Witness Name: GRO-B
Statement No.: WITN0866001
Exhibits: None
Dated: 10 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 March 2019.

I, GRO-B, will say as follows:

Section 1. Introduction

1. My name is GRO-B. I am 40 years of age having been born GRO-B 1978. My address is known to the Inquiry. I am married to GRO-B: H and have been for 23 years. We have 3 children together. H suffers from mild haemophilia A and epilepsy. H also suffers from hepatitis C ("HCV") that he contracted as a result of receiving contaminated blood products.

2. I intend to speak about H's experience of contracting HCV infection, subsequent liver damage. In particular, I will discuss the nature of his HCV infection, the difficulties H has faced receiving treatment and how the diagnosis has affected H, my family and myself.

Section 2. How Affected

3. H was 18 months old when he was diagnosed with mild haemophilia A after he was taken to the Birmingham Children's Hospital for treatment of a cut that would not stop bleeding. Throughout his childhood, H received

blood products as and when needed to treat his bleeds. He received cryoprecipitate and Factor VIII blood treatment on many occasions throughout his childhood and began using synthetic blood products when they became available.

4. During his childhood, H's haemophilia was treated at the Birmingham Children's Hospital ("the Children's Hospital"), where he was under the care of Dr Hill. When he was approximately 16 years old, H's care moved to the Queen Elizabeth Hospital Birmingham ("the Queen Elizabeth") where he was under the care of Dr Wilde until Dr Wilde's recent retirement. All of H's treatment for his haemophilia and HCV has occurred at either the Children's Hospital or the Queen Elizabeth.

5. When H was 19 years old he received a letter from the Queen Elizabeth advising him that he had been infected with HCV. At the time, H and I knew each other but were not in a relationship. At a subsequent appointment, Dr Wilde told H that he had contracted HCV as a result of receiving contaminated blood products for the treatment of haemophilia. H was not told which specific batch infected him with HCV.

6. H was always very happy with Dr Wilde's care. Dr Wilde was always very approachable and would spend long amounts of time with H. After H's diagnosis, H had an appointment with Dr Wilde where he was given general information about his HCV infection. Dr Wilde and his team were at the time, and up until his recent retirement, always available and willing to support H. However, H did not receive any information on how HCV is transmitted or whether anyone else, myself included, was at risk of being infected with HCV through H.

7. Neither H nor his mother were made aware of the risk of being exposed to HCV infection through blood product treatment. The family knew of the risks of contracting HIV from blood products as H's Uncle GRO-B: U1 sadly contracted the disease and passed away from it when H was younger. Our family has spoken many times about how the HCV diagnosis

was a huge shock to H and his parents. After H's diagnosis, his Uncle GRO-B: U2 was also diagnosed with HCV, which sadly led to his death.

8. I think H should have been provided with more information about his infection when first diagnosed. When we started our relationship, we didn't know whether I was at risk of contracting HCV or whether it could be passed on to our children if we had them.

9. When H and I thought about starting a family we had an appointment with medical staff at the Queen Elizabeth. The staff told me that I had a 3% chance of contracting HCV from H. When I fell pregnant with our first child, I underwent numerous tests to see if the children or myself had contracted HCV. Thankfully, the test results were negative.

10. I think the doctors should have told H about the risk of HCV infection from blood products if the risks were known.

Section 3. Other Infections

11. In addition to HCV, H was also infected with 'CPE'. I was married to him at this point. I remember doctors and nurses at the Queen Elizabeth informed us that not much was known about CPE or how to treat it. All I remember being told was that H contracted CPE whilst at the hospital. To this day, H and I know very little about CPE and whether I am at risk of contracting CPE through H.

12. After H and I got married, he received a letter stating that he may have been infected with variant Creutzfeldt Jakob Disease (vCJD) as one of the batches of blood he received had been contaminated with the vCJD. The letter came completely out of the blue and it devastated H and myself. At the time, it nearly pushed H to have a break down. I still can't believe H was told this information by letter. It would have been less upsetting if H was told of the risks in person rather than by letter.

13. Unfortunately, there is no available test to detect vCJD meaning that it is impossible to know whether H has been infected. We were told that the only way to establish vCJD infection is to take a biopsy of his tonsil after

he died. Thankfully, H has never developed any of the symptoms commonly associated with vCJD.

14. I do not believe that H has been infected with any infections other than HCV, CPE and potentially vCJD.

Section 4. Consent

15. H's mother provided consent on his behalf for all the treatment he received as a child, including the cryoprecipitate and Factor VIII blood product treatment. As an adult, H has always consented to blood product treatment following his bleeds.

16. It is possible that H's blood has been tested without his informed consent or knowledge. Certainly, prior to his diagnosis H was not told that his blood was being tested for HCV. The doctors may have been testing his blood for other diseases without H's knowledge.

17. These days every time H and I visit medical professionals he is required to have a blood test to "test his levels". On one occasion in 1997 H was required to provide a large quantity of blood as part of a vaccine against hepatitis B ("HBV"). Both H and I are unsure if the blood he provided was used for the purposes of research or testing.

Section 5. Impact

18. H has suffered liver damage as a result of being infected with HCV for which he is under the care of Dr Mortimer of the Queen Elizabeth Hospital. His liver damage is currently at stage 6 or 7. Significantly, H is unable to receive treatment for his HCV infection, as it would clash with his epilepsy treatment. This means that H's HCV infection is left untreated. My children and I constantly worry that H's liver damage may develop into something more serious in the future.

19. H's energy levels have been significantly reduced as a result of his HCV infection and other medical conditions. Prior to being infected, H was quite active but is now constantly exhausted. H spends a lot of

time at home as he finds leaving the house and travelling to be quite difficult. H's various medical issues mean that he requires day-to-day care and support and I am H's registered carer. I worry about leaving H alone for extended periods of time meaning that I am often at home as well.

20. H suffers from regular headaches and gets sore and tired eyes very easily. He is also in semi-constant pain these days and suffers from joint aches, ankle pains and stomach issues. I think these aches and pains are side effects of his haemophilia and untreated HCV.

21. It is very difficult for my family to go on holiday together and H is often unable to attend family days out. This means that sometimes the family goes on outings whilst H stays at home. Whilst H says he is okay with this and is happy that the family is having fun, it makes me feel extremely guilty and anxious that H has to miss out. I feel bad for having to leave H behind and I worry about whether he will be okay by himself.

22. Although we have gone on family holidays in the past, and will do so again this summer, it is very difficult to plan such holidays and both H and I have been unable to realise our dreams of travelling to and visiting the USA. Travel is very difficult for H and we always have to consider how close to hospitals and treatment centres our destinations are.

23. Both H and my social lives have been significantly negatively affected as a result of his HCV infection and other medical issues. H has both good and bad days meaning that it is difficult to commit to plans in advance as I never know how H will feel on any given day.

24. When H was first diagnosed with HCV at the age of 19, he was reluctant to enter into a relationship with me as he was concerned that he would put me at risk of infection. H felt that I could find a better life with someone else, which is so upsetting for me to hear. I have never been interested in a life without H.

25. H does require my day-to-day care and support to the extent that he was once described as my "fourth child". I find such descriptions really insensitive and upsetting. While I have to care for H, our relationship is

more than that. We have made a life and a family together. Sadly, even some of my friends and family members have made insensitive comments to me regarding H's health and well-being. These comments do nothing to help H or myself.

26. I am lucky that I have a healthy and supportive friendship circle, many of whom are nurses who I am close to and able to confide in. Over the years, I have seen many of H's friends "drop off" as H has been unable to keep up with them socially.

27. I often can't sleep at night for worrying about H's health which is constantly on my mind. I feel I always have to be strong for H and my children but his illnesses do take a huge toll on me. I'm constantly stretched thin as I am responsible for the household chores, finances and day-to-day running. H and the children rely on me for transport and I spend a lot of time in the car driving H to his various medical appointments and ferrying the children around.

28. Over the years, our family has suffered from significant trauma, as many of our family members including my parents, father-in-law and H's uncles have passed away. H's uncles, U2 and U1, were both haemophiliacs infected with HCV and HIV respectively through contaminated blood products. Devastatingly, both U1 and U2 passed away from their illnesses. U2 sadly passed away after a failed liver transplants for treatment of liver damage caused by his HCV infection.

29. Our family is incredibly aware of the tainted blood scandal and its devastating affects. The fact that H is not being treated for HCV in order to prioritise his treatment for epilepsy means that I am constantly worried that H may eventually end up like his uncles. I remember clearly visiting U2 in hospital when he was dying. He was so yellow and hooked up to numerous machines. I'm terrified this will happen to H.

30. The deaths of U2 and U1 and H's HCV diagnosis have had a profound impact on our family dynamic. Our family is all too aware of death and illness and H's health is always at the front of our minds. Our children also hold these fears. Due to H's health issues, he has not

been able to play with our youngest daughter as much as he did with our two eldest children, which makes me feel sad and upset for their relationship.

31. Our children get emotional when they discuss H's health, and we all worry for the worst when H suffers a bleed, seizure or any other medical issue. Sometimes, I am forced to lie to my children and tell them that their father will be okay when I don't know if that is true.

32. Although H presents as a happy go lucky person, I am able to sense that sometimes he is sad and depressed on the inside. On one family holiday, H said that he would be better off dead than alive, which was devastating to hear. I think H's health issues weigh on his mind and impact his moods. When he receives bad news about his health, he will tend to withdraw and present as flat.

33. I am aware of and feel the stigma attached to H's HCV infection. However, our family tries not to be affected by the stigma, and we live our lives with smiles on our faces. My children all enjoy healthy social lives.

34. I often think about how my relationship with H is very different to the relationships of other married people of the same age. H's health impacts what we can and can't do we do as a couple and we don't tend to socialise as regularly as many of my married friends as H finds it quite difficult and tiring.

35. Our family has been affected by the stigma associated with receiving disability pensions. I think this is made worse by the fact that H does not appear outwardly as physically disabled. I have found people assume we have made the choice not to work, and pass judgements on us. Strangers on the street have made offensive and insensitive comments for our use of blue-badges for car parking. I find when people see H doesn't use a wheelchair they make snap judgements that we shouldn't have pass as we are not "disabled enough" to have one. Whilst H takes such things well it impacts on my mood and makes me feel stigmatised and upset.

36. I would like to be able to work, as would H. Prior to having children, I did work which I enjoyed and I would have loved to return to work at some

stage. H and I have been unable to work because of H's health issues.

37. Although H's education was impacted by his treatment for haemophilia and epilepsy he was neither interested in nor enjoyed school. After he left school, H had a lot of job applications refused due to his health issues. People were scared to take him on in case he injured himself. Due to a combination of his epilepsy, HCV and haemophilia, H had to give up work when he was in his early twenties.

38. Over the years, H has found that he has been refused health, travel and life insurance on a number of occasions. Our family has relied on Government benefits and financial assistance from the EIBSS and its predecessors.

Section 6. Treatment/Care/Support

39. As previously stated, H is unable to receive treatment for his HCV infection as the medication reacts dangerously with his epilepsy treatment. In order for H to receive treatment for HCV, he needs to be clear of his epilepsy treatment for at least one year. On two occasions, H has attempted to stop his epilepsy treatment in order to commence HCV treatment. On the second occasion, he suffered a severe epileptic fit, which caused him to hit his head and suffer brain damage.

40. As H's HCV infection has been left untreated he runs the risk of developing serious medical complications in the future. H has been told that it is unlikely that new treatments for HCV will be developed, as the current treatment is considered perfect.

41. I don't believe H was offered support or counselling when he was first diagnosed with HCV, however he has since been offered both over the years. To date, neither H nor I have accessed counselling or other available support. I am aware that the Inquiry is currently working with the British Red Cross to provide psychological counselling.

Section 7. Financial Assistance

42. I can't recall when, but H were made aware by the Queen Elizabeth Hospital of financial assistance available to H from the Caxton Foundation and Skipton Funds. The medical staff helped us apply for financial assistance for H, and we faced no obstacles in receiving financial support.

43. In 2001, H received a £20,000 lump sum payment from the Skipton Fund, and we received £2500 annual payments from the Caxton Foundation for our heating and utility bills. I do not remember if H or was required to agree to any preconditions prior to receiving the financial support.

44. H currently receives monthly payments from the England Infected Blood Support Scheme ("EIBSS"), which has replaced the Skipton Fund and Caxton Foundation. I do not know the exact figure of the monthly payments we receive.

45. At one stage, H received a back payment of £7,000 for backdated payments owed to him. H has applied for his financial support to be topped up due to our low income, and whilst we are grateful for the financial support H receives, I believe that the amount of support we receive should be higher.

46. I have not personally received any financial assistance.

Section 8. Other Issues

47. Neither H nor myself have been involved in any litigation or campaigning relating to the Infected Blood Scandal as we are private people and have not to date been interested in participating.

48. However, I do keep in touch with the political and media coverage on the Infected Blood Scandal, more so than H. I once heard a half-witted apology on TV given by someone from the government that left me very annoyed. I felt as if the government was brushing off the genuine concerns of people who have been infected and affected by the scandal.

49. I would like to see the government own up and take responsibility for what has happened, and for there to adequate financial compensation to all those infected and affected.

Statement of Truth

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

Signed GRO-B

Dated 16/04/2019