A non-B hepatitis / HCV.

18. As I no longer trusted most NHS staff, I went to be tested at the sexual health clinic in GRO-B I went in and requested a full check-up. I trusted them to tell me the results more than those who had been treating me already. The tests were taken and I was informed that the only thing that I wasn't tested for was HAV as it cannot be caught through sexual contact or via a blood transfusion.

19. When the results came back the sexual health clinic wrote a letter to my GP. My GP then phoned me asking me to make an appointment and come in as soon as possible.

20. My GP, Dr GRO-B told me that it was 'really bad news' and that I had tested positive for HCV. He was a nice doctor and I don't believe he would have withheld information from me. When he told me about my infection, he looked really unwell and he said he was sorry that I was HCV positive. He told me that the average life expectancy was 20 years but as I had Multiple Sclerosis (MS), it only would bring my life expectancy down a small amount. I told him that I didn't have MS and that I was infected when I was 18 so effectively I should have died a year ago.

21. I reminded Dr GRO-B that I had been experiencing the symptoms of HCV since October 1974 and had persistently asked them to investigate this further. I informed him the source of the infection was from the blood transfusion that I had at aged 18. After I said this, all the colour drained from his face and he nearly collapsed. He was concerned about how he had shared the diagnosis with me. I sought to reassure him that he hadn't done anything wrong. I didn't expect him to be able to remember all that I told him considering I am one of many other patients.

Section 3. Other Infections

22. When the test for HIV became available I asked to be tested. I was aware that they didn't know how long HIV had been around and I felt there was a slight risk that I could have contracted it during the blood transfusion. I was asked to take part in a trial where I agreed to be tested every three months for a year. Fortunately, the results were negative.

23. I had not been informed about my infection with HBV. Recent tests show that I have not got active HBV but I have antibodies for it which means I've been in contact with the virus and must have been infected at some point in the past. The only way I believe I could have been infected is through the blood transfusion I received when I was 18. I had lived a safe life otherwise.

Section 4. Consent

24. When they went ahead with the blood transfusion, I wasn't aware that at that stage they had not viewed the blood results. If I had known this I would have requested that they wait. Recently I was tested for HBV without my knowledge and told I have HBV antibodies from a previous HBV infection.

25. I was erroneously placed in a psychiatric ward where I was subject to severe abuse. The psychiatrist wouldn't listen to me and stated that if I didn't agree to be admitted, I would be sectioned and never get out of the psychiatric ward.

Section 5. Impact

26. I was well aware of the major symptoms of HCV but some of my other symptoms that I thought were to do with my EDS I later realised were in fact to do with HCV.

27. I suffered from a sore, tender, painful and bloated stomach, frequent bowel movements, benign polyps, haemorrhoids, frequent rectal bleeds, and severe joint pains in my ankle, knees and hips. These symptoms were different from the symptoms I experienced from EDS. These pains were so bad that they ate away at me psychologically to the point that the pain caused me to be suicidal. I made numerous attempts to commit suicide by taking massive amounts of prescribed drugs and had to have my stomach pumped multiple times.

28. The fatigue I experience is so severe that I cannot sit up to do the washing up and if I do the washing up, or brush my teeth, it is so exhausting that I am unable to use my arms for the rest of the day. Due to the exhaustion I have to make choices every day as to what to use my energy for - do I clean my teeth; do I wash or do I get dressed? I have washed/bathed/showered less than four times in two years and less than 20 times in ten years.

29. This is in stark contrast to before I was infected when I used to get up and do paper rounds, stand up in the church choir, visit elderly and other members of the parish, and many other activites on top of my school work.

30. As soon as Interferon and Ribavirin treatment became available for HCV, I was made aware of it. I was offered it. However, I refused the treatment.

31. I have suffered PTSD and other adverse consequences from the treatment that I have received from the NHS. I believe the NHS has been negligent when my foot was damaged during my 10th operation and when treating my EDS. My PTSD is so severe that renders it extremely difficult to accept medical help when I need it.

32. At every single appointment I have regarding my HCV infection, I have been encouraged to have treatment. I was pressurised even more when the treatment drugs changed. Due to all the damages the NHS have caused me, there is no way that they can convince me to be treated in any way by them again. I have resisted the pressure I have been put under to be treated. Furthermore, I am under the impression that if I have treatment for HCV, it can cause my dormant and inactive HBV infection to reactivate.

33. The impact of being infected with HCV on my social and family life has been massive. Due to my infection, I cannot have relationships with anyone due to the fear of giving the HCV to people. Furthermore, many individuals are still ill-informed and believe that they can easily catch HCV from me. Once people find out I am infected, distance themselves or do not want you in their house.

34. Since I was erroneously admitted to the psychiatric ward at the age of 18, many people have tried to be supportive, but I notice little things that people do to treat me differently as people have frequently assumed that I was infected with HCV following drug use.

35. The HCV also affected my education. I wanted to be a doctor then a speech therapist. I loved the poetry, speaking and drama lessons that I received. I was doing well and receiving distinctions in my exams. However, despite being very close to finishing and getting my teaching diploma, I had to stop as the HCV was making me so fatigued. I found it totally exhausting to get up the stairs to the top floor to have my lessons with my teacher.

36. When I left school, I was placed as a trainee insurance clerk by the local job centre in a firm called the GRO-B in GRO-B Dorset. I was on top London wages. The Department of Social Security paid the first six months of my wages, and after that, the company decided to keep me as I was good at my job, and was a hard worker. I was forced to leave this job when I was put in the psychiatric ward against my will.

37. I was later employed by the RNLI as a purchasing clerk. I then moved to GRO-B GRO-B as a process chaser. My HCV meant it was hard for me to get to and from work. I used to get so tired that sometimes I would get blurred vision and other symptoms, and it was not safe to drive. The combination of HCV and EDS exacerbated my fatigue, brain fog and pain so much that I would have to take caffeine tablets to get me through the work day.

38. Due to the excessive fatigue as a result of HCV, I required extra rest and needed to sleep during the day. My husband and I had to move house as I could not cope with noise emanating from the area. As a result of this forced move we had to take out a bigger mortgage to move to a quieter part of the estate.

39. Before I started at GRO-B I had informed them that I may have to take a day off every three months to attend an appointment. After taking just one day off for an appointment, I received a letter that was hand delivered through my door terminating my employment. This had a massive impact on both, my husband and I as I was the higher earner in the marriage.

40. Following the loss of my job at GRO-B I struggled to get another full-time job. As we had just taken a large mortgage, the financial effect of losing the job was devastating. We couldn't pay any of the bills and we were taken to court. We immediately put the house up for sale to prevent losing it.

41. It put my relationship with my ex-husband under a lot of pressure as we were both extremely stressed about our financial situation. My ex-husband worked all the hours he could to compensate for the loss of wages but it wasn't enough. Also due to mobility issues I needed to live on the ground floor but couldn't afford a bungalow. We had no savings or anything else we could fall back on. Furthermore, the fear of transmitting the HCV impacted upon our sexual relationship.

42. After this, we were forced to buy a property that needed a lot of work. A 'family friend' was slowly doing all the work on the house at a cheaper price. I was unable to look after my daughter due to the extreme fatigue caused by the HCV and as a result I feel my daughter suffered immensely. Frequently my daughter would be left at school as I was so exhausted that my multiple alarms didn't wake me up. On one occasion she was left till at school till 6.30pm.

43. I couldn't look after my daughter and was forced to send her to boarding school. I found this heart-breaking as she was only aged six and it was at a time she needed me the most. All this still affects my daughter to this day.

44. Since my husband left I have not had any real relationships. I found it impossible to get into a relationship with someone due to the fear of transmitting my HCV. I couldn't even consider having a relationship with someone as I wouldn't be able to deal with the guilt if I ever transmitted the virus.

45. I have faced a great deal of stigma due to my HCV. On a few occasions I have been rushed to hospital, where I have always been put in a segregated ward. This is not something I particularly want as I am quite a sociable individual. Whenever I left my hospital room and went into the general ward I was constantly watched and followed by the nursing staff.

Section 6. Treatment/Care/Support

46. Following my HCV diagnosis, I had to put on a form at my dentist that I was HCV positive. As a result, I was told that my dentist was not able to see me that day. I was also told that I had to be seen at the end of the day so that the dentist could do a deep clean after seeing me.

47. This angered me as it made me believe that I was being put at the end of the day as the dentist was not doing a good enough job at cleaning up between each patient. This was also putting me, and others, at even greater risk of catching other infectious diseases.

48. I raised my concerns regarding this practice with the reception staff but was told to lower my voice. I objected as I believed that the other patients needed to know that the practice was not cleaning up well enough throughout the day to remove the virus.

49. Following this incident, I was referred to the community health dentist. The community health dentist was much more prepared. They wore protective clothing, and cleaned up properly in between appointments.

50. I was frequently admitted for surgery and other medical procedures only for them to be cancelled due my HCV status.

51. In 2013, I was diagnosed with non-specific interstitial lung disease and told that I required an urgent double lung transplant. Due to my HCV and EDS, I was told I would not be considered for transplant. I was later put on supplemental oxygen. I now permanently carry around an oxygen tank and I have to monitor my oxygen levels on a constant basis. The need to be on oxygen will remain with me for the rest of my life. Once again, I believe this is a result of my HCV.

52. It is well documented that a high percentage of people on the liver transplant list suffer from severe hypoxaemia.

Section 7. Financial Assistance

53. In 2010, I was in danger of losing my house in Scotland as I was on an interest-only mortgage and couldn't repay it. In desperation, I telephoned the HCV trust because I feared for my future. They advised me to apply to The Skipton Fund for support.

54. The stage one application was successful. I later applied for stage 2 which was initially declined. However, I was invited to submit further evidence. I provided Skipton a whole medical thesis that took me a year to compile and as a result, I was eventually given the stage 2 payment. There were no preconditions attached to these awards and I didn't have to sign anything.

55. The payment was not adequate. I needed help, care and assistance given the physical requirements caused by the HCV. Even recently I have had issues with the grant system in relation to urgent car repairs. I was told verbally that the grant was approved so I authorised the work to be undertaken on my car only then to be told that because I had paid the amount on my credit card as agreed the money would not be immediately forthcoming and would be subject to the normal six-week review on a non-urgent basis.

56. I am currently in receipt of payment from the English Infected Blood Support Scheme and receive payments ever three months.

Section 8. Other Issues.

57. It's my opinion that the concerted efforts of the medical profession to cover up the infected blood scandal has caused an even greater impact on my life and that of many others. I also feel that in their efforts to cover up the infected blood scandal, the false persona they created in my medical notes still affects me till this day. Since my carer died on GRO-B 2021, I have not been able to access any essential help or care.

Statement of Truth

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

Signed GRO-B

Dated 2nd August 2022