ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN3874001
Exhibits: **WITN3874002 – 009**
Dated: 1 AUGUST 2020

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 31 January 2020.

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 my address is known to the Inquiry. I work for an GRO-B firm.

2. I intend to speak about my infection with HIV and the Hepatitis C virus (HCV), which I contracted as a result of being given contaminated blood products to treat a bleeding disorder - Haemophilia A.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. I was born with a Factor VIII deficiency which was diagnosed when I was 18 months. On my first treatment of Factor VIII the doctors discovered that I had an inhibitor to Factor VIII. This means that administered Factor VIII products do not have any effect, because my body produces antibodies to neutralise it. This was emblazoned on my medical notes and Factor IX was therefore always the indicated treatment. Factor IX was not as far as I am aware subject to the same levels of HIV infectivity as Factor VIII.

6. I was a high user of blood products and blood transfusions because I had a lot of bleeds whilst growing up. I missed a lot of school due to my bleeding condition and the frequency of bleeds reached a peak when I went into adolescence. Prior to home treatment, and until I started university, I was always treated by the haemophilia centre at the GRO-B GRO-B Newcastle. My main Doctors were Peter Jones and Peter Hamilton.

7. When I started university, my treatment transferred to the Norfolk and Norwich Hospital and then to Addenbrooke's, Cambridge. I moved back to GRO-B after my post-graduate degree. Dr Katherine Talks and Dr John Hanley are my current consultants.

8. I recall only one occasion at the GRO-B when I was administered with Factor VIII. I would have only been 6 or 7 years old at the time so around 1980 or 1981. It was an out of hours admission and one of the junior doctors was preparing Factor VIII concentrate rather than Factor IX. My mother informed him that I had an inhibitor and that I was not to have Factor VIII. He phoned one of the consultants for more information and for some reason they instructed him to administer both the Factor VIII with Factor IX in equal quantities. This incident has always stuck in my mother's mind. This was at a time when one did not question a doctor's

decision. My inhibitor rocketed as a result of the erroneous treatment. The decision process of the professionals at the time makes no sense.

9. When it started to emerge that factor products were infected, the social worker at the haemophilia centre spoke to my mother to put her mind at ease and said that I would not pick up any infection, because I never received Factor VIII. It was at that point that my mother's heart sank as she instantly recalled the time I had been given factor VIII in error.

10. Other haemophiliacs that were only treated with Factor IX were infected with HCV, but not HIV.

11. According to my recollection, I was only exposed to Factor VIII once, but a patient annual treatment record indicates that I also received the product in 1979 (exhibit **WITN3874002**). Other haemophiliacs who were treated with Factor VIII regularly had a constant and repeated exposure to the infection.

12. In the mid 1980s a porcine product became available and there was a discussion at the haemophilia centre whether it was feasible to use from a cost perspective. From my recollection, it was the cost implication that prevented me from receiving the product, despite my consultant pushing for its use, please see letters exhibited as **WITN3874003** and **WITN3874004**.

13. Exhibit **WITN3874005** discusses the potential use of the Bonn Regimen. This practice involves administering high doses of plasma-derived factor VIII rich in von Willebrand factor and pulsed intravenous immunoglobulin, to lead to the eradication of inhibitor. The regimen was never carried out. I don't know why exactly although 'resources' are mentioned as an issue in the letter.

14. I did receive blood transfusions prior to being diagnosed with HIV and HCV. It was the norm for me to receive a blood transfusion after a nose bleed as I could lose substantial amounts of blood when these occurred which was fairly regularly. I do not recall ever being given any warnings that there may be a risk associated with blood transfusions or indeed the use of blood

products. If my parents had been so warned at any time, then they would have passed that information on to me.

15. I have never been an intravenous drug user and I do not have any tattoos or piercings nor have I been sexually promiscuous.

16. My parents were told that I had HIV in 1985 after having to push the medical professionals as results of my tests had apparently been lost. It was not until GRO-B 1987 that I was informed. This was just before my 13th birthday and just prior to starting high school. Amongst the other patients at the haemophilia centre, there was a natural consensus not to tell the children of their diagnosis initially. Twelve or thirteen was seen as an appropriate time to disclose as we entered puberty so that we could be warned off unprotected sex.

17. The testing would have taken place at the GRO-B GRO-B I do not recall going in for a test, but I was always having blood taken. I do not know the reasons for why I came to be tested for HIV and neither do my parents. **WITN3874006** states that I was HTLV III Antibody positive on 24 May 1985. Patient HIV data in my medical file **WITN3874007** states my last negative test for HIV on 4 June 1981 and the first positive test as 21 May 1985.

18. I recall going into the hospital and the nursing sister explaining about the viruses. She said that I was HIV positive, but I did not have AIDS. I got rather upset during the meeting and came out of the appointment confused about what that meant. Around that time HIV and AIDs were heavily reported in the press, but I did not have much understanding.

19. There was not much practical advice given in regard to the HIV diagnosis as far as I recall. Nothing about precautions, just that I should not have sex, although my parents may have been advised in that respect. It was a case of live with it.

20. The HCV diagnosis came as a surprise. I was informed of the infection in September 1995 when I was 21 by my new GP in my first few weeks at

university at my initial appointment with him. I think I was HCV positive for a long time before being told as the GP mentioned it in such an assuming way, as if he thought I already knew. For a long time, the virus had been known as 'Non-A Non-B Hepatitis'. The infection did not mean much to me and it was not on my radar as being particularly bad. I was not subsequently given much information about the virus and the resounding message from medical professionals at the time, was that the infection was minor compared to HIV.

21. I remember appointments with Dr GRO-D during my teenage years. He told me to keep my alcohol consumption to a minimum, but I do not recall him saying this was due to the HCV infection or explaining the potential for liver damage

22. I am not aware of my HCV genotype.

Section 3. Other Infections

23. I was tested for HBV in 1982 and I am pretty sure that I tested positive for the virus. The HIV diagnosis meant that HBV was never at the forefront of my mind and it has not been mentioned to me by a medical professional since.

24. As part of obtaining my medical notes in order to provide this evidence, I have noted that I have been exposed to vCJD via blood products. I had suspected this but when the initial risk was highlighted I chose not be informed as there was, and remains, no treatment or cure available.

Section 4. Consent

25. I do not think that I have been placed on a medical trial without consent.

26. I was not asked for and did not give consent to be tested for HCV. As previously mentioned, I was informed of the diagnosis sometime after I had been tested.

27. I am now curious when my blood is taken and always question the purpose.

Section 5. Impact

28. A few weeks after being told of my HIV diagnosis I remember suffering with an upset stomach and my consultant at the GRO-B Dr Jones prescribed diazepam. In a letter from Dr Peter Jones to Dr GRO-B **(Exhibit WITN3874008)**, it is noted that I arrived to the appointment in a state of abject misery and that I was worried about my HIV infection coupled with the fear of death and starting at a new school. I was thirteen. Even now I can still recall those feelings of confusion and the worry over whether I was going to die.

29. I was always tired as a child and my mother found this rather worrying. I would come in from school and go upstairs to fall asleep. I had very disrupted sleep patterns and I struggled with this until early adulthood.

30. During the late 1980s and early 1990s I was put on an AZT trial and I would regularly go into hospital to be put on a drip of gamma-globulin for a few hours every few weeks. At that age, I did not feel as though I could say yes or no to the proposed treatment. It was equally horrendous for my parents – they just accepted what needed to be done. There was not much discussion or explanation of the treatment, including side effects or what it may mean for me going forward from the consultants. I also recall no discussions about the cessation of those treatments and what new medical opinion decided they were no longer necessary nor why they were necessary at the outset.

31. I was prescribed Dapsone to prevent Pneumocystis Pneumonia (PCP) infections, but this medication could not treat the HIV.

32. There were a couple of times when I developed a rash on my skin, but it was never diagnosed as anything specific.

33. I did not really present with any major symptoms until my second year at university when I started to develop opportunistic infections. I had measles at 22 which was so serious as to be life threatening and require hospital admission. I developed shingles at 23 in my final year university. At 24 I developed a chest infection as part of a heavy case of influenza which required me to be off work. All were probably due to my lowered immunity. It was at this point that my doctors in Norwich and Cambridge recommended starting combination therapy.

34. I returned to university to study an MSC, so I started the HIV treatment at Addenbrookes under Brian Colvin and the Norfolk and Norwich hospital. I found myself spaced out after taking the treatment. This was while trying to complete my thesis so I was forced to take it in the evening which affected my social life. Even now if I have something planned, I will take the medication once I am back home. I will not take the medication during the day and would not attempt to work or drive afterwards.

35. I started this triple combination treatment for HIV in 1999/2000. I tolerated this daily medication for some time, but it has changed fairly recently. Further research indicated that other treatment has now become available, with fewer long-term side effects. I now take this newer medication (two tablets a day) and will continue to do so for the rest of my life.

36. After returning to GRO-B after university and upon discussion with my consultant at the time, I started a course of pegylated interferon and ribavirin at the end of January 2004, to clear the HCV. I had previously put off starting the treatment because of starting a new job and not recognising the seriousness of the virus, but it got to the stage where I was advised that my liver had got to the point that it should not be delayed further. The course of treatment was intended to be 52 weeks, but by reducing the period between injections I reduced it to 47 weeks. The side effects were so awful

that the thought of having to continue even for only 5 weeks longer than necessary was unthinkable.

37. The treatment consisted of a daily tablet and a weekly injection.

38. The HCV treatment was horrendous and in terms of my mental health that year was horrific.

39. I started the treatment not long after finishing university, so I was back living with my parents at the time. I do not think I could have got through this period if I had not been at home. I suffered with chronic fatigue, flu-like symptoms and I was plagued with suicidal thoughts. My skin felt itchy at times and I found it hard to concentrate for any period of time and would easily lose focus on the task in hand. I don't recall any weight or hair loss.

40. Every time I administered the weekly injection, I had an immediate bout of fatigue.

41. I tried hard to put my head down and power through with the course of treatment. I did not take any anti-depressants during this period. I disclosed the fatigue to health professionals, but there was a different mindset about mental health back then. I did not feel as though I could discuss the suicidal ideation with the consultants.

42. I was off work for months during this year. I went into work following the first injection and my boss questioned why I had come in – I looked green. I took 3-4 months off of work and then another 3 months at the end of the year.

43. At the conclusion of the 47-week treatment I returned to work. The medication successfully eradicated the HCV, but I still felt rather sluggish and still had an inability to concentrate.

44. I was told by a number of medical professionals, that I would see an immediate improvement in my health once I finished the course of treatment and that the side effects would disappear. Any link between either the infections or the treatments to ongoing issues were always often

downplayed. It was not until the additional special category mechanism support scheme was introduced that I realised there were many others who were still suffering the same issues. It angers me that I still suffer with brain fog and I have trouble concentrating – both of which have worsened in recent years. Growing up with a bleeding condition meant that I could never pursue manual work, so I relied heavily on my brain being able to carry me through my working life. Dealing with brain fog and fatigue in particular has been very difficult and means tasks at work often take me longer than they should. Even routine daily tasks are difficult to the point I often have to make micro lists of tasks to get through the day (eg 1. Take cup to sink, 2. Wash up cup, 3. Put cup away).

45. In 2008, I developed a cough as a result of a common cold. Through coughing I broke a couple of ribs and was as a result diagnosed with osteopenia and osteoporosis. There have subsequently been studies linking these conditions to both HIV and HCV infections and treatment. There has been no acknowledgment of this linkage by the doctors I have spoken to however.

46. My HCV viral load was regularly monitored throughout the course of treatment and I had an ultrasound on my liver. I do not recall there being any scarring to the liver, but I have not had an ultrasound for some time

47. My joints are bad but this is down to the number of bleeds I had growing up. I had a knee replacement approximately 10 years ago.

48. Any dental work is done at the GRO-B During the 1980s and early 1990s I hated visiting the dentist because they would double glove and put on a full surgical outfit, including masks. The dental nurse would sit at the other end of the room as a precaution. This was the type of thing that as a child would prey on your mind. It made you different. I was still at the age where my mother would accompany me for appointments and it would upset her as well.

49. I am not sure if I had any dental treatment refused because of my infection with HIV or HCV.

50. Up until quite recently, my routine dental appointments have always been at the end of the day to allow the room to be sterilised afterwards.

51. At university I had a couple of admissions to Addenbrooke's Hospital, Cambridge because of bleeds. On one occasion I was put onto the infectious disease ward as a result of my infections, which consisted of sterile individuals' rooms. On another occasion, again during a stay at Addenbrookes, I was not allowed to eat with metal cutlery because of my infection. Instead the usual cutlery and crockery were replaced with disposable plastic ones. This was not in the early 80s. This was in the late 1990s – the hospital staff outside of the haematology department were not very sensitive in their conduct.

52. There have been times when I have noticed red hazardous stickers on my medical files. I think doctors are better at keeping the notes discrete these days, but I was always conscious of the sticker being visible to someone else.

53. Living with HIV over the years has caused me to be a very secretive person and I find it very hard to disclose the infection to anyone. I still have close friends that I have not disclosed this information to. To me it was shameful and something that no one could find out about. I understand that there is less stigma surrounding the virus these days, but it is ingrained within me to keep it to myself. I even find it difficult to tell people that I have haemophilia, in case they make a connection.

54. I have always pushed relationships away completely. Every time when I get to the point where I need to disclose about the HIV and HCV, I cut all ties. I can't do it, it's a mental block. Living with HIV has therefore ruined any potential relationship. I find myself putting up barriers and the other person is probably aware that I am hiding something or at least that's what I come to believe. For a long time, I told myself that I did not want a partner or

children in order to ensure the infections would die with me and not be passed on or transmitted to anyone else, but now I realise I have certainly lost out on having a family.

55. Medical research on HIV is always progressing and the phrase "U=U" is widely campaigned. It stands for "Undetectable=Untransmittable", indicating that if a person with HIV is on medication with a consistently undetectable viral load, the virus cannot be transmitted to a sex partner. Whilst this is great progress, I still have spikes in my viral load so I can never be sure that I would not pass the infection on.

56. I do not have much to do with other haemophiliacs. When I was growing up, about 15 of us of around the same age attended the haemophilia centre at the GRO-B Only two of us are left now and the majority of the boys died in the late 1980s and early 1990s. During a visit to the clinic you would notice another of the boys looking pale, then they would look even worse the next time, then they would be admitted to hospital and sometime further down the line you would learn they had died. They died at a time when they were so young and should have been enjoying their lives. The death of other haemophiliacs at the centre would have been hard for my parents as well. I can't imagine how they coped with all the uncertainty throughout those years.

57. Despite having a very close relationship with my grandparents, they were never informed of my HIV or HCV infection. The stigma was so great and ingrained at the time that it was felt that if more people knew, there was a greater likelihood of someone else finding out. There may have been a suspicion in the wider family that I had been infected from the blood products.

58. My two older sisters were told of my HIV diagnosis a few years after I became aware. Both of them would have been in their late teens or early twenties when informed. They are both angry with the medical profession that their younger brother has been infected with HIV and HCV, through blood products used to treat haemophilia. I had not recognised their anger

until fairly recently. I feel guilt at the fact I have been the cause of upset for them.

59. My parents and siblings would be unable to provide a witness statement to the Inquiry because it would be too much for them. Whilst they have all been affected, the emotional trauma it would generate would only be to their detriment. It is even hard raising the contaminated blood scandal with my parents, especially with my mother as I suspect she feels responsible for my one treatment with Factor VIII, although the responsibility clearly does not lie with her.

60. I feel very guilty for the worry I have caused my parents. They have suffered a lot over the years because of my infection. My mother was the primary carer in terms of my haemophilia treatment and she would administer products at home.

61. My father has always been very secretive about my HIV and HCV infection to protect our family and I am sure this will have had an effect on him. I walk with a limp because of damage to my joints and my father would say that I hurt my leg playing football as a child. The threat of anyone else finding about my condition was unthinkable.

62. My parents have had to worry about me for a lot longer than what is normal and my father still worries about my infection becoming public knowledge. Nevertheless, their support has been unwavering and they have both been very strong and have shown no outward signs of a breakdown.

63. I had to repeat some years at school, but most of the absence was due to the haemophilia rather than the HIV infection.

64. During the time of my A levels I went through a 'nothing matters' period. This was due to my HIV diagnosis and the amount of absence from school. I always had it in my mind that 30 was as long as I was going to live, so I did not see the point in academia or planning for a future

65. I ultimately went back to college to restart another set of A-levels and then I went on to university.

66. I have definitely suffered financial loss as a result of my infection with HIV and HCV, but I have never tried to quantify the loss in earnings.

67. In 2004 I had to take a substantial amount of time off as mentioned, during treatment for HCV. My HR department was already aware of my haemophilia and my consultant would normally write a very general sick note.

68. Ultimately, I had to disclose the HCV treatment as a reason for taking further time off work, but the note went centrally to the HR department to ensure my colleagues were unaware of my condition. I have continued to live a lie with the majority of my colleagues of nearly 20 years in case they discover either my haemophilia and/or the infections.

69. I only realised quite recently that my boss of 18 years was even unaware that I had haemophilia.

70. I was paid sick pay during the HCV treatment, but at some point, it dropped to 50% of my salary. I vaguely remember my holiday entitlement being used for some of the time I was off sick.

71. The amount of time off work due to my HIV and HCV infections (including as result of the side effects of treatment and the mental health impact), has certainly impacted my career progression. My peer group have all moved on far further than I have. I have remained at the same accountancy firm for 19 years.

72. I heard a 2016 Radio 4 programme with Peter Jones where he stated that the desire for a further inquiry into infected blood was being pushed by a small, greedy manipulative group of people and that the anger around the issue should have by now dissipated. I had always respected Dr Jones and I still do to a large extent however I feel those comments were at best misjudged. Prior to hearing these I'm not sure I would have been ready to

provide evidence, preferring instead to continue to bury my feelings and anger. The upset and anger those comments caused in me however have, ironically, precipitated a desire for my voice to be heard now.

73. In recent years I became rather angry about everything and I started a haemophilia treatment that had some side effects. I took three months off work because I was 'burnt out' and I returned in early 2019. After a few months I found myself back in the same position where I felt mentally fatigued and depressed. I felt that it was appropriate to reduce my hours and decided to work 3 days a week.

74. I am able to take out travel insurance policies now, but the premiums are very expensive due to my infections with HIV and HCV. It used to be that I could not travel to certain countries including the USA because of entry restrictions applicable to those with HIV.

75. I was not able to take out any cover on my mortgage because of my health conditions. This created additional stress over the possibility of having to give up work due to my medical conditions.

Section 6. Treatment/Care/Support

76. I was not for a long time offered counselling to deal with the impact of my HIV or HCV infections.

77. I was referred to a psychiatrist during my A levels, but this was driven purely by the consultant at the hospital because I was not applying myself academically.

78. My parents and my siblings have never been offered any counselling.

79. Things came to a head in recent years when the social worker at the Haemophilia Centre picked up on some mental health issues in me and referred me to a psychologist at the RVI. This was a short course of sessions with a health psychologist which although helpful to some extent did not help me resolve my issues. Subsequent to this I was prescribed

antidepressants and I have engaged the services of a private psychologist (with partial funding from EIBSS). The issues related in part to the new Haemophilia medication I was on but also it was around the time of the Inquiry starting and there was a lot of publicity about infected blood and this brought back many memories and stirred emotions within me that I had long tried to supress. The strain at the time led to me being signed off work for an initial 3 months, and then another couple of months after returning to work. I have since returned to work but have reduced my hours to three days per week.

Section 7. Financial Assistance

80. From my medical records, I found a letter from Dr Peter Jones supporting my mother's application for mobility allowance on my behalf. I exhibit this as **WITN3874009**. He explains that I have severe haemophilia A with a Factor VIII level of less than 1% and that at the age of 18 months developed a high titre antibody to Factor VIII. It was of Dr Jones' view that I fell within the criteria for mobility allowance.

81. My parents were notified of the financial support offered by the Macfarlane Trust and I received the original ex gratia payment in 1990. From what I remember it was graded in terms of the number of dependants you had, so (as a teenager) I was on the lower end of compensation offered. I think I received about £20,000 initially. The money was held in a trust and transferred to my account when I turned 18. There were conditions attached to the payment of the order it was a full and final settlement with no further recourse to litigation. At the time of signing, my parents were not aware that I had been subject to infections additional to the HIV.

82. I do not recall when I first received the ongoing payment, but this happened much further down the line after the ex gratia payment.

83. I found that the criteria for financial support from the Macfarlane Trust changed every year. I remember applying for assistance whilst at university

but it was not accepted, yet I received help during my post graduate degree. There certainly was a lack of consistency.

84. I remember receiving financial assistance towards driving lessons.

85. The Haemophilia Centre put me in contact with the Skipton Trust, in relation to compensation for HCV. I did not find any difficulties with the application process and I received a stage one payment of £20,000. I did not receive a monthly payment from the Skipton Trust and I do not recall any conditions for the one-off payment.

86. There is a very supportive social worker based at the GRO-B GRO-B (the same one who noticed my mental health issues) and she directed me to the England Infected Blood Support Scheme (EIBSS). My application was eventually successful. From my own experience, I have found the flat management structure at the EIBSS ineffective. It does not work when junior administrative assistants have so much responsibility, because you end up receiving boilerplate emails that do not answer your specific queries. Without the assistance of the social worker at the GRO-B I would not have given up on the application. It makes you wonder how many others have given up due to the difficulties with bureaucracy. I have been informed that changes are being made to the structure at EIBSS.

Section 8. Other Issues

87. I do not blame any particular people for the contaminated blood scandal and I have never held any anger towards my consultants other than the recent Radio 4 comments. However, there were never any options given to haemophiliacs at the time and the risks associated with factor products were not disclosed.

88. I now question every treatment provided for my haemophilia condition. I started on new haemophilia medication 2 years ago and there are a number of side effects. It has been hailed as a wonder drug, but in the back of my mind I wonder what we will find out later on in terms of unwanted effects.

89. What causes me much anger and which I find most infuriating and sinister is the way my medical notes have ben seemingly decimated. There was always a running joke at the Haemophilia Centre about the voluminous nature of my notes when was a child. When I requested my records as part of this evidence process under a Subject Access Request, the volume of notes retrievable bore no resemblance to those I had when I was young especially considering the amount of time I spent at the hospital.

90. It would be more understandable if there was a cut-off point before which no notes were available. This is not the case but rather it would seem there has been selective and deliberate destruction of certain periods. The question that is raised in my mind is therefore under whose instructions was this carried out, and by whom, and for what purpose. This would have happened before the NHS moved to electronic only records so this was not an automated process but rather seemingly someone has deliberately and consciously gone into my hard copy files and removed certain information.

Statement of Truth

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

Signed **GRO-B**

Dated 1 AUGUST 2020