Witness Name: GRO-B
Statement No:WITN2942001
Exhibits:
Dated: April 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 I was born on the GRO-B. I live at GRO-B with my wife and GRO-B children. I am currently unemployed and my wife is my full-time carer.

2. **This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.**

Section 2. How infected

3. I have Haemophilia type A, classed as severe. I wasn't diagnosed until I was around three years old. My GRO-B brother was also diagnosed with Haemophilia.

4. I was originally treated with Factor IX blood products. I was very young at this time so I am not sure why Factor IX was the blood product I was given rather than alternative treatments that were available at the time.

5. I attended Lord Mayor Treloar School in the GRO-B where I received Factor VIII concentrate. The Factor VIII was not effective, however despite that they continued to give it to me for a year and a half. Due to my inhibitors and the fact Factor VIII didn't work I still required Factor IX. I was treated prophylactically and was injected with Factor VIII so much that my veins collapsed. I now receive Factor VII blood products.

6. I was born in GRO-B and I remained a patient there until I was around 5 or 6 years old. My Consultant was GRO-B and she treated me from birth. GRO-B transferred to GRO-B and me and my family also moved to GRO-B in order to continue my treatment under her care. She was my consultant until I started at Treloars and I must have been approximately GRO-B

7. My parents were never informed that I could be at risk of infection through receiving blood products and they never would have let me receive anything that could have jeopardised my health. I recall that they constantly asked the doctors if the blood that was being given to me and my brother was safe. My parents were assured everything was fine. I would be brought into the same room every day where they would stick a needle in my arm and send me on my way. I was very young when I started receiving blood and I was never told I was at risk of potential harm.

8. I was infected with two strains of Hepatitis C (HCV) as a result of receiving contaminated blood products. I am not sure if I was infected with both strains at the same time. I was given so much Factor VIII I could have received them at different times.

9. I am not sure exactly when but my parents were called into a meeting at Treloars where they were informed that I had been infected with Hepatitis C. I

believe that Treloars knew of my infection for some time before they told my parents.

10. I was not told of my diagnosis with Hepatitis C until I was GRO-B in GRO-B My parents were the ones who told me and I remember that it was a very short conversation. I was very young and I didn't know what it meant. I assumed it was just a part of the disability that I had in regards to my Haemophilia.

11. I don't believe adequate information was provided to my parents to explain what Hepatitis C would mean for my health or how I was to be treated. They were barely told anything. The general gist was 'your son will be fine' and to get on with life.

12. I was not offered any treatment at the time of infection and I was not told of any treatment that was available to me.

13. The first treatment I received for Hepatitis was in GRO-B which was 18 years after I was initially diagnosed with Hepatitis C. It was a type of combination therapy of Interferon and Ribavirin. I had to take 4 tablets a day and an injection that I self administered once a week. I had horrible side effects from this treatment. After 6 months on the Interferon I was told that it wasn't working and I was taken off the medication.

14. After my first unsuccessful course of treatment I was offered an alternative treatment, I believe it was called Harvoni. I was told that it had an 80% chance of success.

15. My second course of treatment was successful and my Hepatitis is no longer detectable. Even though the treatment was effective I am constantly worried that the Hepatitis will return. In addition although the HCV virus is no longer detectable I still suffer from the symptoms that I had previously. The only difference is I am no longer receiving help for it which makes the whole situation worse.

Section 3. Other Infections

16. Other than the two strains of Hepatitis C I don't believe I received any other infections from the contaminated blood.

Section 4. Consent

17. I was definitely tested for infections without my knowledge. I was under the impression that I was being tested so regularly to see how the Factor VIII was affecting my body because that is what I had been told. In reality, they were testing to see if I had received contaminated blood. There is no other explanation as to how they found out I had Hepatitis C.

18. I feel that I was lied to about all the tests and that the reasons for them were completely misleading and neither myself nor my parents ever consented to them.

19. My parents weren't told that I was being tested for any possible infections. Nobody was aware other than those taking he blood tests. When my blood was being taken we were told it was just to see if the Factor VIII was working and that anything concerning my blood was to treat me for Haemophilia. Therefore my parents had no idea I was being tested and could not consent to it.

20. I do not have proof that I was used for research purposes but I really do feel that I was used for experimental purposes.

Section 5. Impact of the Infection

21. As a child I wasn't really affected by the news that I had been infected with Hepatitis C. I was very young and I didn't know what Hepatitis was and the doctors never gave me any information so I didn't see it as a big deal. I went

to a school for Haemophiliacs and a lot of people I knew were infected with Hepatitis C (HCV), Hepatitis B (HBV) or Human Immunodeficiency Virus (HIV). It seemed like a normal thing or just a complication from the Haemophilia. I had so many difficulties already with my disability that it just seemed like an additional problem. It wasn't until later in my life when I found out more information that I came to understand just how truly terrible it is. I have friends that have died as a result of receiving contaminated blood.

22. I recall vividly that in 2013 my life changed dramatically. I was in the bath and things had all been fine and then everything hit me at once. It was the beginning of starting to suffer from terrible symptoms. Since that day I have never returned to my normal state. I used to be full of life and always happy, I was completely carefree and enjoyed life. I then had what I can only describe as an emotional breakdown; I felt completely lost and didn't know what was going on.

23. This incident in 2013 was a turning point for me and has effected me ever since. I suffer from dizzy spells all the time, wherever I am. I'm always tired, even when I sleep well I wake up tired and I constantly feel fatigued. I have been so badly affected that recently a councillor told me that I should have been sectioned regarding how I was feeling. I was on anti-depressants for a year and it never helped me. I tried two different types of anti depressants and neither of them were successful.

24. Along with the headaches, fatigue and dizzy spells I also have a constant ringing in my ears that is torturous. I have not been able to get any respite from this. I also suffer from constant hot and cold sweats.

25. I have had MRI scans and my heart monitored but no explanation for my symptoms is ever given to me. The neurologist I was seeing has now signed me off and told me I can't be helped any further. I feel like I have been let down. I was given a horrendous infection, through no fault of my own, by people that were meant to help me and now I'm being sent away by those who are meant to help rectify their mistake. I feel despair and a constant fear

that nobody is ever going to help me and my condition will keep getting worse. I feel like I have tried everything.

26. Because my physical and mental wellbeing has been affected so drastically I have tried everything to figure out what is causing it. The neurologist I was seeing put me on a lot of tablets that made no difference. They were supposed to help the dizzy spells I suffer from but they have persisted and if anything have gotten worse. I have been told that these symptoms are likely a result of either Hepatitis C or the treatment I received for it.

27. When I started receiving Interferon and Ribavirin treatment for Hepatitis C in GRO-B my mood was affected. I became much angrier. I had a bad reaction and was constantly itching all the time. I would pass out on occasion and my memory was badly affected. It was so bad that when my GRO-B was growing up I would have to make videos of important milestones in his life because I wouldn't be able to remember them. This is really hard to accept and understand and it is something I cannot control.

28. As a result I would argue with my wife. When I started the treatment we had just had a baby and my wife had to deal with the stress of a new-born in addition to the issues her husband was facing. It was a very difficult time for both of us and unfortunately the effects of this treatment have not disappeared.

29. I also experienced hair loss as a side effect of my first bout of treatment.

30. After the first set of treatment failed I was offered a new treatment. This ended up being much better and had fewer side effects. I was no longer passing out or experiencing hair loss. However I did experience some side effects such as itchy skin.

31. I told my wife in the first month of dating of my infection because I didn't want to keep something so big from her. I think it was only fair to let her know as it wouldn't be right to keep something like that from someone that you intend to have a relationship with. I let her make an informed decision. My wife handled

it very well at the time. She had a lot of questions and wanted to know if she was at risk of infection. She was told she couldn't be infected unless there was blood to blood contact but we were advised by doctors not to share toothbrushes or razors. To this day I still keep my toothbrushes separate from my wife and children. We have learnt a lot more about the condition as knowledge of Hepatitis has improved and it no longer affects my wife as much as it did at the beginning of our relationship.

32. Other than my wife and a few family members I have always kept the fact I have Hepatitis C a secret. There's a stigma around it and I don't want anyone to know that I have it as I know people will treat me differently. I remember it was on the news that Haemophiliacs had been infected with contaminated blood products and people had very negative perceptions. On one particular occasion another parent at my son's GRO-B approached me and said GRO-B GRO-B I lied and said I wasn't but it just reinforced the idea that people wouldn't think of you as a person or treat you with respect. There isn't awareness around the infection and people don't want to go near you because they think you can be infected just through touching someone or sharing a cup.

33. I used to have much more of a social life before I started experiencing life debilitating side effects. I can no longer even go to the local stores without getting dizzy and being unable to function in a normal way. I used to go on family trips with my family but can now only manage a few hours out of the house before it becomes too much. I want to enjoy the time I spend with my wife and children and living with these effects makes normal activities almost impossible. Social situations are so much harder than they were 6 or 7 years ago before I began having these terrible side effects.

34. My infection also affects my relationship with my youngest child GRO-B GRO-B gets away with murder because I can't physically cope with the demands of having to discipline a young child. I know this is an effect of the Hepatitis C or the Interferon treatment I received because I never had this issue with my GRO-B GRO-B Arguing with my youngest child makes the issues I am facing

such as dizziness and headaches much worse and it makes parenting much harder.

35. I worked until I was about 20 years old. I used to work GRO-B I found it really rewarding and it would brighten my day. I loved what I did. Unfortunately I had to stop because of complications arising from my disability, it wasn't sensible.

36. My wife worked on and off until about GRO-B She had to stop working because I needed full time care. I wasn't coping well at all and either my infection or the treatment I received for my treatment started to affect my memory. It was so bad that on one occasion my wife came back form work to find I GRO-B Anything could have happened and we agreed it was too dangerous and we couldn't risk the chance of this happening again. It was very unfortunate as my wife had just been offered GRO-B at the time which would have resulted in a higher salary, she had to turn this down in order to look after me and the children.

37. Being infected with contaminated blood products has had a huge impact on my family life. I do not tell anyone of my infection because I know of the stigma that is attached to it. I have never told my children of my infection and they are not aware to this day. I have not been able to tell my wife's family either which has created arguments with my wife. I don't want to worry anyone and I feel like I have to carry a secret from people.

38. Everyday I am tormented with the idea of telling my wife's parents. I want them to know but it is difficult and I don't know how to explain as I have had to keep it a secret for so long. They would probably be angry that I hadn't told them and worried about their own health. I still argue about it with my wife regularly as she also doesn't want to keep it from her family.

Section 6. Treatment/care/support

39. Since I was cleared of the Hepatitis C I have no longer been able to receive treatment although my symptoms still persist. In fact, my symptoms have been consistently getting worse but I am told I am clear of the virus and there's not much more they can do.

40. I have never been offered any counselling or psychological support. I feel that it would have been beneficial to have someone to talk too and it would have also been good for my wife. Unfortunately this has never been offered to us.

41. I am now on Factor VII. Since being put on this treatment I have only have one bleed. The treatment I now receive is called Hemlibra and i haven't had to use it in over a year as it is so effective. Before Hemlibra I was on Feiba which was horrendous.

42. I have had a GRO-B I got GRO-B and in quick succession of each other. The GRO-B GRO-B was manageable but the GRO-B was awful. It was very painful and difficult to manage. I have been told by the NHS that I am only allowed GRO-B for financial reasons. I am worried I won't get treatment I need in the future.

Section 7. Financial Assistance

43. I received £20,000 from the Skipton Fund. I can not remember when I received this but it was before I met my wife GRO-B

44. I receive £1,500 a month from the EIBSS. This began around 4 months ago at the beginning of the year. Before this I didn't receive any monthly payments in relation to my Hepatitis infection and I would have to apply for grants in order to get things that I needed.

45. I receive a disability allowance and a mobility allowance that has allowed me to get a car.

46. I receive employment and support allowance along with my wife. We live in a GRO-B together.

47. It has not been straight forward to get things. Nobody tells you where to apply for funds. I have had to research everything myself.

Section 8. Other Issues

48. I want to know the truth. I want to know why they did what they did. Someone is at fault but nobody has been found culpable. Are we ever going to find out who is responsible?

49. I want to know if we were used as Guinea pigs and experimented on.

50. The whole time we have been made to feel like we have done something wrong and it is time somebody apologised to those who have been infected and affected.

Anonymity

51. I wish to remain anonymous.

52. I do not wish to give oral evidence at the inquiry.

Statement of Truth

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

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

Dated 21/05/2019

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)