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Witness Name: GRO-B

Statement No: WITN1620001

Exhibits: WITN1620002-6

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B, will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B and I live at GRO-B. I have been in a relationship for the past 3 years but I live alone.
2. I am not currently working. I gave up work in 1997 as a result of my illness.
3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I suffer from severe Haemophilia A, whereby I have a clotting Factor VIII deficiency. I was diagnosed at a young age because my older brother also suffered from haemophilia.

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5. My condition requires regular treatment and I have therefore been treated with many different blood products from different suppliers over the years, including Factor VIII concentrate. There is now shown to me marked **WITN1620002** a copy of my records from the National Haemophilia Database.
6. When I was very young there was no treatment available for haemophilia, so I only started being treated in the 1960s. This is when I started to travel to the Royal Victoria Infirmary (RVI) in Newcastle, which was only a Haematology Department at the time, in order to seek treatment. I was treated by Dr Peter Jones, who, I believe, set up the Haemophilia Centre.
7. Whenever I needed a treatment, I had to travel 50 miles in an ambulance in order to be treated with plasma on a drip. This happened, on average, a couple of times a month; therefore I received quite regular treatments.
8. I believe that I moved on to Cryoprecipitate in the early 1970s.
9. I believe that I first had Factor VIII treatment in 1974, when I was around 16 years old. I believe that my brother and I were some of the very first people to be treated with Factor VIII. I note that my UKHCDO records state that I was given Oxford FVIII in 1969, though to my knowledge, FVIII was not available in the UK at that time and this is probably an err on the UKHCDO database.
10. I also started home treatment in or about 1974.
11. I recall one specific instance, in summer of 1974, when I, my parents and my brother attended a meeting with Dr Peter Jones at the RVI. The purpose of the meeting was to discuss our future education and treatment. Dr Jones described Factor VIII as a wonderful new medication and encouraged us to start this new treatment. He taught us how to administer it by ourselves, enabling us to go on to study at the Hereward College. He arranged for the college to have a constant supply of Factor VIII so that we could access it. He also promised us that there will always be someone to offer medical support and oversee our health.

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12. My brother and I attended Hereward College from the summer of [GRO-B] to the summer of [GRO-B]. Whilst Factor VIII was available, there was no supervision or expertise to manage our health. There were two nursing staff on the site, and a GP might have visited occasionally, but that was it and the GP didn't really deal with haemophilia.
13. This led to some dangerous situations because we did not have the medical support that we were promised. I recall a number of instances where it became apparent that the local doctors lacked the necessary knowledge and experience to deal with our haemophilia.
14. On one occasion I was involved in a car accident which resulted in flesh on my hand being scraped away, exposing the bones of my knuckles. I was sent to the Coventry Hospital. My hand was hung up on a drip stand to reduce the bleeding, and despite my requests, I was not provided with Factor VIII or any other clotting factor.
15. Another instance was when following an internal bleed in my brother's knee the onsite doctor decided to aspirate the joint without prior blood clotting treatment, which is well-known to be very dangerous for haemophiliacs.
16. This highlights Dr Jones' attitude in adopting the latest medications without ensuring that it was the best for the patients or safe. Furthermore, despite his promises, he did not ensure that we had the appropriate medical backup whilst at Hereward.
17. I self-administered Factor VIII whenever I suffered internal bleeds which was about twice a month whilst at Hereward College. At the very beginning the doses were quite small, as the supply was limited. In around 1990 I started administering Factor VIII on a prophylactic basis twice per week with additional doses as required.
18. I was infected with Human Immunodeficiency Virus (HIV), Hepatitis C (HCV) and Hepatitis B (HBV), as a result of being treated with contaminated blood products.

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19. According to the medical records available I first tested positive for Hepatitis B antibodies on 15 May 1980.
20. From September 1980 to December 1984 I was under the care of the Royal Free in London. During this time the dangers of FVIII or possible HIV infection was never mentioned.
21. I am not certain when exactly I was infected with HIV; however, I suspect that it might have been during the summer 1983. This was around the time that I developed a number of allergies and started suffering from hay fever. It was never proven, but I suspect that all these symptoms were as a result of my infections.
22. I was never informed of any potential risks related to being treated with Factor VIII.
23. According to my UKHCDO records the blood sample tested for HIV was taken on 2 October 1984. I believe that the hospital had stored samples from earlier dates that were also subsequently tested as the records state that my last negative HIV test was on 11 October 1982 and my first positive test was 18 October 1983 which is long before I was told about my HIV status.
24. The Royal Free Haemophilia Centre became aware of my HIV+ status on either 18 October 1983 or 2 October 1984. I was registered with them until December 1984 which gave them ample opportunity to inform of my HIV status which they failed to do.
25. It is clear from my medical records that I was being monitored for any HIV symptoms before I was tested in October 1984. There is now shown to me marked **WITN1620003** a copy of a clinic note dated 2 September 1984 in which I was asked whether I was suffering from fevers or night sweats which were recognised symptoms of HIV.
26. From December 1984 to March 1985 I was moving around the country with work and had little contact with any Haemophilia Centre. During this time

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period, however, I did receive supplies of FVIII from Leeds on one occasion.

27. In March 1985 I registered with the Leicester Royal Infirmary Haemophilia Centre.

28. I was first contacted regarding the potential infections in 1985, when Carol Martin (a nurse) from the Leicester Royal Infirmary (LRI) phoned me and asked whether I had been tested. The LRI did not have my medical history and were unaware of previous tests carried out at the Royal Free. I agreed to have tests done and I was told that I had tested HIV positive by Dr Mitchell from the LRI in or around May 1985.

29. The way in which I was told about my HIV status was very basic. I do not recall being given any further information regarding my infection or what it meant. I was also not offered any follow up or support at that point.

30. I do not believe that I was provided with adequate information about my condition, particularly in relation to how to manage the infection. I was given only the most basic information, such as that it could be transmitted through sexual intercourse, and nothing more.

31. I am not certain, as to when exactly I found out about my HCV infection. I believe it was around 1989 or 1990. I was told at one of my clinic appointments that I was being tested for HCV and Dr Mitchell then told me that the test was positive.

32. I was infected with Hepatitis C, genotype 4.

33. I cannot recall whether I was given any information about how to manage my HCV infection. However, generally I believe that at the time the focus was mainly on HIV, not HCV. I do not remember the manner in which I was informed about my HCV.

34. Overall, I do not believe that I was given sufficient information about my illnesses; in particular the implications for my liver and of drinking alcohol were not explained.

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35. I strongly believe that the doctors should have given me more information about HCV and the information should be given a lot earlier.

Section 3. Other Infections

36. In or around 2000 I realised I was suffering from significant memory problems. I was then in contact with several other haemophiliacs, and this is when I started coming across some information about the Creutzfeldt-Jakob disease (CJD).

37. I was told in September 2004 that I was given blood products infected with CJD. I was asked whether I wanted to be tested for CJD, which I said I did. The tests that were carried out suggest that I am infected with CJD.

Section 4. Consent

38. While my brother and I were at the Treloar College, in or around GRO-B there were medications tested on us. According to my UKHDCO records I was given Oxford FVIII in 1969 and in 1974 it is recorded that I was given Travenol/Hyland/Hemofil FVIII as part of Dr Craske's research work. I therefore believe that I was treated/tested for the purposes of research.

39. I am certain that my parents were not informed about any potential risks relating to being my treated with Factor VIII. In fact, quite to the contrary, Dr Jones presented it as a new great miracle treatment.

40. When my parents complained to Dr Jones about the two incidents referred to at paragraphs 13 and 14 above he showed little interest.

41. Once there was an increasing awareness regarding Factor VIII and the potential risks the treatment, my parents questioned Dr Jones. He dismissed their concerns and said the risks were only hypothetical and he there was nothing to worry about.

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42. I believe that it all comes down to the question of what the doctors knew at the time. I am certain that they knew about the dangers of treating haemophiliacs with Factor VIII at an early time. We were not provided with that knowledge or given the option of alternative treatment. Therefore, I could not have given a fully informed consent to my treatment, due to not being aware of the potential risks of it.
43. I was informed when I was tested for HIV and HCV at the Leicester Royal Infirmary and gave my informed consent to those tests. I was not asked or informed about blood tests performed at the Royal Free which my medical notes and UKNHD records show to have taken place.
44. There is now shown to me marked **WITN1620004** a copy letter from Dr Kernoff at the Royal Free Hospital to my GP dated 31 October 1983 which makes it clear that I was also being having Liver Function Tests which presumably were being done to monitor for any signs of hepatitis.

Section 5. Impact

45. At the time I was diagnosed with HIV, I was in a relationship. I had just moved to **GRO-B** and planned to buy a house and eventually have a family. However, the relationship did not last as a result of the dangers arising from my infection and the stress surrounding it. I believe that my conditions have robbed me of the chance to get married and have a family of my own.
46. I fully immersed myself in the job I had at the time. I enjoyed my job, and therefore I focused myself fully on it; however, my social life suffered as a result and I became a lot more introverted.
47. There were also various campaigns in the 1980s regarding HIV, which made me feel like an outcast and even more isolated. Some of those campaigns provided false information, for example that one can be infected via a minimal contact. This had a huge effect on me, how I felt towards other people and my ability to have social life, because of the social stigma.

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48. I was extremely anxious about the idea of ever being in a relationship. The thought of ever having to speak to a future partner about my conditions was very stressful for me and I felt like I was not mentally prepared to do it.
49. Over time I have restricted my group of friends mainly to other disabled people. I believe that my life would have been totally different if I had not contracted HIV and HCV. I would have had a family and friends; instead I have lived a very isolated life.
50. On top of that I was constantly reminded through press reports and other sources that my life expectancy was at most 2 years. I was never offered any counselling to learn to deal with it.
51. I believe that if it was not for HIV, I would have stayed at my previous job until my retirement age. However, I never got to think that far ahead, as I didn't know how long I would actually live for.
52. I was also never able to take life insurance; however, I always wanted to and if it was not for my condition. I would have made other long term financial decisions if I had not been infected such as taking out pension AVCs.
53. I quickly became depressed and I resorted to alcohol at times, to help me to cope. This was prior to me finding out that I had HCV; however, even after I found out about it, I was not aware of the extent of danger that alcohol posed on my liver because it was not explained to me.
54. Whilst the infections I contracted did cause me major psychosocial issues, they did not cause many direct physical symptoms in the early years. What caused my major physical symptoms were the treatments I underwent for my HCV. I received 3 treatments for it; two of which failed and the last one proved to be successful, as it cleared the illness.
55. I was first treated for HCV in or about 2001 when I was given Interferon and Ribavirin. The side effects included dry skin, rashes, nausea, vomiting, dizziness, severe headaches, joint pains and aches. It made me feel like I had

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a very severe flu all the time. This lasted for 3 months. Eventually I was taken off the medication before the end of the course due to the severity of the side-effects of the medication.

56. I was then given round of Interferon/Ribavirin treatment in 2012, which lasted for 18 months. The side-effects were similar, but not as severe, which is why I was put on the treatment for so long. However, my HCV returned around 6 months after I stopped the treatment.

57. I then had my third and final set of treatment in 2015 when I was treated with Harvoni. This treatment was successful. I still experienced flu-like symptoms; however, they were not as severe as those I had suffered with the previous two treatments.

58. I am not certain as to whether it was the effect of the medication or the infections, but I was left with some physical problems, such as cirrhosis, oesophageal varices, osteoporosis, low bone density, severe tiredness and lack of concentration. I still experience those effects now.

59. I have also been suffering from major memory problems, both short-term and long-term. It is not currently getting worse; however, I had a brain scan some time ago and the consultant who was performing it said my memory problems are likely to affect my ability to drive in the future.

60. I also had to give up my job prior to my treatment due to a mixture of work related stress and symptoms from my illnesses. I once passed out whilst at work, which made me realise that I was putting too much pressure on myself and that my body was not dealing well with it, so I felt I had no choice but to give up work.

61. I eventually gave up work on Christmas 1997, which subsequently led to a significant financial loss as I held a well paid managerial post at that time. I have not been able to work since that date.

62. I was also offered HIV treatment, which eventually made me feel better. However, as I was getting better, my brother's health was deteriorating. He

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eventually passed away from HIV in GRO-B 1998. Experiencing this was a very difficult and stressful time for me. It had a huge impact on both myself and my parents.

63. Prior to my brother's passing, he attempted to commit suicide. He gradually lost all control of his nervous system such that he had no control of his limbs and was unable to talk. I constantly worried that I might suffer from the same thing in the future, which was extremely stressful.

64. I am also finding the Enquiry itself and revisiting the past 30 years to produce a witness statement extremely traumatic and stressful.

65. My partner of 3 years is fully aware of my infections but wasn't aware of what I have been through over the past 30 years and the full background this medical disaster. She has found helping me with the enquiry and learning the full facts extremely upsetting and distressing.

Section 6. Treatment/Care/Support

66. I was not initially offered any treatment for my conditions. I am not sure whether that was a negative thing, as I am not certain as to whether a treatment was available at the time.

67. I was first offered a treatment for my HIV in 1998.

68. I was then offered a treatment my first HCV in 2001. I started the treatment in February of that year. Overall, I had three treatments for HCV, two of which were not successful, but thankfully the last one proved to be successful.

69. There was never any psychological support or counselling offered to me. I believe that it would have been very helpful, as my illnesses are not something that people are happy to openly talk about. Therefore, I think that it would be very useful to be encouraged to speak to somebody about it.

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70. I did attend a few group therapy sessions at a local HIV aid society some time around 2000. However, I did not find it very useful as my cause of infection was very different from everyone else and socially had very little in common. I believe that individually tailored sessions would be more suitable and helpful.

Section 7. Financial Assistance

71. I received a mail from the government regarding the MacFarlane Trust and registered with them. I received an initial payment of £20,000 in 1991. I then received a further £46,000 in 1995.

72. I initially received monthly payments of £80, which later increased to £1,500.

73. Initially there were no lump sum payments for the HCV but I eventually received £20,000 from the Skipton Fund. I recall that there were levels of payments depending on the liver damage that HCV resulted in.

74. The regular payments from the MacFarlane Trust are means tested and there were also a few extra things available, such as extra help when one needed to move house or for a new washing machine. However, I was always financially stable, so I never needed to ask for much.

75. I have not personally suffered from any difficulties caused by the application processes. However, I am aware that those people who needed help urgently might have suffered, as I understand the process of decision-making as to whether or not the application would be granted tended to be quite lengthy.

76. I also believe that the organisation of the financial support could have been a lot less complicated. Help was originally divided between many different trusts, which was quite confusing when you tried to work out to who to call and where to get information from. Seeking information from the different sources could also be very time-consuming, when you do not know who to contact.

Section 8. Other Issues

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77. I signed up for the group litigation in the 1980s. I had to pay high solicitors fees, as a result of it, and I would not have gone through the expense and the stress if I was not infected. I do not believe that it should have gotten that far. I should not have had to litigate in order to seek justice. I wish that the government had taken responsibility for their action and the effects of it in the early days rather than allowing this debacle to continue and for people to continue to struggle with their ruined lives.
78. To obtain the financial assistance listed in Section 7 I had to cease litigation and sign a document that I would take no further legal action. This document had to be signed by ALL infected haemophiliacs prior to the Government making any payments to any haemophiliacs. This put me under extreme pressure to sign as it affected the whole haemophiliac community. If continuing the litigation only affected payments to myself I would have most likely continued with the action and not signed the document as I wanted to find the truth about how and why we were infected.
79. There is now shown to me marked **WITN1620005** a page from my medical records which states "This patient must not be treated with or given supplies of commercial factor VIII concentrate. NHS products only are to be used". The original date is "from 1st August 1983" but this has been changed, by hand, to read "17 February 1984". The note is signed off by Peter Kernoff. I want to know why this date was changed. My treatment records clearly show that I was receiving commercial Factor VIII concentrate until 17 February 1984. I was put on NHS concentrate on 18 February 1984.
80. There is now shown to me marked **WITN1620006** a copy of my treatment record for the period 1980 to 1985.
81. The Inquiry should also be aware that the medical records provided to me by The Royal Free Hospital contain notes for other patients.

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82. I believe that it is very important for the Government to admit to the problem it had caused and recognise the connection between haemophilia treatments with blood products and the various infections. I believe that this should have been done a long time ago, as I think it would have raised awareness and helped the entire haemophilia community to function in society without a cloak of secrecy because of the fear of stigma.

Anonymity, disclosure and redaction

83. I would like to apply for anonymity and understand that my statement will be published as part of the Inquiry.

84. I would only like to be considered for oral evidence if the Inquiry considered that it would be helpful to them.

Statement of Truth

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

Signed.....

Dated.....

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Dated... 18/02/19