Witness Name: GRO-B
Statement No.: WITN2171001
Exhibits: None
Dated: 5th November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 November 2018.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966. My address is known to the Inquiry. I am employed as an GRO-B GRO-B and married to my husband, GRO-B: H. I intend to speak about my experience in dealing with my husband's diagnosis of hepatitis C following his infection through the use of blood products in relation to his Haemophilia A. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

Haemophilia

2. My husband has received treatment for his Haemophilia A for the entirety of his life. He has told me that he was 18 months old when he first received treatment for this.

3. H haemophilia was treated with Factor VIII.

4. When H was a child I believe he was treated at Yorkhill and Oakbank, which does not exist anymore as I understand it. Once he was of age – possibly 16 or 18 – he would have only been treated at Glasgow Royal Infirmary. I believe that H has required transfusions on a number of occasions.

5. It would be very hard to pinpoint when H was infected due to him having received treatment for his haemophilia over the course of his life. We did try and get his medical records but we were told that the records from 1971 to 1975 were missing.

Infection

6. I believe that H was diagnosed in 1991 or 1992 with hepatitis C. We differ on when we think that he was diagnosed. He will be able to tell you when he thinks he was diagnosed. I believe that it was while H was at an appointment at the hospital that it was suggested that he get tested. I am unsure if it was a doctor or nurse but I believe that it would have been at the Glasgow Royal Infirmary.

7. I am unsure of the quality of the advice given to my husband to manage his infection.

8. I am unaware of if there is any reason that this information could have been provided to my husband earlier.

9. I am unsure how well the information about my husband's infection was communicated to him.

10. I myself got tested as I was pregnant and had my daughter in 1993, to ensure that she would not have the infection. I understand that if the mother of a baby is negative then a baby born from a couple where the man has Hepatitis C would not have been affected. I am unable to recall what information was given about cross-contamination or the risk of infection to others.

11. H GP would have been at H from 1959 to 1987 and H from 1988 to present, but he does not attend his GP often.

12. When H was tested they tested for Hepatitis, HIV and other blood borne diseases but only hepatitis C came back positive.

Section 3. Other Infections

13. I do not believe H has been infected with any other infections known to be related to infected blood.

Section 4. Consent

14. I do not know if H was treated or tested without his consent. As I have stated I am sure at no time was there any risk mentioned in relation to his necessary treatment for haemophilia.

Section 5. Impact

15. If you were to ask H how he has coped with his diagnosis and subsequent treatment, he would say that he was fine. This would just be him being stoic, as he does not like to give in to anything placed in his way.

I would say that his diagnosis, treatment and his condition generally have had a huge impact on our lives, both separately and together.

16. H received his first treatment around 1993. H received further treatment in 2014 (following the treatment I will go on to describe). It may have been around then that he was diagnosed as having liver issues and had to attend the liver clinic. I believe they said that he had fibrotic scars and general scarring on his liver.

17. A consultant saw the scans of H liver and it had reached a level where they thought treatment was necessary. I believe this is the normal course of action; to wait until the damage is a certain level. I am unsure of the name of this treatment, but it would have been at Glasgow Royal Infirmary.

18. I believe that once H was diagnosed they put him on a course of Interferon. I do not recall exactly how long this went on for but it felt like forever. I am unable to give an estimate for how long he went through this treatment.

19. H did not seem to have any flu-like symptoms that were obvious to me until he got the Interferon treatment. It seemed to spur on the flu-like symptoms. H is not the sort of person to let anything hold him back and is the type to just to get on with things.

20. It was only when H started looking into how he might have been infected that he found out that this was likely through blood products. This information was not given to him by the NHS at any point between being tested and his diagnosis. I believe that he discovered somewhere that it was American blood from prisoners. I recall that other countries had stopped doing this but Scotland had carried on.

21. H was put on the Interferon treatment straight away around 1993, and right away he seemed to have the tell-tale flu-like symptoms. I do not feel that any adequate information was given to him.

22. When H was on his second round of treatment in 2014 he was supposed to be on the treatment for a year, but his health declined so much while he was being treated that he only lasted six weeks of the course. I do not recall any alternative treatment being offered at that point.

23. The treatment they gave him was in injections and pills. These were just done at home. Every second day he had to inject himself in his tummy and his thigh. He would alternate as this is what he was told to do. The pills he was on, which I do not recall the name of, left him in a rash.

24. H did not need treatment for some time until his liver levels were bad enough to warrant treatment.

25. I am unsure if H had any difficulties in accessing treatments.

26. I am unsure if there are any treatments that ought to have been made available to H.

27. I think H coped not too bad considering what was going on. A lot of things happened at the same time. He was rushed into hospital and they said there was no connection to his hepatitis, but it was his kidneys that were affected.

The treatments H did have were very draining and at one point we had to turn our dining room into a bedroom for him as he was so physically weak that he could not manage the stairs. I do not recall how long this went on for but it felt like forever. It was a long time. It affected our relationship as it was more like we were living as brother and sister than husband and wife.

28. I do not believe that H hepatitis C diagnosis affected the likes of his access to dental care. H had access to a specific dentist for haemophiliacs, and had someone privately to deal with chiropody as this is something that is affected by haemophilia.

29. With H work, he is now considering going part time, and this is due to his employer pushing him towards promotions. Due to his symptoms and what we call the brain fog, H would not be capable of taking a higher position at his place of work. He would rather just go part time, where there is no scope for promotion or moving up the ladder, than explain to his employers about his condition. H GRO-B GRO-B GRO-B

30. Were it not for his condition H would definitely have gone for these promotions as they came up. He is sitting doing the same job as people who are less qualified than he is, but this condition has really stifled any ambitions he had. Without his condition I have no doubt that he would have moved up the ladder at his job and gone for promotions, because he was very good at his job. I think his condition now causes concentration issues at times and this does not help in his day to day work.

31. H does suffer from mood swings and has suffered from depression since his diagnosis. H had not gone for treatment about this but I do feel that haemophilia group meetings have been helpful for him. I think part of why he has not gone to just a regular doctor for treatment is that if he goes he will have to disclose why he feels the way he does. I feel that this has been true throughout the time following his diagnosis,

but especially in the past where more stigma has come from press coverage.

32. H generally avoids any conversation that might lead back to his hepatitis C.

33. H condition has had a huge impact on our family life. It was not good. I was a young girl of around 26 or 27 years old at the time of H diagnosis. I was 27 when I had our daughter GRO-B. Things were never the same due to his diagnosis. It certainly affected how many children we had. GRO-B and would definitely have had many more children if it was not for H condition. I would have been too worried about getting infected. I did not want to take any chances.

34. I think his condition did also affect how capable H was with raising GRO-B He was too weak to really assist a lot of the time. He has poor concentration due to his condition and I was wary of leaving him with her by himself because of this. I have a big family though so if they knew H was in by himself they would sometimes make an excuse to pop in and check in on him.

35. I believe that his condition has also had a big impact on H social life. H has a lot of friends and he would go out for drinks with them. He would not drink a lot, which made it especially shocking when a doctor at one stage tried to infer that the liver problems were related to H's drinking. H started going out much less once he was diagnosed. We have not told many of our friends about his condition.

36. We have two friends that know everything about H condition and I think that makes him more comfortable around them. GRO-B GRO-B

37. Our other friends only know what little H feels comfortable telling them. Generally they just know that he is in poor health, but with his limp he quite often just blames it on with arthritis.

38. I do feel that we have to push him to get him to do things. He was very social before his diagnosis. I think he is worried about questions being asked, especially with any news coverage going about relating to his condition and with this new inquiry. I think it makes him more wary.

39. H condition has also affected me. I had to go on anti-depressants at one point and required a period of time off of work, and going part time. I really got angry about the whole thing and upset. The fact that this inquiry is taking into account those of us who have been affected has been helpful with my anger about the situation as it is good to finally be heard, rather than ignored.

40. As my daughter grew up she would ask for a sister and I had to brush off the subject. I also had the difficult task of telling her she would be a carrier for haemophilia, which must be hard for a young girl.

41. Due to her being a carrier for haemophilia, my daughter would sometimes have to go in before having anything done at hospital to top up her levels. This had to be done when she was going in to have her tonsils taken out.

42. When my daughter was between 10-12 years old we told her what we thought she could reasonably understand. We answered any questions she had and had to make sure that she knew not to discuss the situation with anyone outside of the house. We had to wait until she was at an age where we thought she would not just blurt out about her dad's condition.

43. I do not think my husband's condition had much lasting impact on my daughter. We got her through school and through university. We never

told her how bad things were. We kept as much as we could from her. I do not believe that anything in relation to her dad's health had any impact on her school or university performance. She would complain if her dad didn't turn up to the likes of her school plays, but I always went so that helped. She is such a daddy's girl. I would make excuses when she was younger like that he had a bleed. I would blame it on something beyond just him feeling terrible.

Section 6. Treatment/Care/Support

44. While it was suggested at Glasgow Royal Infirmary that my husband get tested, I am not aware of any follow up support having been offered by them upon his diagnosis, nor before when he would have felt he was at risk of having a blood borne disease. I think there may have been some sort of counselling offered through Haemophilia Scotland. He has not accepted this yet, but I think he is coming round to the idea. I hope he will accept it. He does go to these support meetings when he is free and able and I think that helps.

Section 7. Financial Assistance

45. I believe that we have received £50,000 from the Skipton fund over two payments consisting of £20,000 and £30,000. I do not recall exactly when this was paid to us.

46. The Caxton fund has been helpful with paying out for a new roof and boiler through a grant for this. I do not know how much we received for this. I think we may have sent them quotes and they picked one to go with. I believe they also give us £500-1000 a year for heating. I am not entirely sure and H may be best placed to answer about that.

47. H did any of the applications for any funding so I am not aware of if there were any difficulties with this. I think it may have been an online

application but I am not sure. Any funds received were for H and nothing was specifically assigned to me as an affected person.

Section 8. Other Issues

48. At no point has the NHS accepted any blame for what happened to H. The government insultingly said that they were sorry for what happened to those who were infected but did not seem to accept or infer any blame. H gave a statement to the Penrose Inquiry, which he and I both feel was a total waste of time as the only thing to come out of that was that they told people that if they received a transfusion or other blood products then they should be tested for blood-borne diseases.

Statement of Truth

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

Signed GRO-B

Dated 21/1/19