ANONYMOUS Witness Name: GRO-B
Statement No.: WITN1827001
Exhibits: WITN1827002 – WITN1827005
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1950. My address is known to the Inquiry.

Section 2. How Infected

2. I was infected with Hepatitis C (HCV) through a two-unit blood transfusion which was administered to me after the birth of my twins in GRO-B 1990.

3. My twins were born on GRO-B 1990 by emergency caesarean section at St Helier hospital. Following this, I developed a wound haematoma which needed evacuating and re-suturing, and this was performed on GRO-B 1990. My records say that my postnatal haemoglobin was low and as a result I was given a blood transfusion **WITN1827002**.

4. I was not provided with any information at the time of the transfusion about any risks involved. All I knew was that I needed to be stitched up again after my stitches came undone after the caesarean, and it wasn't until after this took place that they mentioned I would also need a transfusion.

5. I was diagnosed with HCV in 2009. Before then, I did experience some symptoms which may have been associated with HCV. I had a pain in my side which worsened over time and suffered fatigue at work. I never sought medical advice about these symptoms because I did not know they could be evidence of a serious illness.

6. On GRO-B GRO-B 2009 I went to see my GP because the pain in my side had gotten very severe. The GP said she would do a blood test. She then phoned me a few days later at work and said, "I'm really sorry to tell you, but you've got hep C". She did not provide much information about what that meant. I remember she was apologetic about having to tell me at work and told me she would refer me to a liver clinic at St George's Hospital in Tooting. I then started researching HCV myself as I didn't know much about it.

7. A few weeks later I had an appointment with the liver specialist at St George's. I had more blood tests to confirm my HCV diagnosis and assess the extent of my liver damage. When my diagnosis was confirmed, the doctor asked me all sorts of questions about if I had taken drugs and things like that. When I said no, they asked if I had had any blood transfusions, and I said yes, after my twins were born. They said it's pretty likely that I had contracted HCV from the transfusion because at the time blood wasn't being screened for HCV.

8. In GRO-B 2009, I had a liver biopsy and a few weeks later I received a phone call from the liver unit saying that I had developed cirrhosis as a result of the HCV. I also had an abdominal ultrasound which determined that I had an enlarged spleen and fatty changes to the liver. At that time, I was told that there was a

treatment available which involved injecting yourself in the stomach with a medicine called interferon.

9. When I first found out that I had HCV, I was shocked. After I did some more research on it, I became even more frightened because I found out that if I had cirrhosis, that could mean I could have a shortened life. I was very upset that this had happened without me knowing, nearly 20 years prior.

10. I was given the opportunity to speak to the HCV nurse before I saw the consultant at each of my appointments. He was very nice and explained how to administer my treatment. However, I was not provided any counselling or anything at all to help with the emotional impact of my diagnosis.

11. I feel the practical information I was given was adequate enough for me to start the treatment, but I was not given any assistance to help me come to terms with my infection in general. I do not consider that there were any delays in receiving treatment or information, because I was offered treatment at my second or third appointment and was given the medication straight away once I agreed to take it.

12. I was given some information by the liver unit about the risk of infecting others. They told me not to share cups and toothbrushes with my partner, and advised that my partner and my youngest son GRO-B: S, get tested as well to be sure he did not have it. GRO-B: S was born in 1997, 7 years after I was given a blood transfusion in 1990.

13. My partner's test came back negative. Unfortunately GRO-B: S's test was positive. I remember bringing him into the hospital for the test and being told straight away

after the blood test that he had hepatitis and had been born with it. I had passed it on to him at birth, six years after I myself became infected.

14. GRO-B: S was also given a liver biopsy and assessed for liver damage, but it was determined that the HCV had not affected his liver to the same extent it had mine because he was so young.

Section 3. Other Infections

15. I was infected with HCV only.

Section 4. Consent

16. I do not believe I was ever treated without my consent.

Section 5. Impact

17. I continued to experience the pain and fatigue I had been experiencing for some time after my diagnosis. Since I began taking my treatment shortly afterward, however, it is difficult to tell how much of my symptoms were directly from the HCV and which ones were from the treatment.

18. Emotionally, I struggled to cope with the HCV diagnosis. It shocked me and worried me as I was not sure how it would affect my health long term. Then when my son GRO-B: S was diagnosed, I found it even more difficult to come to terms with

the fact that he was infected. On some level I felt guilty for having infected him even though it wasn't my fault.

19. My son and I both underwent a course of pegylated interferon and ribavirin treatment in 2009. The treatment lasted for 48 weeks and consisted of pills and injections. My partner would inject both of us at the same time.

20. The treatment came with horrible side effects. I felt constantly nauseous, sick, and tired. I missed a lot of time at work because I couldn't face commuting in case I was sick on the train GRO-B: S's missed a lot of school because he felt so sick.

21. After the treatment had concluded, my doctor did a blood test and determined that it had not cleared the virus. I was not offered any further treatment at that time. I was instead told to return to the hospital for scans every 3 months to keep an eye on my liver to make sure it wasn't becoming cancerous.

22. GRO-B: S's treatment was successful at clearing the virus, so after a year of follow up appointments he was discharged from the liver unit's care.

23. A few years later, around 2015 or 2016, the liver unit phoned me and told me that there was another treatment available for my HCV called Harvoni. They said it consisted of only 12 weeks of taking a pill. They also told me that it was expensive (around £50,000), but that if I wanted, they could put me on a trial. I felt guilty after this conversation because I felt like I was taking the money away from someone else who needed it. However, now I realise that it was inappropriate for them to tell me how much the medicine cost, as that was irrelevant to whether I needed it.

24. The side effects of this treatment were not as bad as those from the pegylated interferon and ribavirin. In the end, the treatment successfully cleared me of HCV but it was too late to fix the damage the virus had already done to my liver since 2009. I was still required to attend clinics every 3 months to assess my risk of liver cancer.

25. I went to my clinic appointments every 3 months for the next 5 years. After my clinic appointment in September 2019, I received a phone call from the hospital informing me that I had liver cancer. I was referred to Kings College Hospital, which has a clinic that specialises in liver cancer caused by HCV. I saw Professor Heaton there, and he said it was a possibility that I might need to have a liver resection - where they cut the cancerous piece out - but that they didn't want to do that because of my age, which was 69 at the time. I was instead referred to have a treatment called TACE, where they inject chemotherapy directly into the liver up through a vein in your groin. I went in on GRO-B 2019 to do this, and it successfully killed the cancer.

26. Professor Heaton also told me during my time at the clinic that it was extremely rare for a woman to pass on HCV to her child through childbirth. He said that it only happened about 0.02% of the time. This is one of the reasons I wanted to give a statement for the Inquiry, as I understand that GRO-B: S becoming infected with HCV through childbirth is rare and wanted to ensure our stories were told and accounted for.

27. Ever since then, I have gone back to Kings College every 3 months for a scan to check the cancer hasn't come back, which it thankfully hasn't.

28. Luckily, I have been able to clear the HCV and overcome liver cancer. However, I still have some symptoms of the liver damage I sustained, such as pain in my side, because my liver is still swollen.

29. I have also had dental problems as a result of the HCV. I have had to have more dental treatment that I would have expected throughout my life because HCV can cause teeth to rot and require removal.

30. I struggled to maintain a normal social life during my treatment. I was feeling so unwell and so tired that I slept for most of the days and never wanted to go out and meet people. After the interferon treatment was over, I began to go out a little more, and I now feel I am able to do most of the things I was able to do before in terms of social and family commitments.

31. I would say the biggest impact for me of contracting HCV and undergoing treatment was that I ended up having to resign from my job. I was working as personal assistant to the director of GRO-B at the time of my diagnosis. It was a stressful, high powered job. My employers were understanding about my needing to go on treatment, but there were only so many days I could take off sick before staying in the job became untenable. Often, I would try to go in to work but get sick on the commute and have to return home. I resigned in GRO-B 2011, about a year after finishing the treatment. By this time I had missed so much work that I didn't feel able to continue, and was still feeling tired all the time.

32. As a result of my resignation, my family suffered a significant financial loss. I was able to get my state pension as I was 61, but the loss of my salary still had a significant effect on my family life. At the time I had 18-year-old twins – one at

home and one in college, and my younger son was still at school. We had to survive on my partner's wages alone, which made things difficult.

33. In terms of the stigma against HCV, I do think there are still negative perceptions of the virus although it may not be as bad as it was 10 years ago. I personally have not had negative experiences when interacting with friends or professionals, but I feel the media attention around HCV is always centred on drug users and other lifestyle choices and so a lot of people are not aware it can be contracted by NHS blood, and therefore make judgments about the type of person who is infected, out of ignorance.

34. In additional to our financial losses, my son GRO-B: S suffered significant educational losses. During his treatment he was not able to go to school consistently as a result of feeling ill, and eventually stopped attending altogether. He missed two years of school in total; years 9 and 10. In the beginning he would try to go to school but come home half an hour later saying he felt too nauseous or had been sick and was sent home.

35. During his time out of school, GRO-B: S lost the motivation to do his schoolwork and seemed to lose any ambition he had around preparing for university and a career. His teachers tried to send work home for him to do, but he felt so ill he was unable to do it and it was difficult for him to understand how to complete it without having attended the lessons. He also missed out on peer interactions which had previously been a motivating factor for him to attend school and do his work.

36. Though he was only 11, he had previously been a very good sportsperson and loved football and tennis. He had plans to go to university and study to become

a sports therapist. After treatment he no longer was interested in playing sports or going to university. He went back to school to take his GCSEs, but he didn't do well because he had missed so much learning the years before. He would go to school and would come home early crying as he had no energy and was too weak. He then went to sixth form college but dropped out of his first college and I had to find him two more colleges to try to see if he liked them better. By this time he was 17 and told me that he would rather just leave and get a job. Eventually he decided to become a landscape gardener, which is the job he still does to date. He is 24 now and does not want to go back to university or change career.

37. I feel that having his treatment aged 11 and the interruption this caused to his life at that time has severely impacted his ability to stay on track academically and pursue a fruitful career. Had GRO-B: S's education not been interrupted who knows, he could have gone to university. His life may have turned out differently.

38. Additionally, GRO-B: S was impacted socially as he no longer wanted to mix and play with his friends. He was exhausted all the time and didn't have the energy. I think he felt a bit of stigma around his infection. Luckily the twins were very good at looking after him, so he had them to socialise with.

39. Having both myself and GRO-B: S undergo treatment at the same time was obviously very difficult for my partner, who was tasked with injecting us both with interferon and caring for us when we were ill. He has a stressful job anyway and then had to come home from work and see both me and my son suffering every day. I feel GRO-B: S is just not the same boy ever since his diagnosis. He should not have had to go through what he went through at such a young age.

40. My twins were not physically present during our treatment as they were at college. However, they were emotionally impacted by our diagnoses as they felt that somehow it was their fault that I was infected since it happened during their birth. I do not blame them at all, but I think they do still carry some guilt about this.

Section 6. Treatment/Care/Support

41. I have not faced any delays in obtaining treatment, and neither has GRO-B: S

42. No counselling or psychological support was made available to either of us after our diagnoses. I do think it might have been nice to have someone who knew about HCV to talk to because I didn't know a lot about it.

Section 7. Financial Assistance

43. I found out about the Skipton Fund from the liver unit at St George's. In June 2009, the doctor there asked me if I had claimed my payment from the Skipton Fund and I asked what that was. She told me about it and explained how to fill in the application. I received my Stage 1 payment shortly afterward and my Stage 2 payment once it was confirmed I had cirrhosis.

44. I remember having to take the application forms to my GP to get her to sign them, but there were no difficulties with this and she signed them promptly.

45. I still receive quarterly payments from EIBSS. This has helped me financially some, especially after the loss of my job.

46. My feelings about the level of payments provided is that it does not make sense that infected people have no say in how much money we receive. I think that the Government should have accepted responsibility for what happened long ago and awarded everyone compensation, because then they would not have to keep paying out quarterly. If I had received a lump sum I would have more options to ensure my future is stable, like purchasing a home or investing the money, and would not have to rely on regular payments to pay my rent and hope they continue until I no longer need them.

47. I do not think payments should be made based on financial need and I think the same amount should be provided to everyone, as we were all infected equally.

Section 8. Other Issues

48. In 2009 I sought to bring a legal claim in clinical negligence against Epsom & St Helier University Hospitals NHS Trust, which operates St Helier hospital, arising out of my infection with HCV. I instructed Russell Cooke and they sent a letter of claim to the Trust **[WITN1827003]**.

49. In my hospital records, there is a note from Brenda Sharp in Complaints and Legal Services at the Trust to a Consultant Haematologist enclosing the letter of claim. The note states "Am I correct in thinking that the solicitors are "barking up the wrong tree" in that they should be directing the claim toward the Blood Transfusion service, as they would have taken, screened and supplied the product, and we would have given it in good faith?" **[WITN1827004].** There is

no response to this letter on file. I was not aware of this note in my records until my solicitor brought it to my attention.

50. I recall Russell Cooke wanted to bring a 'wrongful birth' claim **[WITN1827005]**. I had a meeting with my solicitor and barrister and they told me the chances of me winning the claim were slim and advised me to abandon it, which I did.

51. My impression of the Inquiry so far is that it has largely concentrated on haemophiliacs. I look forward to the evidence relating to those of us who had a blood transfusion.

52. My GP surgery, the GRO-B has refused to provide my solicitors with a full copy of my medical records. They state:

> Please ask your client to apply for online access to his medical records so that he can make the information available to you or allow you to access them with his consent. If however, you need any records that cannot be accessed online ie clinic letters, please confirm which records are required as your request must be specific. If you want these records sent to you, please make arrangements for collection or alternatively ask your client to collect them from the surgery.

53. This has prevented me from having access to my full records. I am not aware of which types of records may exist that are not available electronically so I cannot specifically request them. I think that clinic letters would be important for me to review and I would like to receive a copy of all of them.

54. My biggest worry at the moment is not about myself but about my son. I am concerned that his diagnosis and treatment have had a serious impact on his

life and career trajectory and want him to see justice for this. It has affected his life so badly.

Statement of Truth

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

Signed GRO-B

Dated 11 July 2022