Witness Name: GRO-B
Statement No: WITN1572001
Exhibits: WITN1572002- 03
Dated: February 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 GRO-B and I live at GRO-B GRO-B.

2. I currently live on my own and my GRO-B is in GRO-B.

3. 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

4. I had suspected Haemophilia when I was a child as I used to bleed a lot when I had teeth extractions. I was never diagnosed as a Haemophilic.

5. I believe I was first given Factor FVIII (FVIII) on the GRO-B when I had a tooth extraction, aged about GRO-B years old. I believe this was the first and only

time I was given FVIII. I was treated at the GRO-B GRO-B. After this, I was given heat treated FVIII for my bleeds.

6. I was not provided with any information or advice beforehand about the risk of being exposed to infections from contaminated FVIII blood products.

7. As a result of being given FVIII, I was infected with Hepatitis B (Hep B) and Hepatitis C (Hep C).

8. I was never informed that I had Hep C even though I had it in my body for many years. My father died in GRO-B as a result of being infected and even then I was kept in the dark. I did not understand the nature of his death and I only just became aware of the issues that things were not quite right. I therefore had a Hep C test in GRO-B, and the test results came back positive. No one at any point thought to test me or tell me that I had Hep C.

9. When I had my Hep C test, I did it under an anonymous name at the sexual health clinic at GRO-B as I live in a very small town and I did not want people to know about my test results or that I was tested for Hep C.

10. The doctor just told me my test results over the phone and then I went to see my GP. He did not provide any information about Hep C but just referred me to the hospital where I was offered treatment. It was not until I finished the treatment that I realised that I had Hep C in my body for over GRO-B years.

11. At the hospital, I rarely got to see a specialist doctor, it was just a nurse. I had scans which revealed that I had bright patches on my liver. The nurse informed me that I should take the Interferon treatment sooner rather than later as there was a risk of liver damage. Even at that point no one told me where the Hep C came from or how long I had had it.

12. I do not believe I was provided with adequate information to understand and manage the infection.

13. I believe that adequate information about the infection should have been provided to me earlier. I was pregnant in GRO-B and I had visits at the

Haemophilia department. I believe the doctors must have known that I had Hep C at the time, but they failed to tell me. I did not want to put my unborn baby at risk so they should have told me. I also do not know who I could have inadvertently infected along the way over all those years.

14. I believe that the whole situation was handled appallingly and I believe the whole cover up was an act; otherwise I would have been informed of the infection years ago.

15. I was only given very vague information about the risks of others being infected as a result of the Hep C. Once I knew I was infected with Hep C in GRO-B, my son was GRO-B years old and I had to get him tested for Hep C too. I would not have known there was a risk to myself or to my GRO-B to start with unless I got myself tested.

Section 3. Other Infections

16. In GRO-B I also had a HIV test at the same time as the Hep C test at the GRO-B I wanted to be tested for all possible infections as I was fearful that I could have contracted them too. Fortunately, the test results came back negative. I do not have any other infections other than those stated above.

Section 4. Consent

17. I believe that I was treated and tested without my knowledge and consent for sure. After looking though my medical records I found a letter from GRO-B GRO-B to GRO-B, dated GRO-B which states that "preliminary screening showed her to have antibodies to Hep B core antigen, although she is Hep B surface antigen negative". A copy of this letter is exhibited at "**WITN1572002**". At the same time I was also tested for HIV, which was negative. I was never told that I was being tested for Hep B let alone HIV in GRO-B I was shocked when I saw this letter in my medical records. It is quite scary to think that this was happening under my nose and nobody told me.

18. There is a further letter in my medical records, dated GRO-B, which states that the doctor was very aware of the problems associated with non-heated blood products and that it was recommended that all the patients should be tested for HIV. This shocked me as it seems that the doctors knew there was a risk involved with FVIII. I was never told that I was going to be tested. A copy of the above letter is exhibited at **"WITN1572003"**.

19. I do not think my parents and I were told that I was being given FVIII treatment. There are no consent forms mentioning FVIII in my medical records.

20. I believe we were not given adequate or full information about FVIII or the risks involved. The doctors and nurses did not offer me anything unless I asked and they always tried to keep me in the dark whenever I asked questions.

21. I believe that I was tested for the purposes of research. I know I was tested in GRO-B, when I was about GRO-B or GRO-B years old and I believe it was for the purposes of research.

Section 5. Impact of the Infection

22. I suffered mental effects as a result of the infection. I was living in secrecy as everyone knows each other in the town where I live. I did not want the fact that I was infected with Hep C out in the public domain. Living in secrecy is awful as I have to keep people at arms length. I am very isolated, lonely and only have a couple of acquaintances who know of my infection. I am always very miserable, tired and have brain fogs all the time. The brain fogs and fatigue continue today. I have suffered very bad insomnia since treatment and use sleeping pills.

23. My GRO-B has had to look after me since he was GRO-B years old. Being his mother, this was very difficult for me putting a burden on my young son. The fall out with my family is also tragic. My mother went into GRO-B, and my sister has also become very ill after she has seen my father die from Hep C, and

knowing that I had also been infected. It is just so horrible. I am so sad and angry that no one ever told me that I was infected with Hep C and that our small family is so damaged.

24. I also suffered physically as a result of the infection. I was getting tired all the time and had swollen ankles which I thought were unusual. I also had pain in my liver which made me very uncomfortable. This was all prior to the diagnosis and I just got on with it without thinking much further about it. After the diagnosis, I suffered from depression and my health started to deteriorate. I did not suffer from severe cirrhosis but the nurse told me that I had some liver damage.

25. As previously stated, I was offered treatment in GRO-B. However, I did not start the treatment until GRO-B. I waited to have the treatment to get my head around it and for my son to be slightly older. The treatment consisted of Interferon and Ribavirin which was horrific and I do not ever want to have this treatment again. The course lasted a year, which I completed and it cleared the Hep C.

26. I did not face any difficulties or obstacles in accessing treatment. I was initially offered it but I refused it as stated above.

27. I believe the hospital could have made it clearer that there were new treatments on the horizon, with a likely time frame.

28. I suffered from mental and physical effects as a result of the treatment. I lost a lot of my hair and my hair is now really thin. My weight loss was extreme and I became so thin. I developed eczema and I was utterly exhausted and could not walk down the stairs without having to lie down and rest. During this time, I could not look after my young son who was only about GRO-B years old. When he came home from school, I often could not even make a cup of tea for him or wash up the dishes. It was like this for a whole year and I just could not live a normal life. I also suffered from depression and it was awful at the time. I asked for depression medication but was discouraged. I lost my quality of life

as a result of the treatment. My eyesight also went from being perfect to needing both reading and distance glasses.

29. I had monthly blood tests and there were a few staff at the hospital who did not want to take my blood, which was horrible. Some staff at the hospital were so judgemental, which was not nice.

30. I kept the infection private and as a result my social life was affected. I was unable to drink any alcohol and whenever I had one cup of wine, I felt very wheezy. I therefore isolated myself to my home and kept the infection a secret between my son, myself and two close friends. I did not even tell my mum as I did not want to worry her, as my father had died after having been infected with Hep C. I did tell my sister who did not really engage with it as she was too upset.

31. There was a stigma attached at the time to the infection. I remember an incident at the hospital when a nurse screamed, recoiled and jumped away from me. I was confused and teary and I did not understand why she was doing this. I knew things were not right but it was appalling the way she reacted.

32. As a result of the infection, my son was heavily impacted and went through a lot of burden. Whilst I was going through the treatment, my son became my carer. He has lived since GRO-B years old not being able to tell anyone about the Hep C which is a lot for a young child to take on. He has had counselling and now permanently struggles with anxiety and depression.

33. My sister has GRO-B which I suspect she probably got through watching my father die and hearing about me. It became too much for her.

34. I used to have a good job and was in a secure financial state, but had to give it up as I was getting too tired and was unable to cope whilst on the treatment. I went back to part-time work later but on a much lower level and salary than I used to be. I am still working only part-time. This caused a huge financial affect and loss of self-confidence in me.

35. It is devastating to think about what my life could have been like, which is so tragic.

Section 6. Treatment/care/support

36. I faced difficulties in trying to see a doctor. It was not simple to see the liver specialist. I saw him rarely and then I educated myself and had to request having my viral load checked early on in treatment. I needed a friend to support me with this request as it was a battle and I was too weak to fight alone. Unless I asked, I was not offered visits with the specialists. After treatment, the nurse told me to 'put it in a box and forget about it' which I believe was the hospitals way of trying to stop me asking more questions.

37. The GP referred me for Cognitive Behavioural Therapy (CBT) in order to help me with my anxiety and stress. However, this was wholly inappropriate counselling and it was totally useless. If I was offered the correct counselling I believe it would have helped me as it always helps to talk about things.

Section 7. Financial Assistance

38. I received the Stage 1 lump sum payment of £20,000 from the Skipton Fund just after my diagnosis.

39. I also receive a top-up payment of £18,500 (£1,500 a month) from EIBSS. To get this payment I had to convince my GP to fill in the form for me.

40. I believe I heard about the Skipton Fund from the Tainted Blood Group.

41. I believe that the financial assistance I received was not enough and we have no financial security as we do not know how long the payment will last. As it stands, in 2 years time all these payments could stop and I do not know where that would leave me and my son. That is my biggest anxiety. We were told that this monthly payment only runs for a period of time and will run out in 2 years time or at the whim of a new government.

Anonymity, disclosure and redaction

42. I confirm that I do wish to apply for anonymity.

43. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

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

Dated 28-2-19