ANONYMOUS Witness Name: GRO-B
Statement No.: W3917001
Exhibits: [WITN3917002 -
WITN39170010]
Dated: October 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

I, GRO-B, will say as follows: -

1. My name is GRO-B

2. I live in GRO-B My full address is known to the Inquiry.

Section 2. How Infected

3. I believe that I contracted Hepatitis C after the birth of my first daughter in GRO-B GRO-B GRO-B My daughter was delivered via forceps, and I had a bad experience during my delivery; I was all torn inside and had lost a lot of blood.

4. After my daughter was born, I was taken into theatre and given a blood transfusion. This was without my consent. I was given the transfusion while the doctors were giving me stitches following my delivery **[WITN3917002]**.

5. I was quite out of it at the time and was not told what was happening or that I would be given a transfusion. I am not sure how much blood I was given, however I do recall the midwife saying to me after the procedure that I had been given 3 pints of blood. I was in hospital for a further 7 days after this.

6. I remember waking up with tubes in me and a catheter, and one of the medical professionals told me that I had had a blood transfusion. I cannot remember whether it was a doctor or nurse who told me.

7. Prior to receiving the blood transfusion, I was not told about the risk of being exposed to infection. I did not consent to the transfusion in the first place.

8. I believe that I was infected as a result of being given blood products at **GRO-B** **GRO-B** However, I only started to get ill in or around **GRO-B** I am not generally one for going to the doctors, however I thought that I needed Hormone Replacement Therapy (HRT) to treat the symptoms of my menopause.

9. As part of the doctors' investigations, I had some blood tests done and they found that I had an autoimmune disease. The doctor then asked me whether I had taken drugs or whether I had any tattoos. I answered the questions and told them that I did have tattoos and that I had taken drugs in the past. I thought that this line of questioning was very strange. This was the first time that hepatitis

was mentioned, and the doctor said that I may have it and that it would be confirmed with further tests.

10. In GRO-B My daughter was with me at the time, and I was told by the visiting Hepatologist at GRO-B

11. I did not have a positive experience when I initially went to see the hepatologist. I was asked all these questions about my history with drugs and alcohol, and my tattoos, before they had even asked me my name.

12. When the doctor asked me whether I had ever taken drugs, GRO-B GRO-B He told me that I could have become infected by sharing joints with other people. He said that if someone had a cut on their lip, the hepatitis could be transferred that way. I told the doctor that I did not share joints with anybody. I made my own for my use only. He said that it was usual for people to share and would not accept my answer.

13. In July 2018, after the doctors discovered that I had an autoimmune disease, but before I was diagnosed with HCV in GRO-B I did take amphetamines intravenously. I had not taken any drugs intravenously before GRO-B **[WITN3917003]**.

14. I felt as if the doctors made me look like some sort of alcoholic junky. The way it is written in my records, is not how I told them. I was upset and angry about this and asked the doctors to remove this from my records. I told them that they had written down what they wanted, and not what I told them; it was the wrong

information and I wanted it amended **[WITN3917004]**. They told me that they would, however I don't think they did because I remember seeing references to this on my records more recently.

15. In relation to my tattoos, I believe that the needles used were clean. I saw them come out of fresh packets **[WITN3917005]**.

16. The doctor also asked me whether I was going to make a claim for having been infected with blood products. I got the impression that the doctor did not think I would be successful if I did claim as I have a few tattoos and have a history with drugs and alcohol. I felt like the doctor was judging me instead of making me better **[WITN3917006].** They knew nothing about my previous battles with my mental health. It was only months after my diagnosis when I was seen by a doctor from another hospital, that they told me I could have become infected through the transfusion that I had during my daughter's birth [**WITN3917007]**.

17. Over time and once I had found out about the infected blood inquiry it made more sense to me that the doctor was attributing my HCV to my history rather than infected blood. It was to make them look better and to point the blame away from the NHS.

18. I was not provided with any information about the infection from the doctor at **GRO-B**. I was told in a very blunt way that I had hepatitis C. I had no idea how dangerous it was, or how serious it was. I just thought it was an infection. The doctor said that they would find a treatment for me and that was it. I was not provided with any information about hepatitis.

19. I was not given adequate information to help me manage and understand the infection. I was not provided with any information at all. I had no idea what was going on at the time, and the doctors made no efforts to explain the infection to me. I was only told to eat healthy and to take my tablets as part of the treatment. I had to rely on my own research.

20. During the appointments there was a lot going on, and a lot for me to take in. I was not in the right headspace, and so it was only later on that I would think of questions to ask the doctor. I used to call them frequently to get answers, as I did not feel like I got enough from them during my appointments.

21. I am glad that my daughter accompanied to my appointments as a lot of the information did not sink in for me. I could not remember a lot of it; it was all confusing and upsetting.

22. I believe that information should have been provided to me earlier. I think that I should have been told after I had the transfusion that there was a chance that the blood was infected, and I may have contracted HCV. The doctors should have done a test after the transfusion to make sure that everything was okay. It is my belief that they knew the blood was infected, so why was it not tested then?

23. When I was told that I had hepatitis C, I believe this could have been communicated to me in a better way. I was confused and dazed, and nothing was sinking in. The doctors should have understood that and explained more about the infection to me. Over time, I have found out more information about it but that is because I did my own research and I got in touch with an infected blood group on Facebook. I actually got more from the group than I did from my own doctors.

24. I was not given any information about the risks of others being infected as a result of the HCV. The week after I was diagnosed I did some research online and discovered just how easily I could pass it on to my family. The main thought which sprung to mind was that my children and grandchildren be infected. I was concerned about them having it, and I told the doctor that I wanted my family members to be tested. Fortunately, they were all negative, however I find it shocking that when I was initially told about the hepatitis the doctor did not tell me that there was a chance that I could have passed it on to them. In my mind, they should have tested my family as soon as I tested positive for hepatitis.

Section 3. Other Infections

25. As far as I am aware, I have been infected with hepatitis C only.

Section 4. Consent

26. I was tested for hepatitis with my knowledge and consent. Initially, when the doctors were trying to diagnose me they said that I could have hepatitis and I agreed to be tested. They also asked if I wanted to be tested for HIV, and at the time I said that they may as well although I did not understand why they asked at the time.

Section 5. Impact

27. In relation to the mental effects of being infected with HCV, I suffered a lot and even though I have now cleared the hepatitis this is something that I still struggle with today. I felt dirty and sad that I couldn't hug or kiss my grandchildren as I was terrified that I was going to infect them. I would have to tell them to stay away because I had a cold, and I didn't want them to catch it. This was heart breaking.

28. I was terrified that my children and grandkids would get it, and they would have to go through all of this. Through my internet searches I had learnt that I should not share certain things with family members, so I didn't touch anything that they were touching because I was so scared of passing it on to them.

29. I felt bad for my kids. I was trying to work harder so that they would not have to pay for my funeral, and so that I could leave them some money behind. I really thought that I was going to die.

30. I had nobody to talk to at the time. I couldn't offload to my kids as I did not want them to carry that burden. There were times that things got so unbearable that I wanted to commit suicide, but I did not want my kids to know that their mum wanted to kill herself.

31 GRO-B I felt scared that I could infect people. I also did not want people talking about me and the fact that I had this disease. The hepatitis really messed with my head and my whole life has changed because of it.

32. The doctors had told me that I was safe to continue working, and at the time I worked as GRO-B I kept thinking what if I cut my finger, I could pass it onto someone and I was terrified of this. The doctors just told me to be careful.

33. I felt terrible and I completely changed as a person. I felt that I was no good anymore. I did not want to socialise or go on dates anymore, when previously I had been a sociable and bubbly person.

34. It was a horrible time and mentally I was a mess. Not only was I physically ill, but I also suffered from brain fog and was getting confused a lot. I remember once I was GRO-B at work and suddenly thought what is this in my hand, and my mind went blank. I was holding a GRO-B but I had no concept of what simple things were, I was getting that confused.

35. I was do depressed and anxious about everything. I am still like this now even though the hepatitis has gone, it is something that stays with you. It is always in my mind will I get it again? Just last week when I went to see the hepatologist I kept asking them is there a chance that it could come back. They told me it was unlikely, but I am constantly worried that it will come back.

36. In relation to the physical effects of the HCV, I had a lot of issues with my legs and feet and could not walk very much at all. I still struggle with this today.

37. I also suffered from numbness, cramps, joint and muscle pain, itchy skin, headaches and nose bleeds. I also struggled to sleep and I lost a lot of weight, as well as my hair. I used to bruise for no reason, and I had terrible redness on my face which I still have today. I still suffer with cramps in my hands, feet, and legs. I also still have trouble sleeping.

38. I suffered with jaundice after the birth of my first daughter, and I believe that this was related to the hepatitis, and should have been checked following my transfusion. I cleared the jaundice during my time in hospital, however my daughter had to be put under UV light and after we were discharged, I still had to take precautions with her such as giving her a lot of water.

39. Following my transfusion, I suffered with migraines and back pain. This started in my early twenties and as soon as I cleared the hepatitis, I no longer suffer with any of these. I believe that these could have been possible side effects of the HCV.

40. I believe that I have cirrhosis of the liver as a result of being given infected blood products. There was just a month between my HCV diagnosis GRO-B and cirrhosis GRO-B. Some doctors have told me that the cirrhosis is in relation to the HCV, however others have said that it is related to 'alcohol abuse', as stated on my records. I do not agree with this term. GRO-B

GRO-B

41. In relation to the treatment that I received for the HCV; I was on Epclusa for three months. I was treated at GRO-B **[WITN3917008].**

42. I did not face any difficulties or obstacles in accessing this treatment, although the doctors constantly reminded me of how expensive the medication was. The doctors also used to make my appointments to collect the medication which was helpful. However, I feel like the doctors did not effectively deal with my side effects at the time. I have lots of nerve damage on my feet which I believe is from the HCV but they did not treat this at the time and let it go on. I am still suffering with this now.

43. I am not sure of whether there were other treatments that ought to have been made available to me but were not.

44. I suffered terrible side effects from the treatment that I was on. In terms of the mental effects, my head was all over the place a lot of the time. I was crying constantly and I just wasn't with it. Normally I am a very bubbly and outgoing person however I completely went inside my shell.

45. In relation to the physical effects that I suffered from the treatment; I lost a lot of weight and my muscles seemed to have gone. I was very weak and tired all the time, and I still am today. I just felt lousy all the time, and I did not know whether I was coming or going. I couldn't even have conversations properly; the brain fog was terrible **[WITN3917009]**.

46. The doctors did not explain any of the side effects to me before I had the treatment. They just told me to take the medication and that would make me better. Fortunately, the treatment was successful and in January 2019 I cleared the virus [**WITN39170010]**.

47. I believe that my infected status did impact my medical and dental care for other conditions. As a result of the HCV, my teeth became weaker and a few of them broke. When I phoned the dentist and said that I was being treated for hepatitis, they refused to see me. I have not been to a dentist since. The whole encounter made me feel so bad, and I do not want to receive any more comments like that.

48. On another occasion, I visited A&E for a stomach issue that I was having. This was after I had cleared the hepatitis. When the medical professionals saw HCV on my records they came in with extra personal protective equipment on. Although this was in April 2020 when Covid-19 had set in, I noticed that they wore extra protection such as aprons and gloves as well as a mask when they came to see me. Initially, I was in a bed next to other people in A&E, but when they found out that I had had HCV I was separated and left on my own.

49. I also had a negative experience at my GP surgery when I went in for something unrelated to hepatitis. The receptionist had mentioned loudly about me having HCV. There were other people in the waiting area, and they heard everything. I told the receptionist off and walked out. I was humiliated. **GRO-B** **GRO-B** I then had to explain myself to people **GRO-B** who had heard about what had happened. I felt that I had to explain myself so that people were not saying the wrong things about me. This was unnecessary and had the receptionist not been mouthing off I would not have had to do this. I wanted to keep my hepatitis quiet. **GRO-B**

GRO-B My hepatologist then made a complaint about the receptionist.

50. Being infected with HCV totally ruined my private and social life, I no longer have one. I used to be very outgoing and always out socialising, but I don't go anywhere now. GRO-B GRO-B

51. my infection with HCV has actually brought my family closer together. My children were extremely supportive, and I always had one of them attending my appointments with me. However, as I mentioned previously, I felt devastated that I felt dirty and was terrified to go near my grandkids. They would run up to me for a hug and I would have to say granny has a cold. It was horrible.

52. In terms of the stigma associated with my HCV diagnosis, I am not sure about how the kids felt but I felt dirty. I felt like everyone in my GRO-B was talking about me and people wouldn't come near me. This is how I felt, and I still do; this is why I stay in the house all the time. It is more the fear of the stigma rather than any actual stigma.

53. I had to stop working in or around GRO-B After I was initially diagnosed in 2018, the doctors said that I was safe to work and so I carried on. I needed the money so that my kids could pay for my funeral, and I wanted to leave them all some money behind. However, I became too weak and suffered with my mobility due to the pain in my legs and feet. I have not been back to work since 2019.

54. I lost money through not working. My kids helped me out a lot until I got my benefits sorted out. I did not need to pay for my HCV treatment.

55. My infection had a big impact on my children. It upset them, and they all worried about me a lot. GRO-B

GRO-B

56. My diagnosis also affected my eldest daughter a lot as she came to all my appointments with me. My daughter understood more than I did about the effects as she had a clearer head and took more in. The whole thing really upset her.

Section 6. Treatment/Care/Support

57. I did not face any difficulties or obstacles obtaining treatment, care and support in consequence of being infected with HCV.

58. Counselling or psychological support has never been made available to me in consequence of being infected.

Section 7. Financial Assistance

59. I have not received any financial assistance from any of the Trusts and Funds set up to distribute payments.

60. A doctor did ask me whether I had made a claim with Skipton, but I told them I did not even know what that was. He explained it to me but said that it was not worth me applying for because I had used drugs in the past and had tattoos. I could not cope with this and further judgement from Skipton, so I did not contact them.

61. Eventually I contacted the GRO-B However, they said that because I had taken drugs, I would not stand a chance. Also because I could not prove that I did not get infected through my tattoos it would be difficult, although I do have some pages of my medical records which show that I had a transfusion.

Section 8. Other Issues

62. I have had a few difficulties in obtaining access to my medical records from my GP surgery. When I asked the receptionist for them, she kept asking why I wanted them. I did not want to give my reasons in front of a waiting area full of people, and I told her that I was entitled to have them. Another receptionist then pulled me to the side, and said I know why you want the records and helped me to request them.

63. I would like to know why people like myself were not told earlier that there was a possibility that we could have been infected with HCV. Following the transfusions, why weren't people tested?

64. It has gone on for so many years and it is ridiculous the damage that has been caused by something which could have been stopped from the beginning. If I had been tested after the transfusion, I believe that I would be fit and healthy today but the hepatitis has messed with my head so much.

65. In terms of what I hope will be achieved by the Inquiry, I want this to never happen again; everything being kept a secret and people dying from it. It is awful how the NHS and government have gone about this, and little kids have even died from it.

Statement of Truth

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

Signed ... GRO-B .....

Dated 20/10/22