Witness Name: GRO-B
Statement No: WITN3015001
Exhibits: 0
Dated: 28th May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I was born on GRO-B. I live at GRO-B. I am married to GRO-B and we have GRO-B. I am a semi-retired GRO-B GRO-B. I am now about to work part time due to constant fatigue I have following treatment for Hepatitis.

2. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How infected

3. I have Haemophilia A (0.14LU/ml) classed as mild. I was diagnosed when I was around GRO-B years old. I had a nose bleed that did not stop and I was admitted to GRO-B under the care of Dr GRO-B for a few days until

they realised that I was a Haemophiliac. I was treated with blood products to stem the nose bleed that I had.

4. In about GRO-B I was working in Cumbria and received a severe blow to the back of my leg in an incident at work which caused my leg to swell. As I was registered with the Haemophilia Centre at the GRO-B under the care of GRO-B the Clinical Head for Haematology, I came back to GRO-B for treatment. I was given blood products by the 'on call' Haematology doctor covering for the weekend. He made up the injections and then administered them. I cannot remember the doctor's name or the products I was given.

5. Between being diagnosed with Haemophilia in GRO-B and receiving treatment at GRO-B I cannot recall if I received any other blood products. I only remember the treatment I received at GRO-B following the incident at work as the date corresponds with a report in the GRO-B on contaminated blood I read a few months later at GRO-B so it stuck in my mind.

6. Following the incident at work I was given blood treatment at various times over the GRO-B as I had various minor operations. However I never received any information or advice about the risk of being exposed to infection from blood products; I was only told that I needed the treatment.

7. As a result of receiving blood products I have been infected with Hepatitis C (HCV) which was originally known as Non A non B Hepatitis.

8. Some time later, probably around GRO-B I received a request from GRO-B to attend a clinic being run by GRO-B for a blood test for Hepatitis and HIV.

9. GRO-B and I attended GRO-B for the blood tests, which were positive for HCV although negative for HIV. We were both told by GRO-B that the prognosis was

terminal as there was no effective treatment available. He said I had been infected from contaminated blood, the same way others had been infected.

10. We were advised to refrain from sex, and that any children would need to be tested. He also joked that we could spend all the money we wanted as I would not need a pension; this always stuck in my mind. GRO-B who I had only recently married in GRO-B was devastated by the news, it was the last thing she or we wanted to hear.

11. There was no guidance either during or after the consultation in terms of understanding or managing the infection, although following the diagnosis I attended GRO-B on a six monthly (later an annual) basis to review my liver function tests.

12. I felt that the advice offered was final and there was no provision to discuss the matter further. I strongly believe that there should have been support, especially years later when we were starting a family.

13. GRO-B and I felt that the consultation with GRO-B was more to deliver the news that, in all probability, I would die in the next 10 to 40 years, but that I would certainly be dead before the age of 50, rather than a helpful discussion on how to manage or understand the infection.

14. I was also informed that there was the possibility of a liver transplant, but that I was not a high priority as it would also become infected. There was a degree of humanity in the way this news was delivered but we both felt it was as a *'when you die, shortly'* conversation.

15. I was told of my infection in the early GRO-B but I was infected well before this so there was a significant delay. I do think I should have been told earlier but I was

told it was incurable and that at that stage there was nothing they could do anyway so it did not really matter to me at that stage.

Section 3. Other Infections

16. As far as I am aware I have not received any other infections.

Section 4. Consent

17. I am not aware of being tested or treated without my knowledge or consent although I do believe the hospital knew I had been infected a long time before I was told.

18. Also while I have had liver function tests every six months, from the time I was diagnosed as well as biannual scans on my liver and ultrasounds to monitor my liver condition, I have a strong suspicion that some of the information will have been used in a larger case study to see how people develop over time. Otherwise why collect the data? I therefore believe that the data and information collected from me has been used for research purposes.

Section 5. Impact of the Infection

19. The main effects I have suffered since I was infected are constant tiredness and depression (not severe), which has had a marked effect on my career. Due to the extremely long nature of the early treatments to clear HCV, I was constantly affected with side effects, detrimental to my work and my career. The treatments also heightened the tiredness which made working very difficult at times.

20. The treatments were long and very painful, lasting for a year or longer on each occasion. I did have severe side effects and do suffer occasionally from paranoia

and depression. The drugs also had a personality changing affect making me short tempered and angry.

21. I was party to two failed attempts to clear my HCV. The first treatment I had was non PEGylated Interferon. I was rushed onto it due to my age, it was something that could have worked well but did not have any effect on me. I had to inject myself every other day; it was extremely painful. The course is normally for 6 to 8 months but I had it for 12 months. The side effects were personality changing. I continued the treatment until it was realised that it was not working for anyone. It was a few years before I received the next treatment.

22. The second course of treatment involved being rushed into the initial trials of PEGylated Interferon with the support of the GRO-B with the claims that there was a good chance the HCV would be cleared. It failed. As a result it had a dramatic effect on the next treatments I received as my body had become immune. The first treatment effectively condemned me further, I was never told of this side effect. The result of the second course treatment had lasting effects on my mood.

23. I had a routine blood test two years ago and my viral load had gone from about 100,000 per millilitre to 600,000 per millilitre. My HCV had just suddenly become viral. If the new treatment not become available when it did, it could have been a very different story; I was so close.

24. Therefore the new treatment became available just in time for me in GRO- The treatment was Ribavirin 200mg tablets and Zepatier 50mg/100mg tablets; produced by MerckSharp and Dohme Limited. Fortunately the treatment cleared my HCV.

25. I have had no medical complications when having surgery but I believe I have had to wait longer for treatment due to my HCV.

26. In terms of my other medical conditions, I have always brought up my fatigue to doctors as it is as a result of HCV and the treatment I have received. I have suffered with it for about 20 or 30 years, I have a high impact job whilst trying to fight HCV as well. I was given the all clear to HCV last year, but my fatigue is even worse. I cannot go dashing up and down the country with my job due to the fatigue I suffer. I feel it is chronic fatigue, (ME) but I have always been told that the fatigue is not related to HCV. The hospital's attitude is *'we have cleared your HCV there is nothing else, go and see your GP and start again'.*

27. My family were very supportive throughout, however it was extremely difficult at times. I had to make sure they did not come near me if I ever cut myself or anything playing football or doing other activities as they would try to help. My young children (at the time) did not understand why they needed to keep away from me. This was very difficult and resulted in my younger son believing for many years that I did not want him.

28. I did not want sympathy as I did and always have played active sports but it was something that both my children did notice growing up; that was not right. I should have been able to play with them without the fear of transmitting a deadly illness to them.

29. My extended family were always suspicious as they thought it was another form of AIDs. People saw HCV in those days as basically AIDS in another word. Even medical staff thought they were related diseases which did not help.

30. Therefore I could not tell many people due to the stigma attached to it. People did not want to come near me and I had to keep news of the infection a secret. Only **GRO-B** my parents and eventually her parents knew. We told our children later after they saw me using needles regularly for treatment, but only when they were old enough to understand.

31. The single biggest impact of that HCV had on me was the effect it was having on the woman I love. I was scared and was prepared to leave GRO-B so she would not see me die.

32. I was told I would not live to the age of 50. So by 45 I was paranoid. I did not want GRO-B to be my carer and babysitter. I did not wish that on her; I loved her. For 3 or 4 years this drove a massive wedge between us and we did temporarily split up for a while. That is why I would have loved counselling but it was never offered as an option. I needed it to fix the mind-set and paranoia I had. We did though have a lot of marriage counselling and fortunately this resulted in us staying together.

33. The impact of my infection on my career has been huge; no one has understood just how much. However, I have had a good career, but I have had to omit HCV from the job applications I have submitted as I would never receive a job offer if I declared it in a "Health Questionnaire". I know that I was turned down or overlooked in GRO-B (which resulted in me leaving after 13 years employment with them) when they found out I had HCV. I believe that it has had a severe financial impact on me as well. After GRO-B I could not get work for 6 months until I left HCV from the application information so it has been a major problem for me throughout everything that I have done.

34. I strongly believe I was capable and able to go further in my career. On many occasions (especially when taking treatment for HCV) my condition was well known to my Senior Management.

35. Latterly, the effect of the final (and successful) treatment has had both an enduring and lasting effects on my ability to work. I feel constant fatigue and cannot even think at times (especially when the job is more stressful). This has

resulted in me having to remove myself from the work place to recover. Again, this has resulted in a great financial burden.

Section 6. Treatment/care/support

36. I have not faced any difficulties or obstacles in obtaining treatment.

37. No counselling or psychological support has ever been offered to me. I would have found it useful should it have been offered.

Section 7. Financial Assistance

38. GRO-B mentioned the Skipton Fund to me but I had to go and find out about it and make the application myself.

39. After GRO-B filled in their part of the forms I received a Stage 1 lump sum payment of £20,000, which in their eyes made it right. I believe I got this payment in about 2004 soon after the fund was set up.

40. I then received my first regular payment from the Skipton Fund in April 2016 of £3,500 per annum, including the winter fuel allowance. This covered the period to March 2017.

41. In April 2017 I received £4,000 from the EIBSS for the next period until March 2018.

42. After an investigation by EIBSS, this then changed to £18,000 per annum for the period April 2018 to March 2019.

43. For the period of April 2019 to March 2020 I will receive £18,500.

44. The main issue I have faced in relation to receiving these payments was to *'prove'* to EIBSS that I was entitled to the payments and the inability to provide details going back over the 30 years. More notice should have been taken by them of my medical files.

45. Additionally, the section my GP filled in was charged for by my surgery; I believe others would have been charged as well.

46. These people hold, and have access to, all our medical records so I cannot understand why they need to come to me for so much information. I have had to fill in form after form giving the same information in order to increase the payments I receive. It seems to be just another stalling tactic. They do not need us to do all that when they have access to all the information themselves.

Section 8. Other Issues

47. I have no other issues.

Anonymity, disclosure and redaction

48. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

49. I do not wish to be called to give oral evidence to the Inquiry.

Statement of Truth

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

Signe GRO-B

Dated: 30th May 2019