Witness Name: GRO-B

Statement No.: WITN5688001

Exhibits:

Dated: 05/06/2022

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 25 November 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1971, and my address is known to the Inquiry.

2. I am a gas engineer, and I have three children.

3. I was diagnosed with severe haemophilia A when I was four years old. I intend to speak about my infection with HIV and Hepatitis C ("HCV") due to treatment with contaminated blood products. In particular, the nature of my illness, how it affected me, the treatment I have received, and the impact on my and my family's lives together.

Section 2. How Infected

4. I am the eldest of two children in my family, and I have a younger sister. When I was four years old, I had an accident at home, and I could not stop bleeding. My parents took me to Oxford University Hospital, which was not too far from where we lived in Buckinghamshire, at the time. I was diagnosed with severe haemophilia A, and it was the first recorded case in my family.

5. Upon further tests, it was discovered that my mother was a carrier of the haemophilia gene. Dr Rizza and Dr Matthews were the leading doctors at the Oxford Haemophilia Centre at the time and were in charge of my care.

6. As a child, my family and I had to travel from our village in Buckinghamshire, GRO-B GRO-B to Oxford so I could receive treatment.

7. By the time I was diagnosed, the new Factor VIII blood products had recently been introduced, and I believe I was among the first set of children with haemophilia who never received cryoprecipitate. It meant that treatment was always a quick process.

8. I do not recall being placed on prophylaxis, and I only had treatment when I suffered a bleed, which was fairly regularly. My right ankle joint was my main problem, and periodically I would have to wear a splint because of bleeds into the joint. I had numerous splints during my childhood.

9. The splints were very restrictive, which meant that I could not play as much as other children. The frequent hospital visits and intra joint bleeds meant that my schooling was regularly disrupted.

10. At one point, I was offered a place at a special school, which was like a medical boarding school, although I cannot recall the school's name, but I declined because I have always wanted to live a normal life.

11. In those days, prophylaxis treatment was not

the norm, and I think because of my age, the best option available to me was to attend the hospital whenever I had a bleed.

12. By 1977 or 1978, my mother was taught how to administer the injections at home, which made life easier. We still had to go to Oxford for regular tests and check-ups, but not as frequently as before.

13. My family moved from Buckinghamshire towards the end of 1983, and I changed hospitals to the Royal Victoria Infirmary in Newcastle, which was the closest haemophilia centre to where we lived. I was trained to do my own infusions by 1985 when I was 13 or 14 years old.

14. In my late teens, I moved to London in 1990, and my first hospital in London was the Royal Free Hospital.

15. In 1998, I broke my leg while at work, and I was taken to the Royal London Hospital. I was living in GRO-B at the time, so when I discovered that the Royal London Hospital also had a dedicated haemophilia department, I decided to transfer from the Royal Free Hospital to the Royal London Hospital because it was closer to where I lived. Since then, I have been under the care of the Royal London Hospital.

16. Throughout my childhood, I received Factor VIII supplied by Oxford University Hospitals until I moved to the Royal Victoria Hospital in Newcastle in 1983.

17. In December 1985, I found out I had contracted HIV. However, I did not find out about my HCV diagnosis until 1995/1996.

18. I can recall that it was just before Christmas in 1985, when Dr GRO-D called my mother and I in for a meeting. At the meeting he informed my mother and I that I

had contracted HIV due to contaminated Factor VIII products.

19. He was pretty blunt because I don't think there was an easy way of delivering such news to any parent or child. Now that I am a parent, I think about how devastating the news must have been for my parents because they must have thought the diagnosis was a death sentence.

20. After we were told, it was back to business as usual. They did not provide us with any information regarding how they would make future treatments safe, and as far as I can recall, the treatment remained the same, down to the brand used, for a long time.

21. They did not provide us with any advice on managing the risk of spreading the infection to other members of my family. There was no particular advice about dental care, and probably because there was no treatment for HIV available at the time, they did not offer us any treatment options.

22. I believe I found out about my HCV diagnosis in or around 1995 / 1996, at the Royal Free hospital, at a regular hospital appointment. I cannot recall the exact details, but I believe it was mentioned casually in the tone of "you have this as well", and again no advice was provided on how to manage the infection and any potential risks to others.

23. They explained that I had tested positive for HCV following an HCV and Hepatitis B (HBV) test. They also confirmed that I did not have HBV.

24. I have never received medical treatment abroad, and although I have tattoos, I got them done at a professional tattoo shop about ten years after my HIV diagnosis.

25. I have, in the past, had my ears pierced, but again I did this long after I was aware that I had contracted HIV and HCV.

26. I have never used intravenous drugs or lived a lifestyle that could have put me at risk of contracting HCV.

Section 3. Other Infections

27. I do not believe that I have received any other infections other than HIV and HCV due to being given infected blood products. I had jaundice in 1980 / 1981, and I was treated at the John Radcliffe Hospital, Oxford. This incident may be the origin of my HIV.

Section 4. Consent

28. I believe that I have probably been treated and tested without my or my parent's consent, given that I was receiving treatment in the 1970s and 1980s, and this practice was common in the medical community at the time.

29. As an adult, I have always refused to be part of any research programs. Therefore, if my name comes up as part of any trials, I have not consented to these.

30. My mother may have given consent for a trial or study when I was under the care of Oxford Hospital during my childhood, but I would not have any information about this.

Section 5. Impact

31. For the first few years following my HIV diagnosis, life carried on as normal until I started to feel unwell in the late 1990s. I was experiencing hot flushes, my heart was racing, and I felt that something was severely wrong with me.

32. My illness was what I would describe as a low-level illness until then, and I was ill enough

to decide to go to the doctors. Before this, I was reluctant to engage with hospitals or doctors. However, my girlfriend at the time encouraged me to see the doctors because she was concerned about the way my heart was racing and the hot flushes.

33. I had been offered HIV medication when it became available some years before, but I resisted because my viral load had been within acceptable parameters.

34. After I became ill, I went to the doctors and took up the offer to start HIV treatment. All treatment at the time in question was via Knutsford ward at the Royal London. The Graham Hayton unit did not exist in the early days, or at least I was not referred there immediately.

35. I had already moved out of my family home by this time, so I did not tell my family members when I began feeling unwell or that I had started receiving treatment because I did not want to worry them.

36. At the time, treatment for HIV was still quite experimental, everyone had different ideas of what you should be doing, and they seemed to be making it up as they went along.

37. Luckily for me, I responded well to the HIV treatment, and things got back under control after that. The treatment consisted of three pills, but I cannot recall their names.

38. I am glad that I did not take the earlier HIV treatment AZT because I believe it had extreme side effects and may have contributed to the deaths of some people.

39. My viral load has been zero for many years now, and I am monitored every six months down from every three months initially. The system in place these days is pretty good compared to what was available back then.

40. I have also received treatment for HCV about

four or five years ago. It was an eight or ten week course, and the treatment consisted of only tablets. I did not have to take any injections, and I did not experience any side effects.

41. I believe that it is important to try and live a normal life as much as possible. I work, and I do not dwell too much on these things. Perhaps my positive psychological mindset has also had an impact on my physical health.

42. I have had a fibro scan which confirms that my liver is fine. I feel lucky all things considered, that my body has held up well despite all the things I have been subjected to.

43. Not long after I started HIV treatment, my long term girlfriend and I attended the Graham Hayton Unit at the Royal London Hospital to speak to the HIV specialist, Dr Skinner, about having children.

44. Dr Skinner advised us regarding unprotected sex and how to ensure that neither my girlfriend nor the children could contract the virus. Not long after, our first child was born in 2002.

45. I believe the children have been tested and are negative. In terms of haemophilia, it only passes through the female side, and all my children are male. My sister was also tested, and she is not a carrier, so I think I am the last in my family with the gene.

46. I think one of the reasons the doctors and medical professionals did not provide adequate information was because back in those days, there were adverts everywhere about HIV and then later HCV. They may have assumed that you would follow the advice available on the TV and in the newspapers.

47. I have never had any issue securing a mortgage or going on holidays. I can now get holiday insurance as long as I provide a letter from the haemophilia centre stating who I am

and who my doctor is.

48. Even though I have been relatively lucky, both my HIV and HCV diagnoses and treatment have impacted on my physical health. I now suffer from lipodystrophy, which affects the distribution of fat in my body. For example, I have lost fat in my legs and tend to gather fat in my abdomen.

49. The HIV treatment caused the lipodystrophy, and it is a permanent change. Although the treatment saved my life, it is not a good look. I have to go to the gym regularly to combat some of the effects on my physical appearance

50. Before I received HIV treatment, I was ill on and off for a long time. I used to run a temperature, and my heart would race. I was a motorbike courier, and my ill health was affecting my work.

51. When it got worse in the late 1990s, it felt like it came on suddenly. It was clear to me that I had avoided the negative aspects of the diagnosis while many others had died, but if I did not do something, my health could take a downward turn rapidly.

52. The symptoms stopped and my condition stabilised within six months of receiving HIV treatment. I have always responded to most of the medications doctors have given me, except on one occasion.

53. I was offered a new drug (the name of which I cannot remember but I'm sure the problems with that particular medication will be well known) The doctors warned me that there was a 10-15% risk that it may have some psychological side effects. I had severe side effects and insisted on returning to my previous regime.

54. There is a massive stigma surrounding HIV and HCV, so aside from my close family, I do not tell anyone about my diagnosis.

55. Newcastle was an extremely tough area in the 1980s, and was not the place to discuss HIV with anyone.

56. I feel like haemophilia was a limiting factor on my life when I was growing up because there was a real risk I could bleed to death from a serious injury . HIV has had huge social consequences, due to the need to be secretive and the fear of discovery. However, it did not affect my education and work. Later, when I pushed back against some of the suffocating limitations of my haemophilia, the doctors were horrified because I rode a motorcycle for a living, and that I had tattoos.

Section 6. Treatment/Care/Support

57. I think there was no treatment for HIV in the 1980s, but as soon as it was available, I was offered treatment. I have been offered various treatments for HIV and HCV along the way, and sometimes I may have chosen not to do it because I wanted to make sure it was a treatment that worked before I decided to go on it. The early treatment protocols often felt very experimental.

Section 7. Financial Assistance

58. In 1993 or 1994, I received a £50,000 lump sum from the Macfarlanes Trust.

59. I have also received financial support from the Skipton Fund. I made an application for support in 2004 and received the stage one payment of £20,000 in 2017.

60. I do not know why there was such a big gap between when the initial application was made and when I received support. My philosophy is not to go begging for support, so I did not think about it in the intervening years.

61. I now receive £3594 monthly from the English Infected Blood Support Scheme (EIBSS).

62. I found the application process for the EIBSS much more challenging than the previous schemes.

63. I received an email in March requesting information but with a deadline to supply the information by April. They expect you to gather a lot of administrative information in just a few weeks. They asked for payslips, council tax and information about my children because they mostly live with me.

64. I had to contact my son's college to provide information, my eldest son is working, and I had to get his payslips too. It was also important to get it right because if you don't, they will not backdate payments for longer than two months.

65. I appreciate that it is a lot of money, and it is helpful however it comes across as an excessively bureaucratic system.

Section 8. Other Issues

66. The people responsible for this scandal should not be allowed to get away with not taking responsibility for what they did.

67. It's easy to think of HIV or HCV as just an infection you have, but it radiates into every area of your life. In the 1980s, the stigma against HIV was huge, and you cannot underestimate the impact the fear of discovery had on many people like me. It felt like I was keeping a huge secret, and I was afraid of what would happen to me and my family if the secret got out. I believe there is still a huge stigma around HIV.

68. These were the people that were entrusted to look after you and make you feel better, yet they made you worse than when you walked in through the door.

69. It is bad enough to do that to someone, but to now pretend that it never happened, or to treat

it so casually as some officials questioned by this Inquiry have done is unconscionable. For example, saying they cannot remember events clearly, where they were, details of meetings etc.

70. If you knew and you said nothing, that makes you an accomplice. All that was necessary was for someone senior to flag up that something was wrong and that they needed to stop and examine what was going wrong before proceeding any further. Instead of doing that, they did not stop. They kept going.

71. I do not believe that politicians higher up back then did not know what was going on. They say they cannot remember if they were told or made aware formally or informally.

72. Even if they were told informally by a phone call during the weekend and they then went back to the office on a Monday morning and chose not to take any action, and we're still talking about this nearly forty years later, that is wrong.

73. Many people have died just because people higher up do not want to be embarrassed about this contaminated blood scandal. They have had the reports that people had been dying for decades, yet they can sit and give evidence today, saying they can't remember being told and can't remember if they knew or not. What kind of person does that when there are so many people that are dead? Many children have lost parents, and hundreds of partners have been widowed over the decades. Those involved at the higher levels of this scandal should be ashamed of their actions in the past and also of their desire to evade responsibility today.

Statement of Truth

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

Signed GRO-B

Dated 05/06/2022