Witness Name: GRO-B
Statement No.: WITN0426001
Exhibits: None
Date: 10 April 2019

INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 March 2019.

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

Section 1. Introduction

1. My name is GRO-B and I am 42 years of age having been born GRO-B 1976. My address is known to the Inquiry. I live in Birmingham with my wife of 23 years, GRO-B, and our three children aged 22, 19 and 14 years old. I suffer from mild haemophilia A and epilepsy, which prevents me from working. GRO-B is my full-time carer.

2. I intend to speak about my experience of contracting hepatitis C ("HCV") as a result of receiving contaminated blood products for treatment of my haemophilia A. In particular, I intend to discuss the nature of my HCV infection, the difficulties I have faced receiving treatment and how my diagnosis has affected my family and my life.

Section 2. How Infected

3. When I was 18-months old I was diagnosed with mild haemophilia A after I attended the Birmingham Children's Hospital ("the Children's Hospital") for treatment of a cut

which would not stop bleeding. While at the Children's Hospital, I was treated with blood clotting factors for the first time.

4. Since my haemophilia diagnosis, I have received blood-clotting products more times than I can keep count of. When I was seven years old I nearly died when I had 'epiglottitis' which required an operation at the Children's Hospital during which I received large amounts of cryoprecipitate and Factor VIII blood products. Growing up I was regularly admitted to hospital for treatment of bleeds.

5. During my childhood, I was under the care of Dr Hill at the Birmingham Children's Hospital. Growing up I was treated with cryoprecipitate until some stage when my treatment switched to Factor VIII products. I don't remember when this was. I started receiving synthetic blood products when they became available.

6. When I was 16 years old, my treatment moved to the Queen Elizabeth Hospital ("the Queen Elizabeth") where I was under the care of Dr Wilde until his recent retirement. I have only received treatment for my haemophilia at the Children's and Queen Elizabeth Hospitals.

7. In 1995, when I was 19 years old, I received a letter from the Queen Elizabeth informing me that I had tested positive for HCV. At the time, I didn't know what HCV was and didn't know that I had been tested for it. The diagnosis was a huge shock and I was really upset by the news I had been infected.

8. I was aware of the risks of HIV in blood products as my Uncle GRO-B:U1 passed away when I was 14 years old as a result of receiving HIV from contaminated blood products. I also knew about hepatitis B ("HBV") from the media and how bad that disease was, but I hadn't heard of HCV. I remember my Mum was also shocked by the news.

9. After my diagnosis, I attended an appointment with my Dad and Dr Wilde at the Queen Elizabeth Hospital. Dr Wilde informed me that I had been infected with HCV as a result of receiving contaminated blood products, but I wasn't told when I was infected or the batch number of the treatment that infected me. Dr Wilde explained what HCV was and gave me general information about the infection. Dr Wilde was

very nice about it all. He was always the type of doctor who you could call with whatever issue you had and he would make time for you. During appointments, he would often spend a lot of time with me and allow the appointments to run over-time. The nurses at the Queen Elizabeth were the same.

10. During my childhood, my mother used to provide consent on my behalf when I required cryoprecipitate or Factor VIII treatment. My mother was never informed of the risk of me contracting HCV from blood products, and I was never told, even when I was a teenager, that I was at risk of being infected with HCV through cryoprecipitate or Factor VIII treatment.

11. Looking back, I don't think I was given adequate information about my HCV diagnosis at the time. When I was diagnosed I wasn't given information about how HCV is transmitted or if I could give it to my family or friends. When I got together with my wife, I told her about my HCV when she realised how poorly I was. My wife, my mother and I went to the Queen Elizabeth to discuss the risks of transmissions and were told my wife had a 3% chance of contracting HCV.

12. When my wife fell pregnant, she underwent tests to see if she or the children had HCV. Thankfully, the test results were negative.

13. I think the doctors should have told me about the risks of HCV infection if the risks were known. If I had known of the risks, I probably would have consented to the treatment anyway because I needed it.

Section 3. Other Infections

14. In addition to HCV, nurses at Queen Elizabeth Hospital informed me that I also contracted a "CPE: infection. I don't remember being given much information about CPE or its effects. All I remember being told is that I contracted the infection while being treated at the hospital. To this day, I do not know anything about CPE or how it affects my health, body and lifestyle. I was told the infection does not go away.

15. At some point after being infected with HCV, I received a letter from the Queen Elizabeth Hospital Haemophilia Centre stating that there was a risk that I had been infected with Variant Creutzfeldt-Jakob disease ("vCJD") as I received blood products

from a donor who later developed vCJD. The letter came completely out of the blue and I remember being devastated when I received it. It nearly led me to have a break down.

16. After I received the vCJD letter, I had an appointment with Dr Wilde at the Queen Elizabeth where I was told that there is no test for vCJD infection and that the only way to confirm if I was infected was to if they performed a biopsy of my tonsil if I passed away.

17. I am still unhappy with how I was told about the risk of being infected with vCJD and I can't believe I was told by way of a letter. It would have been better and less upsetting had I been told face to face by my doctors.

18. Other than HCV, CPE and possibly vCJD, I do not believe that I have received any other infections.

Section 4. Consent

19. During my childhood, my mother provided consent on my behalf when I received cryoprecipitate and Factor VIII treatments. As an adult, I have always been treated with my consent.

20. It is possible that my blood has been tested without my knowledge and informed consent. My doctors have been testing and screening my blood for as long as I can remember. They would often tell me they were checking my "levels". For example, my doctors did not tell me that I was being tested for HCV prior to my diagnosis. It may be that doctors were testing me for diseases without my knowledge.

21. I can't say if my doctors were testing me for the purposes of research. I do remember one occasion in 1997 where I had a blood test as part of a vaccine for HBV but I can't remember the specifics.

Section 5. Impact

22. The HCV has caused me to suffer from a number of physical and mental effects. The HCV has led to liver damage for which I am currently under the care of Dr Mortimer

at the Queen Elizabeth Hospital. Currently, I am told my liver damage is a '6.5 rating', which I am told is not too bad considering how long I have been infected with HCV. I have been told '7' is a dangerous level.

23. The fact that my liver damage could develop into something more serious in the future weighs heavily on my mind. My uncle GRO-B:U2 who like myself was infected with HCV from contaminated blood products, had to have two liver transplants as a result of extensive liver damage caused by the infection. U2 sadly passed away soon after the second transplant, which failed. I remember visiting U2 at hospital during his final days when he was so unwell and he was strapped up to machines. I felt terrified that I could end up in the same position.

24. The HCV has had a huge impact on my energy levels. Prior to being infected, I was quite active, regularly riding my bike, going to the gym and playing football. Over the years, my energy levels have dropped and dropped until one by one I found I could not do these things anymore. These days, even a short walk down the street tires me.

25. I know my lack of energy could be due to my age, but I think it is more than that. I have less energy than other people of the same age. When my two oldest children were young, I had the energy to play with them. My son and I would regularly have a kick of the football or we would go to the park as a family. I can't do that these days because I don't have the energy to keep up. This has impacted my youngest daughter as she has not been able to spend as much time with me as the other kids.

26. I find that these days I never have much of an appetite and only eat small amounts of food such as some toast here and there. The HCV and the epilepsy medication cause stomach and digestive problems meaning certain foods upset my stomach. I used to enjoy going for a curry but I have had to stop this as curries no longer agree with me.

27. It seems I am in almost constant pain these days as I suffer from joint pains, ankle pains and stomach pains. I think these pains are probably combined side effects of haemophilia, HCV and epilepsy medications.

28. I suffer from regular headaches and tired eyes, which I believe is linked to my HCV infection. I can't go to the movies or watch TV for long periods of time without being in pain.

29. Planning family holidays has always been difficult as we are limited to where we can go and what we do. I find travel quite painful and we always have to consider if there is medical treatment near our holiday destination. These days, I don't have the patience or tolerance for family holidays as little things start to annoy me. I can't handle the noise or the disruption. My youngest daughter loves Harry Potter, so my wife and daughter recently went on a trip to London to visit the Harry Potter World but I wasn't able to go.

30. Mentally, my HCV status often weighs on my mind and impacts my moods. My wife would say that the stress of it makes me depressed from time to time. I have noticed that whenever I get bad news from my doctors I tend to feel low for a bit.

31. I have not been able to receive treatment for my HCV as my doctors say the HCV medication would react dangerously with my epilepsy treatment. I am currently prescribed Zonisamide (Zonegran), Carbamazepine and Lamotrigine for my epilepsy. My doctors have told me that I must be clear of these drugs for at least one year before I can start HCV treatment.

32. Currently, I suffer from small seizures on a nearly daily basis. I have tried to stop taking my epilepsy medication on two occasions and both times my epileptic fits became more regular and more severe. On one occasion I hit my head during a fit leaving me with partial brain damage. After this, my doctors and I made the decision that it is too dangerous to stop my epilepsy medication. Therefore, my HCV infection has been left untreated for many years.

33. My doctors tell me that there is no HCV treatment available that I can safely take with my epilepsy medication. I have also been told that no new HCV drugs are being developed because the current treatment is considered perfect.

34. I struggle to believe that I am the only person with both epilepsy and HCV and wonder how I am so 'lucky'. Surely there are other people in the same boat as me. It is so frustrating to know that there is a HCV treatment out there that works but I can't

access it. It doesn't feel fair. I sometimes feel like I am just sitting and waiting for my HCV to get worse, like my Uncle U2's did.

35. I have found that being infected with HCV does impact my treatment for other medical issues, including dental care. My dentists have told me that I have to be treated last so the medical instruments are not used on people after me.

36. I have noticed that paramedics, doctors and nurses immediately put on gloves when treating me, which sometimes makes me feel like a leper. I understand why they do it but I still feel like a leper.

37. Being infected with HCV, epilepsy and other medical conditions has hugely impacted my social life. I have drifted away from former friends because I no longer have the energy to keep up with them. One by one, my friends slowly dropped off. I had to stop drinking when I was diagnosed with HCV, so I lost that social activity. I find that I can no longer do many of the things I once found fun anymore. I don't leave the house much anymore.

38. I used to catch up with my father regularly and have a pint of beer or two but that has all changed. I can't tolerate alcohol at all. If I have even one drink I will feel sick for days. I remember one occasion soon after my diagnosis where I had half a point and was physically sick for weeks.

39. My HCV infection has profoundly impacted my families life. My wife is currently my registered carer meaning she has not been able to return to work. When we first got together I was worried about entering a relationship with her because of my HCV. I did not want to put her at risk of contracting HCV and thought that she would be better off with someone else.

40. Due to my medical conditions, it is difficult for med for me to join my family on days out. Sometimes, I am left at home whilst my family go out to enjoy themselves. I've learnt to be fine with this as I am happy knowing that my family is having a good time. However, this affects my wife who feels guilty and worried about leaving me behind. My family has always wanted to travel, particularly to the USA, but we have been unable to do so due to my HCV status and my discomfort travelling.

41. Suffering from HCV, epilepsy, haemophilia and other medical issues causes my family, including my three children, to constantly worry about my health. Both my son and daughter can get emotional when discussing my HCV infection and other medical issues. There is a constant fear held by my family members that I may die whenever I become ill or sustain an injury.

42. My family has also suffered a lot of trauma, including the passing of my uncles U2 and U1 from contaminated blood. The infected blood scandal is always on my family's mind.

43. My medical conditions have left me with the feeling that everything that is good in life gets taken away from me eventually. The things I enjoy have all been phased out of my life. Sometimes I feel as if I have been mugged of my life.

44. My youngest daughter was recently diagnosed with anxiety, and I know my illnesses cause her a lot of stress. When I have a health scare, my daughter will often ask my wife if I am going to die.

45. I am aware that there is a stigma attached to HCV but I don't let it bother me. I have told some people close to me about my HCV infection. Sometimes, the shock on their face is visible when I do so. My family try not to let the stigma affect our lives and my children in particular have healthy social lives.

46. One stigma I feel is the stigma associated with receiving the disability support benefits. People who aren't aware of my health issues often assume that my wife and I choose not to work. My wife and I wish we were able to work. It is not a nice having to rely on the government for your income. I have also received judgement in the streets for using disabled parking, in part because my disabilities are not obviously visible to others. I have had strangers in the street make comments but I try not to let these affect me.

47. Being treated for haemophilia as a child meant that I often missed school, but, to be honest, I never enjoyed school or education generally. I left school when I could.

48. Before my HCV diagnosis, I undertook some casual work with family members but I struggled to find work because of my haemophilia. Employers didn't want to take the

risk with me. When I developed epilepsy and HCV, my health became to poorly to work.

49. I have been refused bank loans due to my haemophilia, HCV and other medical conditions. I have also been refused life and travel insurance. Financially, my family relies on state benefits and EIBSS financial assistance. Money has always been something my family has had to think about. Growing up I went on a yearly holiday, but my family has had to be more careful with our money.

Section 6. Treatment/Care/Support

50. As stated above, I have not received treatment for my HCV infection as the treatment would react dangerously with my epilepsy medication. My doctors have told me that I need to be 'off' my epilepsy medication for at least one year before I can commence HCV treatment, which could lead to potentially life threatening seizures. My doctors have informed me that it is highly unlikely that a suitable HCV treatment will become available to me.

51. Given my past experiences, I am reluctant to accept new or non-conventional treatments for any of my medical conditions as I have been left with less trust in my NHS. If I find out that a new treatment carries new risks, I decline the treatment and ask for it to be trialled on someone else before me.

52. While I wasn't offered counselling or psychological support when I was diagnosed but it has since been offered to me. I haven't accessed these services, as I'm a private person. I have found that these days my doctors ask about mental wellbeing.

Section 7. Financial Assistance

53. I was made aware that I was eligible for financial assistance by the doctors and nurses at the Queen Elizabeth Hospital, and they helped me apply for financial assistance from the Caxton Foundation and the Skipton Fund. I found the application process to be quite easy and I did not face any obstacles in obtaining financial assistance.

54. In 2001, I received a £20,000 lump sum payment from the Skipton Fund, and around the same time I began to receive £2500 annual payments from the Caxton Foundation to cover heating and utility bills. I remember that when I was first offered the lump sum payment from the Skipton Fund, I thought it was a pay out to keep me and other people in my position quiet. I don't remember if there were any preconditions that I had to agree to in order to receive the payments.

55. Over the years, I have found the Skipton Fund's letters to be unhelpful and lacking information. They seemed to send letter after letter with the same information, going in round-about circles. The Skipton Fund would often send letters inviting me to attend seminars in London, which wasn't particularly helpful. Financially, it was difficult and I find travelling long distances physically painful.

56. I asked the Skipton Fund if they could send me some useful information in layman's terms but they never did. Instead, they continued to send repetitive and unhelpful letters. I ended up throwing half of the letters in the bin. I found the Caxton Foundation to be much better as they provided me with financial assistance for heating and utility bills despite the fact that I did not apply for it.

57. I have received monthly payments from the England Infected Blood Support Scheme ("EIBSS") since it replaced the Skipton Fund and Caxton Foundation. I do not know the exact figure of the monthly payments I receive. When the EIBBS was formed, my doctors helped me fill out the forms for my application and when it was approved I received a back payment of £7,000. I am currently applying to the EIBSS to have my payments increased.

58. I don't like to complain but I feel as if the financial assistance offered could be higher. I sometimes feel that other people get more financial support despite suffering less than what I have. However, I am grateful for the financial support I receive.

Section 8. Other Issues

59. I have been left with a feeling that no matter what I did in life, I could not win. The choice was between receiving blood products that stopped my bleeds and saved my

life, or being infected with HCV. Even now, I have to choose between HCV treatment and epilepsy treatment.

60. I have not been involved in any previous litigation or campaigning in regards to the infected blood scandal. A family member who is actively involved in the blood scandal campaigns referred me to the Inquiry.

61. The most important thing I want to see come from the Inquiry's work is for the government to take responsibility for what has happened to my family and me. I would like to see some accountability.. My wife, GRO-B, keeps up with the political coverage relating to the infected blood scandal and she found the apologies to date to be half-witted and annoying.

62. I would like to see the government provide compensation to all those infected and affected by the scandal. I know that some people have been suffering from infections acquired via blood products and blood transfusions for a very long time, and I want them to receive appropriate compensation.

Statement of Truth

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

Signed GRO-B

Dated 17/4/2019