Witness Name: GRO-B
Statement No.: WITN3104001
Exhibits: None
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B and my address is known to the Inquiry.

2. I worked for local government however I retired at 55 years old to support my husband due to his ill health. We have two grown up children, who are 27 and 29 years old. They no longer live with us.

3. I intend to speak about my husband, GRO-B: H and his experience contracting hepatitis C via a blood transfusion, the treatment he has received, and the impact it has had on his life and our family's life. As H H has already produced a statement providing detail on the circumstances of his infection, diagnosis and treatment, I would like to request my statement to be read in conjunction with his. The focus of my statement is on the impact on our family, and therefore dates and more specific information as to medical treatment should be viewed within H statement.

Section 2. How Affected

4. I had known my husband H for a number of years before we started dating in 1991. I was aware from the beginning that he'd been involved in a GRO-B accident GRO-B during the beginning of 1980s. It was a major accident; he broke his leg. It was mentioned to me that he'd had a blood transfusion but I didn't think anything of it really.

5. I remember us moving to our second house in around 2001 with our two children and that's when my husband started to get ill. He regularly came down with cold/flu like symptoms, felt run down and had a big personality change. He was agitated at times, he would become impatient with tasks and he developed a level of road rage. In 2004 we moved to a new house again. It was around that time that H went to his GP for a health check, he was asked if he'd ever had a blood transfusion and was diagnosed with hepatitis C. He was originally referred to the Huddersfield Royal Infirmary who told us everything would be fine and not to worry as there was a 98% chance they would be able to shift it with Interferon and Ribavirin. We just never expected the side-effects to be as severe as they were.

6. When H was first diagnosed, I remember thinking about all the things we had shared over the years. H felt so guilty that he had had the disease all that time, we had been married for years and had children together. I had to get tested but luckily it came back negative. I was scared case I had it – I didn't know enough about it at that time to know whether I could have contracted it.

7. From the beginning we always felt that things would turn out to be fine. It wasn't that we thought hepatitis was not a big thing, it's just that there was always hope it would get better. In our minds, H was to undergo the treatment of Interferon and Ribavirin, and he was going to get better. Unfortunately it wasn't that simple.

Section 3. Other Infections

8. My understanding is that my husband was infected only with hepatitis C.

Section 4. Consent

9. I am unable to answer questions of consent relating to testing my husband for hepatitis C. Please refer to my husband's witness statement for details.

10. I do not believe that H and I were given full information in regard to his first round of treatment. The side-effects of Interferon and Ribavirin were explained only briefly. I cannot say whether we would have done anything differently had we known more about the side-effects and chance of success however I believe we ought to have known nonetheless. It may have prepared us better. I remember one consultant saying, 'I would be very surprised if we can't shift this' so that gave us hope and confidence that he would clear the virus.

Section 5. Impact

Symptoms of hepatitis C

11. The symptoms of hepatitis are vast and the sheer quantity of them is indescribable. H used to have nose bleeds and he was very easily bruised; you could see the disease was slowly killing him. He was always cold and ill with flu-like symptoms. He lacked energy to do normal day-to-day things and events such as going to parents evening. He could not get out of bed in the mornings for lack of energy. Even now he gets cold very easily, having hepatitis has completely altered the regulation of his body temperature. There have been times when he has not been able to leave the house because he is shivering and freezing to the point of being in pain.

12. Due to the treatment H suffers from brain fog and memory issues to this day. There were times when the brain fog made him delusional. Throughout the time he had hepatitis C the symptoms kept getting worse and worse. Despite all this my husband is a doer and he has tried so hard to get on with his life, and to live a normal life as much as possible. It is difficult for him and it has had a knock-on effect on myself and my family.

Treatment of hepatitis C and liver cancer

13. During his treatment with Interferon and Ribavirin, my husband dropped down to 10 stone, he is GRO-B He was always very good at taking it on time even through the worst of it. The doctors made him aware of some of the side-effects of the treatment but I don't think he was given enough information. There was never a point when we were sat down and explained the severity of the side-effects. Unlike with other serious illnesses and the dangerous treatments offered, the side-effects of Interferon and Ribavirin were almost explained like a minor over-the-counter treatment that you read off a leaflet. He endured terrible symptoms and side effects from the drugs; we didn't think it was going to be as bad as it was.

14. The treatment affected his mental health too, he would go through mood swings where he was up and down. Some mornings he was so emotional and upset I couldn't leave him. It was an awful period but we always thought there was hope, and all the tests they were doing during his treatment suggested the virus was dying. I think the biggest side-effect of the initial treatment was the personality change.

15. There were days when he couldn't even get out of bed. This was really difficult for the children in particular because they had to help their dad with day-to-day life. I used to go to work and he'd still be in bed because he couldn't get up. It all became normal.

16. It affected our personal life too. I couldn't sleep in the same bed as him because he was dripping in sweat and the bedding would be wet through. I had to wake up in the middle of the middle of the night to change the sheets, then I'd have to go into work the next morning.

17. After the treatment H continued to be really ill with the side-effects. To this day, 15 years on, it still affects him physically and mentally. He still suffers from temperature regulation, shivering and freezing cold when it's warm, and we've always got the heating on throughout the year. Every day the bed needs changing due to his sweating. I would say the personality change and the brain fog continues. In some ways his memory is still not good and he can often forget what we have discussed before. From what I've seen, I believe that the treatment and the disease has caused lasting damage.

18. H continued to go for check-ups after his treatment finished. We thought these were just a formality, and that he had been cured. I couldn't attend his 6-month check-up because I was away for work. H called me after his appointment and said I wasn't going to believe it but that the virus was not gone, it had hidden during the treatment and was now back. My husband was told he could go through round two of treatment however it was less likely to be successful. He said he couldn't go through those side effects again.

19. H is very up to date on things, he likes to do his research and so he decided to wait for a better treatment with fewer side-effects. I think if my husband had not been as tenacious with his research he would not have received the new treatment. If my husband was not the determined person he is, I think he would be dead. He discussed all possible options with the consultants at each stage and had to fight for the treatment he received. My husband had a lot of appointments at Huddersfield Royal Infirmary about possible treatments, we went back regularly and they said on numerous occasions that the treatments he had found out about in his research had not yet been approved by the NHS.

Every time we went the treatment was a long way off. It was like H was taking a gamble on the disease by waiting for a new treatment.

20. During this time, H had to undergo several biopsies, they're absolutely horrible procedures and very painful. After one of the two biopsies he underwent, he was diagnosed with cirrhosis of the liver. From that point on, he then had to have regular CT scans under the specialist hepatologists at the Huddersfield Royal Infirmary. The first scan was clear but the second, some months later, showed a tumour on his liver. The medical staff told us not to worry. They said that they would refer H to St James University Hospital in Leeds, and the doctors at St James would cut out the tumour as it was in an easily operable place. We again put our faith and hope in the NHS. Even though this was another obstacle we were always given hope. We always put our trust in the NHS.

21. I found our first visit to the liver specialist ward at St James really traumatic. The patients there looked so ill and I thought to myself, are we going to go through this with H The mental impact of all this was so draining, the constant worry and fear for the future.

22. Unfortunately they couldn't remove the tumour as easily as they expected because it was close to a major blood vessel. He had to have a procedure before the major operation to remove the tumour. It was incredibly painful for him and waiting for him to come out of the operation was a traumatic experience for us. He was awake the whole time, although he was given morphine and local anaesthetic. When he came home I had to take time off work so that I could look after him, run the household on my own and to try to keep things normal for the girls.

23. After he was sent home we had to wait another 6-8 weeks to see whether the other side of his liver had grown enough to remove the part of the liver with the shrinking tumour. The wait to know whether it had worked was really traumatic. Thankfully, his liver had grown sufficiently so he had it resectioned. They took

two thirds of his liver out and H had to stay in the ICU at St James Hospital for around 10 days. The day of the operation was really scary. It was just horrible waiting for him to come out of the theatre and worrying whether he was going to be okay.

24. H brother is a GP and he told H that he might not come out of this operation alive. The night before he went in for his liver resection, my husband handed me all the passwords for the computer and the bank books. He really thought he was not going to survive the operation. I told him no, stop it. Can you imagine what that feels like?

25. After he had recovered sufficiently, H continued to fight for the new treatment for hepatitis C. It wasn't a normal treatment that you receive with a doctor's prescription. There were a lot of meetings and conversations about the suitability and the cost of it before they could recommend the treatment to him. Eight weeks after the operation, the NHS provided him with it and it successfully cleared the virus. He suffered no side-effects like he did with the Interferon and Ribavirin.

26. After my husband's big resection operation, it took him years to feel better and start getting back to being himself. The symptoms of hepatitis C had crept up on him and he had not noticed how bad he had felt, but after he cleared the hepatitis he would tell me how much he felt he was slightly improving without the virus in his body. We were able to start going on holiday again and things were returning to some kind of normality. We thought he was free of the virus, that the cancer had been removed and hadn't spread, and so we could get on with our lives. Five years after the operation I thought he was nearly recovered. I thought he was on the road to recovery, he had worked so hard to get well by maintaining a healthy lifestyle, a good diet and keeping fit.

27. Since my husband submitted his statement there have been further developments to his health and this will be where our statements differ. I will outline what has happened from here.

28. The medical staff at St James explained that once we were over the five-year mark it would be an indication that he was on the road to recovery and he would not have to be monitored as much. He continued to go in for regular scans. I remember at the beginning of the first lockdown in March 2020 he had an appointment booked. Due to the pandemic, his scan was delayed for three months, and with the restrictions still in place, his test results were given over the phone. I think you feel safer when you're given bad news in a hospital environment because you have the specialist in front of you to provide advice and information. H was told over the phone that he had another tumour on his liver. He was told they would perform an operation called an ablation, where they insert a little rod into the liver and they microwave the tumour out. He had to be awake for it again.

29. It was traumatising. The doctors said it would be fine, that it was just another blip. But this time it really affected me even more so and had a huge impact on my mental health. Our family were in absolute turmoil and I left our family home for a few weeks so I could be on my own. I couldn't cope anymore so I took myself out the situation. I didn't know what else to do, I had no hope. I felt like he needed me to be strong but I didn't know how to support him, it was honestly the worst feeling I've ever experienced.

30. H went in for the operation in September 2020. I took him to the hospital but I wasn't allowed to go in with him so he had to go in alone. I know the pandemic has affected everybody but watching him go in alone and knowing I couldn't be there to support him was incredibly distressful to go through. The operation was successful. We again thought that was the end and he would be okay now.

Liver transplant

31. A year later, in September 2021, he went in for another CT scan. They diagnosed him with another tumour. H was told that because the tumours were reoccurring, and at such a fast rate, he needed to have a liver transplant. Without a transplant his chances of living more than another five years were only 30%. The only way he could remain on the transplant list was if he still had the tumour because otherwise technically didn't have cancer. The decision was made to embolize the tumour, this way the tumour would shrink but it would still be in his body. Again, he had to go through the most traumatic and painful procedure of his life where he was conscious under local anaesthetic.

32. H was told they needed to perform an operation quickly to treat the tumour with chemotherapy and another procedure. He went in a few days before Christmas eve and was home for Christmas. My eldest daughter is a mental health nurse and so happened to have Christmas off for the first time in years but we couldn't enjoy it because H was so ill. He's still ill now, months later.

33. H is now on the transplant list. The last few months have all been a blur and haven't been easy to get through, especially with him being so ill. You have to take in so much information about how the transplant works and the different types of donors. My head is exploding with everything I need to keep track of: the appointments and all the information. We don't know when he will get a transplant, it's a case of how long a piece of string is. It might be two years, maybe even longer. They explained that if he gets more tumours between now and his transplant, he may be deemed too ill. We were also made to watch an absolutely brutal video which explained what would happen if he was not able to get the transplant. Basically he would be left to die. It's incredibly traumatic looking at palliative care for your husband.

34. H had a scan to see whether the treatment was successful, and they have found a growth on his appendix. He is now under another specialist at St James,

he needs to have his appendix taken out via an operation. We don't know if it's cancerous. Once again it's another awful thing happening and we are all incredibly worried.

35. Living with [redacted] being on the transplant list impacts us every day, it's always on our mind that we could get a call any minute. We can't plan anything as a result, we can't travel any further than one hour away which means holidaying outside the direct area is impossible.

36. With a liver from a dead person there is still a risk because they can't guarantee the liver is disease free. The doctors informed us that that live donors are now possible. They've created a live donor programme, whereby someone in the family can put themselves forward to donate their liver. You have to go through rigorous medical and psychological testing. If you are a match, they operate and leave you with 30% of your liver, which will regenerate in time. I put myself forward, as did my youngest daughter. I shouldn't have been put in a position where I need to do this but I will, for my husband and for my daughters' father. There's a chance my daughter and I may not be compatible.

37. My daughter is 27 and desperate to donate part of her liver. I have to try first though because I'm her mother. I have to do it before her because she's young and she has her own business to run. I fear her having to go through a major operation if I'm unable to donate part of my liver. I'm a bit worried because time is running out and when I turn 60 I'll be unable to donate my liver. I'm scared, so scared – for my husband, for myself and for my daughter.

Impact on friends and family

38. During [redacted] first round of treatment, our oldest daughter was in high school and our youngest daughter was in junior school. They had to go through their education whilst watching him become so ill and tired. He looked dreadful but we tried to carry on because it was 'only six months' and we thought everything

would be fine after he had the hepatitis C treatment. We thought that life would go back to normal.

39. It's hard enough bringing up two teenage girls but it was especially so when their father was struggling. He couldn't be there for them like he ought to have been. After everything we went through in those six months it was even more distressing that the treatment wasn't successful.

40. H infection with hepatitis C really affected out youngest daughter. She was incredibly bright; she even did an AS level when she was 12. Then she started getting into trouble at school. It was nothing major but it affected her mental health and her education. She went to university but came home after three months because she was depressed. I don't think she wanted to be far away from us. If H had not been infected, I don't think that would have happened, I don't think she would have become depressed.

41. I'm amazed and proud at how well our girls have turned out. They have done so well for themselves. I know I took my attention away from them to look after him, and there were lots of things H couldn't do which I know he wished he was able to.

42. Hepatitis has also had an impact on the family and friends around us. My mum is 93 and she is house bound. I have to look after her as well as H but sometimes I just don't have the time. Thankfully I have a brother and a sister however I wish I could do more for her.

43. H and I have a wide circle of friends, but we often can't socialise with them. We'll organise things in advance but then when it comes to the day of, he's too ill or too tired. These are the normal things we're not able to do.

44. I normally take on little jobs since I have retired, just things like helping out during the election with the voting or being an exam moderator. I don't do it for money,

I just do it to see people and have a conversation. I can't do it this year because we're waiting in limbo to see what will be done about the growth on H appendix.

Stigma

45. When he was first diagnosed, I remember how awful the stigma was. Now I tell everybody about the infection because more people have heard of the infected blood scandal due to the Inquiry. It needs to be normalised. The stigma at the time associated the virus with drug users and alcoholics, I used to make excuses for my husband, explain that he doesn't drink and his liver problems weren't associated with alcoholism. If someone has cancer, people react with sympathy, but if you have cirrhosis and liver disease, some people are quick to judge. I often had to justify how my husband got the disease, and I find that hard.

46. Even when we go to appointments at the hospital now, and it might be a young nurse, my husband will explain that he was infected via a blood transfusion. They often don't know about the contaminated blood scandal, even with all the publicity from the Inquiry and the campaigners, people still haven't heard of it. I think the reason it's not as well-known as other disasters is because it doesn't affect everybody and people don't have an issue in common. For example with Hillsborough, everyone was affected because everyone knows someone who plays football or watches it.

47. I remember the Panorama programme coming out in 2017, *Contaminated Blood: The Search for the Truth.* I went into work the next day and asked if anyone had seen it but no one had. If you weren't personally affected by it, you don't know about it despite the fact that thousands of people have died. Even though people don't know about contaminated blood, I still try to explain it, and explain that my husband doesn't drink. It shouldn't make a difference; people shouldn't be treated differently on the basis of how they got hepatitis but unfortunately I think that's the way of things.

Finances and work

48. Whilst I was still working, I often had to explain to my boss why I was late, especially during the hepatitis C treatment. Some mornings H would feel so emotional and upset, and often he hadn't slept. Any time I did take off I felt so guilty. I loved my job and I wanted a normal life, not being able to go into work and be part of the team had a massive impact on me. Although my boss was very supportive, I felt like I had to explain to her far more than I should have.

49. I took time off work to support my husband when he underwent his major operation. I felt guilty for doing so and I rushed back to work as soon as I could. I'm not the type to take time off – the odd sick day here or there is normal but I took just under six months after the operation. It made me feel embarrassed even though I needed that time off although now I think I didn't take off as much time as I should have done. I felt torn because I needed to get back to work but my husband was ill at home. This took a toll on me. I'm not depressed but my anxiety levels were through the roof at that stage. The union became involved and I had to have an interview with my boss. The meeting was about me but because I was taking time off for H I had to disclose information about his medical issues. I think I disclosed more than I should have had to. I never thought I'd actually need the union, especially for that. I've never needed a union throughout my whole working life.

50. Hepatitis C has changed our whole life. I retired at 55 and people always say how lucky I am but they have no idea, I would prefer to still be working. I didn't want to retire and neither did H We had good careers but he was forced into retirement because of ill health and I retired to ensure I could support him. I know that work is not that important, but the normality of it is and I don't have that normality anymore. Work is about interacting with other people but that was taken away from me too. It also affected my finances. I retired at 55 but that

means a pension at 55 which is massively reduced compared to if I had retired at 60 or 65. I know money shouldn't matter but it will impact the rest of my life.

51. Who would have ever thought we would be in this situation? My husband was infected with contaminated blood in the 1980s, before I even met him, and now I'm hoping to donate part of my liver. You couldn't write this story; I think it's unbelievable. I'm 59 this year, and I look back and see our whole married life has been blighted by this terrible disease. It feels never-ending, there's always another obstacle and the light of hope gets further away. We don't deserve it.

52. The most recent situation regarding the transplant list has brought us closer together. When I look at our daughters, I see how strong they are. They've seen me cry and be upset, they've seen their dad go down to 10 stone and not be able to move out of his chair. It should never have happened. Even if he is able to undergo the liver transplant, the side-effects of hepatitis C and the aggressive treatment will stay with him forever.

53. What you have to bear in mind is that every single day since his diagnosis, our family has been affected in some way. First it was the shock of the disease and the impact it had on him, then the hepatitis C treatment and its aggressive side-effects, then we had to deal with tumours on his liver and now we wake up every day wondering if today will be the day he's given a transplant. My husband will die unless he gets this liver transplant, he's been dying since the day he was infected with hepatitis C.

54. H had his appendix removed after the growth was found and the worry we had to endure whilst they tested to see whether it was cancerous was again traumatic. I have gone through rigorous testing to see if I am compatible to donate part of my liver to H but unfortunately I'm not so this was another blow. Our youngest daughter is now going through these tests to see if she is compatible. This is something we don't want her to do but she is determined. Our eldest daughter has moved to Spain but due to my husband being on the

transplant list we are unable to visit her. We are looking at moving from our three storey house into a bungalow in preparation for H if and when he undergoes a liver transplant as this will make things easier for us. I feel like as a family we have something new to deal with every day and it's never ending. The impact on my mental health has been such that I have now been diagnosed with anxiety.

Section 6. Treatment/Care/Support

55. As I outlined above, we faced difficulties and obstacles in obtaining treatment, care and support. If my husband was not the determined person he is, he might very well be dead. He certainly wouldn't have been given the second treatment as quickly, the treatment which cured the hepatitis C.

56. We have never been offered counselling or psychological support as a direct result of H infection with hepatitis C however we have had some support through other routes.

57. I do remember when my husband went through his first major cancer operation and Macmillan provided therapy. We would often pop into the Macmillan centre after an appointment at the hospital to have a chat with the therapist. I also had counselling through my employer whilst I was off work but it's really difficult to find a counsellor that works for you. The one at Macmillan was beneficial but the others not so much. It's difficult for a counsellor to understand because they've never come across anything like this

58. H and I also went for psychological counselling at St James when our daughter was younger and not performing at school. She was getting easily distracted because she couldn't understand what was happening to her dad. This really affected mine and H s relationship.

Section 7. Financial Assistance

59. Please refer to my husband's statement.

Section 8. Other Issues

60. H and I have attended some of the hearings. It was really distressing and draining listening to other people's stories. I think the Inquiry is going on far too long, not just for my family but for everyone. My husband is sat here with a death sentence and will die without a liver transplant. The longer it goes on the less people who will be around to see its conclusion.

61. For our family, it's not about the money, no amount could ever compensate for the last 20 years of our life. You could give us a million pounds but it would never give us those years we lost. It's about holding people accountable and the main thing is for everybody to know about this disaster. There should be criminal prosecutions.

62. I feel like our situation has been textbook. For us, every worst-case scenario has come true. We never thought he would get cancer even though we knew the risk, but you always think that will not happen to us. My husband is 57 and we never thought we'd get to the point where he would need a liver transplant.

Statement of Truth

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

Signed GRO-B ....

Dated 8 Oct 2022