ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN6646001
Exhibits: None
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 September 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I am the wife of GRO-B: H who was infected with hepatitis C ("HCV") as a result of a car accident when he was 16 or 17. In 1992 we moved from GRO-B in Cornwall to GRO-B in Devon, with our three children.

2. My husband has Alzheimer's and consequently is unable to provide his own statement. My daughter, GRO-B has assisted me with providing this statement.

3. I intend to speak about H in particular, the nature of his illness, how the illness affected him, the treatment he received, and the impact it has had on him, his life, myself, and our family together.

Section 2. How Infected

4. On August 26 1966, when H was 16 or 17, he was living in London. H was riding on the back of a friend's scooter, when a car driven by a drunk driver hit H from behind, leaving him lying in the road. H was left with a broken shoulder, a compound fracture below his right knee, and a fracture to the right femur.

5. H was rushed to Westminster hospital, where he was in a coma for about a month, and received a lot of blood when he first arrived. H was in the hospital for around four months and has been left with one leg half an inch shorter than the other.

6. When H had the accident, his older brother lived in GRO-B and owned a Bed and Breakfast, and following his discharge, H went down to GRO-B to recuperate. H ended up staying in GRO-B and we met a few years later.

7. Before his diagnosis, H had been unwell for some time, but put off going to the hospital for ages. H had non-muscular back pains, was lethargic, had no energy, and just wasn't himself - under the weather as we would say.

8. In 2010, H had a lot of tests done at GRO-B however, they could not find out what was wrong. H was then referred to Derriford Hospital to do more tests. We were then called in to see the doctor, who informed us of H s HCV status. We were in a complete state of shock as it was the last thing, we thought the doctor would tell us. The doctor asked H whether he had ever had a blood transfusion, to which he told him about the accident he had when he was a teenager. The conclusion was that H must have got the HCV from there.

9. At the initial diagnosis appointment, the doctor informed us that H would die within three to five years if he did not go onto a HCV clearance trial straight away. H and I went away and thought about it, although we did not walk away feeling like we understood - we did not get an information sheet about the virus, or information as to how it affects the body or is transmitted. Information about the trial seemed to take centre stage, not information about the virus.

10. H s diagnosis was not long after Anita from the Body Shop made it public knowledge that she had been infected with HCV via infected blood. This was the most we, as a family, had heard and knew about HCV prior to H s diagnosis.

11. Derriford told myself, and our eldest daughter to do HCV tests, but not our two other children. We were told that if the results for myself and our eldest daughter came back negative, it was highly likely that our two other children were negative. We did not tell the youngest two children of H s HCV diagnosis at this time.

Section 3. Other Infections

12. Apart from HCV, I do not believe that H received any other infections as a result of being given infected blood.

13. H was initially just tested for HCV; however, I am sure that he was also tested for HIV at a later date. I believe that H was also tested for all hepatitis viruses.

Section 4. Consent

14. I do not believe that H was ever tested or treated without his knowledge or consent, or for the purposes of research.

Section 5. Impact

15. As H was told that he would die if he did not go on the trial, and no other care was offered, he started on the trial three to four weeks after diagnosis. We did not really think about things, and as the trial was the only option that was made known to us, we did not really think about the consequences of the trial at the time.

16. Whilst on the trial, H was monitored at the hospital every fortnight. H had to take 20 grams of fat with each tablet, three or four times a day, with one being at four in the morning. H was eating full-fat sausages, mars bars, and other very fatty foods. It was horrendous as we did not eat that type of food, and H started to put on a lot of weight. H was ten stone at the start of his treatment and has ballooned to 17 ½ stone now. We thought that the weight would drop once the trial stopped, but it has stayed, and H s appetite has increased as a result of the treatment.

17. During treatment in December 2012, H was admitted to Derriford hospital with pneumonia. He was put into a side room and excluded from the main ward. The hospital staff and the doctor in charge were not nice to him at all, and the doctor was very rude to him - they treated us all like H had leprosy.

18. I explained to the staff at Derriford the importance of H s medication and trial, the fact that the medication had to be kept in the fridge and taken with so many grams of fat, etc. I went in the next day and was surprised when H told me he had not had his medication, and that the hospital staff had 'lost' it. I subsequently contacted the doctor who was doing the trial, who was very supportive and took in the medication for H himself from the pharmacy and explained the importance of it to the staff on the ward.

19. H went on to have another bout of pneumonia after Christmas, in January 2013. H was admitted to Derriford hospital with very high blood pressure, where it was thought he was having a TIA.

20. We, as a family, did not really understand the implications of the trial, or to what extent the treatment could affect H s future quality of life - it was very much the case of, 'he is going to die, so if it is going to extend his life then we've got to try it'. Following completion of the trial, H had his blood taken again, and it came back with the all-clear. However, H s general health has taken a massive toll since.

21. Having someone to explain properly the implications of the treatment, and the implications of having a HCV diagnosis, instead of having to find out for ourselves, would have been very helpful. We felt like we only had one option, and were not given any other routes. If we had a bit more information about the trial, and H s progression without the treatment, our decision may have been very different. Knowing what we know now about the impact and effect the trial has had on H we would not have done it. H has no quality of life now and has done nothing for a long time now. H s world has become very small, and really just consists of the TV. COVID and the lockdowns did not help and resulted in H losing his routine.

22. There has been no ongoing treatment since the trial, and no follow-up. I have rung Derriford hospital a couple of times as H was not well, however, we were told it was just a case of going to the GP - they were not interested in seeing H again.

23. Straight after treatment, H got very depressed and has been steadily declining in his health since. I managed to get him to go to the doctor and got him on anti-depression tablets, however, this made his weight balloon even more. I don't think that H has had a good day since the treatment.

24. H s mobility is not great, which is all part of his COPD. H is pre-diabetic, if not diabetic at the moment - eating the level of fat required for the HCV treatment destroyed his eating habits, and changed his tastes completely. H grazes now, despite eating full, proper meals throughout

the day. It is almost like his body cannot acknowledge when he is hungry, and his brain is telling him he is hungry all the time, although this could be to do with Alzheimer's. We have been told that HCV could accelerate complications such as Alzheimer's.

25 H s HCV diagnosis and the effects of treatment have massively affected our social and private life. It is hard to get him to go anywhere - he can no longer drive as he was not safe to do so, and I had to say he could not renew his licence. Once H could not drive, he got even worse.

26. H faced stigma whilst in Derriford hospital. We can understand, due to the stigmatisation about having HCV, but the doctor, who should have known better, was awful. There was a sign on the door to H s separate ward regarding wearing protective clothing and keeping an arm's length. I do not think they explained to H what was going on, and he was given no reassurance at all despite being very ill with pneumonia - the nurses spent as little time in the room as they could and were not compassionate at all.

27. Myself and our eldest daughter also experienced stigma when having our blood tests done at GRO-B following H s diagnosis. When we said what it was for, the nurses were not their normal chatty selves, and the appointment became much more business-like.

28. There is a huge stigma surrounding HCV, and we have been very private about H s diagnosis and have not told anyone. Furthermore, we did not tell the younger two children at the time H was initially diagnosed.

29. We live in a very small village, which has a slightly backwards attitude towards HCV transmission, and they would not be overly inclusive of us if they knew. Some people assume the only way you can get HCV is via drugs or sex, but there are multiple other ways that you can get it.

30 H s illness impacts me greatly, but you just have to get on with it. I worked in care on shifts part-time, however, I gave this up at the end of July this year - I could not leave H for 12 hours a day, and it was too much to look after those with dementia and Alzheimer's at work and then come home to it. I really cannot leave him - if he falls asleep downstairs, he wakes up confused and in an awful panic. Alzheimer's really does change everything.

31. I have no life really looking after H the only respite I get is when I am walking the dogs, however with my knee problems, I cannot walk for long now.

32. As I cannot drive, my daughter, GRO-B took H to all of his appointments, even when on the trial. GRO-B was living in Surrey at this point and would have to drive back for the appointments. It was horrendous, especially as H developed such bad road rage. H s whole personality has changed since the treatment - he never used to be so angry and argumentative, although this is only in the car.

33. GRO-B has struggled with H when he has refused to get in the car after hospital appointments, and she has had to develop a different way of thinking, and at times treat him like a child, so that he does not get annoyed.

34. The trial seemed like a trigger for H s decline, and it has been hard for GRO-B to watch. It has been a struggle for H to come and watch her compete on the horses like he used to, and the conversations with him are no longer the same.

35. H can no longer go for long dog walks with us, despite being used to walking eight to ten miles, if not more. He can also no longer help look after the horses or generally lead an active lifestyle.

36. Whenever we go for lunch at GRO-B s, after two or three hours, H will want to go home. Our son is also getting married next year, and we as a family are already trying to work out the logistics with H We have to think so differently about things like that now. Even Christmas, we have to think about it logistically so there is the least amount of stress on H It is almost as though I am becoming his parent, and I have to plan everything in advance.

37. H also struggles remembering the names of our five grandchildren, and can only remember the name of the eldest who is now 18. This is especially hard for my eldest daughter. H also struggles with the noise of the grandchildren, particularly the younger ones who are only two, two and a half, and four. This is especially hard for myself, as the grandchildren are not here as much as I would like because of this.

38. H had to take several weeks off of work when he went into hospital during his treatment, and his income was reduced to statutory sick pay only.

39. H also had to stop working as a result of the treatment. After the trial, his working capacity decreased, and H had to cut down his working days, and then eventually give up work due to his memory. This was a particularly horrendous time as four months before H had to stop working, I was made redundant.

40. H had a private pension from his company, which we took out early and did different things to the house such as new furniture and carpets. This subsequently meant that we had nothing when we retired, and no health insurance.

41. H did not try to get life insurance so we do not know whether there would have been any issues obtaining this with the HCV. I think that it would be very difficult to get life insurance now due to H s deteriorating health.

42. H s illness affected GRO-B s education and master's degree. Driving up to Surrey for her exam after H was admitted to Derriford hospital was very stressful for her. We also relied on GRO-B to drive H to and from his hospital appointments, as the bus service here was awful and H was not well enough to go on a bus. This required GRO-B to drive all the way back from Surrey to Devon every two weeks.

Section 6. Treatment/Care/Support

43. I do not believe that H faced any stigma, or difficulties obtaining treatment from his dentist.

44. H has recently been offered an Alzheimer's treatment trial. However, due to his experiences with the HCV trial, we have said no as we are worried it could make him worse.

45. At no point has H been offered any counselling or support following his diagnosis and treatment.

Section 7. Financial Assistance

46. No doctor, or anyone else, has ever made us aware of the financial support schemes that may be available to us. As such, we have not applied to any.

Section 8. Other Issues

47. As a family, we would have never let H go through with the trial had we known of the adverse side effects and deterioration that he has experienced.

48. H has not been well since the trial, and his memory has not been good since.

49. Prior to being unwell, H was a very active person, and would always be up for doing something. Since the treatment, H is no longer the same

person, and has not wanted to do anything or go out, and has started shutting down. As a family, we have lost a lot of active years with H and it feels like he is 85, not 72.

50. H has aged so much quicker than he should have done as a result of the HCV infection. We feel a great loss, and we will never get those years back.

Statement of Truth

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

Signed GRO-B

Dated 8th July 2022.