ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN0568 001
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Dated: 13 March 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 12 December 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B My date of birth and address are known to the Inquiry. I am 57 years old and I am married with 2 daughters and 2 sons.

2. I have been semi-retired for 15 years and I am currently a chairman of one business and a non-executive director of a FTSE public company.. I engage in various charitable activities both in the UK and in Africa.

3. I intend to discuss my Hepatitis C infection and the circumstances that led to this.

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Section 2. How Infected

4. When I was 18 months old I cut my lip and the bleeding wouldn't stop. Upon my visit to the hospital with my parents it was discovered that I was born with severe haemophilia A and 0% clotting factor which I think was extremely unusual at the time. Since then I think I have always assumed that there was an element of new treatment that the reality was that I have at times been a 'guinea pig' for new advances in haemophilia treatment.

5. The view of the doctors was that as a carrier, my mother was a spontaneous mutation, but this was never fully tested or proven. My haemophilia diagnosis was given by Professor Macfarlane who was an early expert in bleeding disorders.

6. I have two sisters and one of them has five children and the other has 3 and we all appear to have a variant gene. Only one child, out of the combined total of the 8 children that my sisters have, has not carried the haemophiliac gene.

7. On this occasion my lip wouldn't stop bleeding and I was told that there was an individual that was directly giving me blood in the hospital as this was before the introduction of cryoprecipitate.

8. I have been looked after predominately by the haemophilia department of the Oxford Hospital except for a circa 15 year period when my care was managed by the Royal Free Hospital. However I believe I have approximately 50 years of medical notes from Oxford Hospital.

9. Although I am not aware of the exact date or indeed the year, I believe I was infected in the mid 1970's whilst taking blood products at boarding school. I was relatively lucky as a child as I was privately educated and enrolled at a boarding school.

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10. Also, despite having a very severe form of haemophilia and 0% clotting factor in my blood, I received less treatment than most haemophiliacs of my generation and this is still true today.

11. In the 1970's I had an intuitive view that medicine, which included blood products, needed to be used sparingly. In 1973-1974 when I was in my mid-teenage years, I remember that both myself and the other haemophiliacs were given our first batch of Factor 8 to take home with us. From my perspective and in the early days of Factor 8, it was used to treat bleeds and it was not until around the late 70's/early 80's that the prophylaxis regime was pushed. Indeed the move to prophylaxis was, in my view part doctor sponsored and part through pressure from haemophiliacs and organisations such as The Haemophilia society. Because I was bought up with a cautious view to extensive treatment, the doctors accepted my view that relatively little Factor 8 was possible despite having 0% clotting factor.

12. Because I was on a low volume of Factor 8, I asked to be on UK blood products and the doctors agreed to give me blood products that were only sourced from the UK.

13. The other alternative was blood products that were obtained from the US and for approximately 15 months prior to this I was given US blood products because the doctors originally did not think there was a significant difference between the two.

14. This was during the time when the doctors were certain that Factor 8 made life for haemophiliacs easier. Factor 8 gave us the chance to lead a normal life and it reduced joint degradation which is common amongst haemophiliacs.

15. However when I was aged 17 or 18 there was, I believe a vague understanding that US blood and blood products were not as good as blood sourced from within the UK.

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16. At some point I was aware that US based blood products carried more risks of infection. I believe the doctors were also aware of this, although I believe there wasn't specific knowledge of this but it was intuitively known that people who lived a life that some people deemed exposed them to greater risk of infections, their blood was likely to be dangerous. For example US prisoners who were exposed to drugs ,donated blood.

17. During my course of care at Oxford Hospital there were 2 leading consultants named Dr Rizza and Dr Matthews and they dealt with the haemophilia centre there.

18. There was also one member of the medical team in the mid 1970's that told me to use UK blood products (I believe evidence of this could be in my medical notes if requested). *Since this was first drafted, I have reviewed my notes and include, in Appendix A, appended to this statement, various extracts (15 pages), including a letter dated 24th November 1978, referencing "acute viral hepatitis" and a letter dated 20th December 1977, which states "He has been Australia antibody positive for some time suggesting he has sub-clinical hepatitis…." And then later in the same letter "The main risk of the treatment in common with administration of blood products in general is of hepatitis B….". I then include some other copies from my notes which reference early detection of abnormal Liver Function Tests and reference to "other Commercial products being prescribed, which I believe refers to "US Blood Product".* (WITN0568003)

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19. I believe that I was infected between 1975 and 1977 and this was the period I believe I received US based blood products. Looking back, it is my belief that because I didn't take large quantities of Factor 8 and because I resisted the trend towards prophylaxis and therefore was predominantly treated with UK blood based Factor 8 that did reduce my chances of contracting HIV also, which I suspect occurred largely from the late 70's to early 80's

20. The first time I was aware of HIV was a newspaper report in a UK newspaper highlighting, the risk to haemophiliacs from contaminated blood, I think in about 1984. I remember receiving a call from the Royal Free haemophilia centre (where I was under the care of a Dr Kernhoff) and they asked me whether I was worried about the prospect of having HIV. They said they were shocked that I didn't contact them with my worries, as most other patients had.

21. It was explained that the risks were serious, there was a discussion about the fact that because I had received the Hep C virus, that there was a strong chance that I had to have been exposed to the HIV virus. For this reason the Royal Free hospital arranged blood tests for me every month to ascertain whether I had HIV. This was largely over the period 1984-1985 and it was to my enormous relief that at some point in 1985, it was confirmed that I surprisingly showed a consistent negative, to any of the HIV tests. This was not expected.

22. In 1980 when I became 19 years old I was treated by St. Thomas' Hospital and in my view I believed the Royal Free Hospital had a more significant haemophilia centre so I moved to the Royal Free Hospital where I received care and treatment between 1981 and 2000.

23. I knew that the incubation period for hepatitis C was 20-25 years. And in approximately 1998 I was told at a routine appointment that there was a strong chance that I was at risk of serious liver damage, and that treatment had a good chance of clearing the virus.

24. Before that I had scans and ultrasounds and from memory, possibly an early scan. My liver function tests had been consistently abnormal since the mid 1970's and my bilirubin levels were high.

25. In the middle-late 1990's when I was in my 30's, I was told that I needed to commence treatment for the hepatitis C. I was initially sceptical as my

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business had just been listed on the stock exchange and I didn't want to start any treatment that would adversely affect my business.

26. The treatment lasted approximately a year and was a combined course of Ribavirin and Interferon which was a horrible experience. Luckily, by 1999 I was cleared of hepatitis C.

27. I believe I developed hepatitis C when I was 17 years old. I was in boarding school at the time and the doctor told me that although I had jaundice and glandular fever, I didn't have hepatitis A or B. I later discovered I did indeed have hepatitis C but as it was somewhat unknown at the time it was just left alone.

28. I have never taken any intravenous drugs and I have not had multiple sexual partners. I also do not have any tattoos or piercings.

29. Without the use of blood products I wouldn't be alive today. In my lifetime I have experienced at least 3 catastrophic bleeds that would have killed me had it not been for cryoprecipitate and Factor 8.

Section 3. Other Infections

30. I did not contract any other infections apart from hepatitis C.

Section 4. Consent

31. I do not believe that I was ever tested without my knowledge however if I was tested or indeed experimented on I believe it would have been for a good cause.

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32. In the 1970's it was understood by my generation that we were being tested on and as we got older it became a case of the doctors asking if they could test the efficacy of different haemophilia-related drugs on us.

Section 5. Impact

33. As a severe haemophiliac I can honestly say that there was an impact on my education and academic pursuits. This most probably affected most of the haemophiliacs of my generation.

34. I spent 1/3 of my childhood in hospital and that was compounded by the fact that I had developed jaundice around the age of 17 which made things harder and affected my attendance at school.

35. Before I turned 18 I remember thinking I was a stupid, wounded and weak person, partly because of haemophilia and also because I had done so terribly at school.

36. Then when I turned 18 I had a transformative moment and I am pleased to say that I later became a successful businessman despite the hepatitis C so I consider myself to have been very lucky despite the circumstances.

Physical Impact

37. Haemophilia caused a lot of joint degradation which I still feel today. However both the hepatitis C and subsequent combination of Interferon and Ribavirin treatment made me physically exhausted.

38. Thus the only physical impact I can say I have felt was whilst undergoing treatment for the hepatitis C virus, however I do also think that the early stages of Hepatitis C did affect my schooling, but this

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could also be due to the fact that I had missed a lot of schooling, due to bleeds and hospital admittance during my schooling years. Because of this, I was poor at school and had considerable immaturity during my teanage years.

Financial Impact:

39. The nature of my job always allowed me to be quite financially fortunate so hepatitis C didn't have any direct impact on my financial situation.

40. However during treatment for the hepatitis C in 1998, I was a chief executive of a public listed company and I remember the company experienced difficulties during that period but I cannot categorically say this was directly attributable to the effects of the Interferon and Ribavirin treatment.

Mental Impact

41. Initially, there was indeed the mental strain of knowing that I had battled with haemophilia and also with hepatitis C. From a young age I had a general awareness that I may not live beyond the age of 30 as this was the predicted life expectancy rate for haemophiliacs in the 1970's.

42. My wife was also warned against marrying a haemophiliac (in the mid 1980's) because the general consensus was that we would all be dead by 30 and that we would most likely develop HIV so that was difficult for the both of us.

43. However I consider myself to have been very lucky to have battled and to be cleared of hepatitis C.

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Impact on family

44. Aside from being a haemophiliac, which is for my generation, a battle I did become aware in the 1990's that hepatitis C was a dangerous and life-threatening virus. In 1998 when I started the treatment it was almost like being told that I had cancer and this caused a lot of worry within my family.

45. My wife was very understanding of my situation and loved me irrespective of having hepatitis C. I remember in the early days of our relationship she was told by doctors that she was exposing herself to the potential risk of contracting HIV by being with me.

46. This was largely because most haemophiliacs who had been given the hepatitis C diagnosis were thought to later develop HIV so it initially impacted our plans to have children.

Section 6. Treatment/Care/Support

47. Initially, I was advised to begin treatment for Hepatitis C in c.1995 but I refused it due to the negative things I had heard about the particular drug that was being used at the time. I was probably aware of the implications of not having treatment, but I was working hard in my career and succeeding and I did not want to take risk with a new treatment

48. Subsequently in 1998 the doctors said they had high success rates for Interferon and Ribavirin as a combined method of successfully treating the hepatitis C virus.

49. Consequently, I agreed to begin treatment as I dealt with risk every day in my line of work. The doctors stated that the success rate was beyond

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80% so my risk-taker mentality gave me the confidence and drive to go ahead with the treatment on that basis.

50. I believe that there was no malicious intent on the part of the doctors and members of the medical profession to do any harm to us at all. The medical professionals were absolutely wonderful towards me and they didn't subject me to stigmatisation or discrimination.

51. I do not have anything derogatory to say about them at all. I was happy with the treatment I received. In my view I would be dead without Factor 8 blood products. I do not believe that the doctors wilfully subjected us to these dangerous blood products.

52. I think we were given freedom by using blood products because it changed our lives. Because both the medical profession and the haemophiliac society believed prophylaxis would transform the lives of haemophiliacs, I believe that there was a greater demand for it than the supply and I understood that there was not enough Factor from UK based blood, which led to blood product being sourced from the USA.

53. At the time, the medical practitioners I believe felt that the benefit of taking the blood products was greater than the prospect of not taking it.

Counselling

54. At the time of my hepatitis C diagnosis and subsequent treatment, the hospital didn't offer me any counselling, emotional support or indeed anything of that kind. I was simply told it would be a tough ordeal but that I needed to get on with it.

55. When I started the treatment I was rather irritable and constantly tired so it was definitely emotionally demanding on my family as a whole.

56. Even though I was forewarned by my doctors that it would be a tough course of treatment, it was certainly tougher than I originally realised.

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But as mentioned previously, I didn't receive any counselling at this stage either. I am not sure I would have accepted it, as I am a slightly "get on with it" sort of person.

57. I think that the lack of emotional support was mostly because counselling wasn't really as big of a deal as it is these days. I believe it was a relatively new concept around the 1970's and even in 1998 when I began treatment, it wasn't as widely known as a valuable source of support as it is now.

Section 7. Financial Assistance

58. I am a recipient of the Skipton Fund although I honestly cannot remember when I initially received correspondence from them but I imagine it to be around 5 years ago

59. I received a lump sum payment of £20,000 also around 5 years ago but I feel that there were and indeed still are people that need the money more than me.

60. I currently receive quarterly payments and winter fuel allowance and although I don't reject the payments the Skipton fund gives me, I like to do charitable things with the money I receive.

61. I think that there should have been more investigation into how much people received and perhaps it should be means tested. However I do understand it is extremely sensitive to say that.

Section 8. Other Issues

62. My concern is that it is so much easier for people to say the infected blood issue was a hard and horrible process. Medical practitioners and

the government have been castigated for an unfortunate event that in my view wasn't maliciously caused.

63. Another example of what I think was the prevailing thought at the time, can be chacterised by considering the issue of vCJD. This has been widely publiscised; there has been fear that haeomphiliacs may have been exposed to dodgy meat, but on balance it is felt that it is better to take blood product (even if as now essentially synthesised) than not..

64. I think the doctors decided to take a balanced view and concluded that the benefits of using blood for haemophiliacs, like myself, or for others that were in dire need of it, outweighed the risks at the time.

65. The life expectancy rate for haemophiliacs in the 1970's didn't exceed the age of 30 as it was and indeed still is a hugely debilitating condition. When cryoprecipitate was introduced it was great but it was rather complicated to use as it needed to be defrosted for around an hour before it could be administered.

66. If a haemophiliac was in hospital treating a serious bleed they would not be able to walk for at least 5 days as the cryoprecipitate was quite slow in taking effect and it would take a few hours to organise trips to hospitals, and so by the time haemophiliacs got to be treated, the bleed was already very severe.

67. However when Factor 8 came it was revolutionary. It didn't take long to administer and was a lot easier to use, it meant that we were able to live more fulfilling lives whilst on it. So I don't believe the doctors felt that it would be right to take it away for a small amount of risk which was relatively unknown at the time.

68. I honestly think in the 1970's medical professionals and health organisations knew there were risks of infection via blood products and this perhaps led to a discussion where it was decided, based on the knowledge at the time, that the risks were sufficiently small and/or

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unknown so they continued making the blood and blood products available to save people's lives.

69. I am acutely aware that what I am saying isn't what the party line is and I know that there are families that have been utterly destroyed by the experience but I sincerely believe that all the doctors did their absolute best for me.

70. I feel a quite guilty for those who have really suffered with this whole issue and the effect it has had on them.

71. I would be happy to be called to give evidence orally but I would like this to via video link and anonymized. I would like my written statement to be anonymous.

Statement of Truth

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

Signed GRO-B

Dated 13th March 2019

Enclosure – see Appendix A (15 pages copied from notes) GRO-B