Witness Name: GRO-B
Statement No.: WITN1922001
Exhibits: WITN1922002-WITN1922014
Dated: 17 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

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

2. My date of birth is GRO-B My address is known to the Inquiry.

3. I live with my wife in GRO-B. I met my wife in 1984 and we married in 1985. My wife already had one son, and we had two daughters together, the first born in 1986 and the second in 1987. Our children are now grown up and have left home.

Section 2. How infected

4. I have haemophilia A of mild severity. I had factor levels of around 1% when I was first diagnosed but my factor levels have since been measured at 11%. This means that I have haemophilia of mild severity.

5. I was born in GRO-B and have been under the care of the GRO-B GRO-B all my life. My granddad was also a haemophiliac and under the same centre. My parents trusted the centre implicitly. My mum told me I had my first bleed when my first tooth came through when I was about one year's old. If I had any bleeds I would go to the centre, and when I was young I would stay in but as I got older I received Factor VIII from the 1970s onwards and from then on I very rarely stayed in for any treatment. The only inpatient stay after that would have been when I had my wisdom teeth removed and stayed in for a couple of days. In the early years I was treated by a Dr Rizza and a Dr Matthews. I attended the centre about once every six months or so for check-ups and very rarely went for treatment. I only needed treatment if I was having teeth removed and once when I fell off a motorbike. The only blood products I have received is Factor VIII and I have been told that it has always been British Factor VIII.

6. Early medical notes from the John Radcliffe Hospital record the severity of my haemophilia, the treatment I received and the reasons for treatment (**WITN1922002**). The records give the type of material and the batch numbers (including cryoprecipitate, EBVIII, 'NHS', 8Y, and DDAVP).

7. In 1985 my wife and I were living on a farm in GRO-B where I was working. I had a minor accident at work where I squashed my finger. I went to the local A&E because it was closer than my GP surgery and the wound was not bleeding, it was just a black nail and I was in considerable pain. They bandaged my finger and said it would be fine. I returned to A&E two days later to have my finger redressed and assessed. The hospital said all was fine but that I should rest my finger and not go back to work. They said I would need a doctor's note from my GP for the time off work.

8. When I saw my GP, D GRO-B he said he couldn't give me a sick note just for a bandaged finger and asked to have a look. He unwrapped the bandage, took some silver pliers out, took hold of my finger nail and ripped it off. I had no

warning he was going to do this and I don't know why he did it. My finger immediately started bleeding and there was blood everywhere. Dr GRO-B said, 'oh, I probably shouldn't have done that to a haemophiliac'. He asked me to wait at the surgery in the waiting room until the bleeding stopped so that he could keep an eye on me. I waited for a few hours and my finger didn't stop bleeding. The nurse bandaged my finger and wrapped my hand up like a mitten. I left the surgery and decided I ought to go to the centre. The staff at the centre were not happy the GP had pulled my nail off. They gave me Factor VIII, which worked and the bleeding stopped. That night I returned home and a few days later I became very ill with a high temperature and thought I had flu which lasted about a week. I believe that it was this treatment with Factor VIII that infected me with Hepatitis C (HCV).

9. **WITN1922002** notes 'nail off – R/Middle finger' on 4 June 1985 and the treatment is described as NHS x 3, 8Y2201.

10. My medical records contain testing sheets which first note a positive result for HCV on 27 February 1990 (**WITN1922003**). Prior to this no results for HCV are recorded so I do not know when I first tested positive for HCV. The testing sheet appears to show I was first tested for HTLVIII in 1985.

11. My medical records also contain a later letter dated 7 March 2001 from my consultant, Judith Trowell, noting 'This patient has probably had hepatitis C for many years. He was one of the first patients to have factor VIII concentrate in Oxford which would make it the early 1970s and at that time we now know that all batches of factor VIII were contaminated with hepatitis C virus.' (**WITN1922004**).

12. No information or advice was provided to me beforehand about the risk of being exposed to infection from blood products. I knew little about hepatitis at the time and thought it was something that could only happen very rarely. My mother was a haemophilia carrier and was treated with factor as a result of which she was infected with Hepatitis B (HBV). I knew that mum had

contracted HBV from the factor but I didn't know it was a virus, I thought you just went yellow.

13. As a result of being given blood products I was infected with HCV.

14. I found out I had been infected with Hepatitis C a few months later when, in 1986, a health visitor knocked on the door and said, 'we think we may have given you AIDS, can we have a blood test?'. She took my blood and went away again. My wife was tested too. The health visitor came back the following week and said they had not given me HIV but had given me 'non A, non B hepatitis'. My wife's test for HIV came back clear.

15. I do not feel we were given adequate information to help us understand and manage the infection. The health visitor told us it was a benign virus, that I would not know when I got it and I would be unlikely to have any symptoms. She said it would be with me for the rest of my life but it wouldn't cause the same damage as Hepatitis A and Hepatitis B would, and I was told to count myself lucky I didn't have AIDS. The only information I was given was not to drink any alcohol, so I stopped altogether. The health visitor said they would like to take a blood test every month for the next six months.

16. I believe information should have been provided to me much earlier and I should have been told about the true nature of HCV, as soon as this information was available.

17. They continued to test me for HIV every month, then every three months, and finally every six months. I think they were concerned I had been exposed to HIV: it felt like they were looking for it all the time, and at the same time they downplayed the HCV. My wife and I were very relieved I didn't have AIDS and we just carried on with our life. **WITN1922005** is a letter from Dr Rizza dated October 1985 noting that they had been carrying out blood tests which show whether there has been contact with the AIDS-related virus. The notes says, 'We have had 6 test results for you so far and all have been negative'.

18. During this time I was also sent for cognitive testing which took place at GRO-B Hospital. They told me it was a study of haemophiliacs to see how those haemophiliacs who had been infected with AIDS compared to those who had not. I went for testing every six months for a few years. The tests involved things like showing you pictures of faces and asking which you thought was scary and which was not.

19. The next time a health visitor came it was a different person and when she arrived she handed my wife a bag of condoms and told her to use them in order to protect herself. We thought the precautions they mentioned, such as the condoms given to my wife, were just in case they had actually given me HIV, which they continued to test me for. As I had tested negative for HIV and because we had been reassured that HCV was not really a problem we didn't use the condoms. In terms of presenting a risk to others, the HCV infection was downplayed and all their concerns seemed to focus on HIV. I didn't realise from what I was told that HCV could be passed on.

20. My wife became pregnant in 1985 and we visited the GP for antenatal appointments. The GP seemed to be scared of us because of whatever virus they thought I was carrying and my wife's pregnancy. On one occasion I took some sharps to the surgery in a sharps box for disposal because I was on home treatment for haemophilia. When I arrived at the surgery I wanted to hand over the carrier bag with the sharps box in it, but was met by nurses gowned up and double-gloved just to take the box from me. They seemed to be petrified of us but never said anything. They treated us very differently to how that had treated us before I was told I had a virus.

21. My medical notes contain some records from around this time, with one entry on 7 June 1985 stating, 'Came to discuss family etc with wife GRO-B (19 yr old) Told about inheritance, carrier daughter etc. Also discussed AIDS and using sheath during intercourse'. On 2 February 1987 is an entry 'At home, keeping well. Agreed to blood tests Re 8Y. Discuss with C. R. Discussed HIV not

anxious. […] Blood taken from GRO-B for HIV. LFT's, HBs Ag and AB.' On 2 March 1987 another entry notes, 'blood taken for 8Y study'. On 6 May 1987 the notes record, 'Home visit. Blood taken for 8Y study. […] GRO-B GRO-B pregnant seen GP once – Mrs GRO-B distressed at situation. Dr Matthews informed, app made 8 May 1987 for GRO-B to see Dr Matthews.' And then on 8 June 1987, 'Home visit. Well. Blood taken for 8Y study (LFT, HBs Ag, HIV). […] GRO-B – baby due GRO-B 87 blood taken for HIV.' (**WITN1922006**).

22. Further notes from 1987 include a 'Home Treatment Follow-Up Clinic' record where the type of materials used (NHS VIII) is listed, and the form asks questions about general health, jaundice, and a physical examination of lymph nodes, recording weight loss, diarrhoea, dehydration, sore throat, fever, etc. The note also records an examination of my liver and spleen, 'NP' (non-palpable) and that a HBV vaccine was given. (**WITN1922007**)

23. My medical records contain a note of a 'Hepatitis C Checklist' which is undated, though appears in amongst other records dated around 1993, and records,

'I have discussed the following topics with the patient:

1. Anti-HCV result
2. Current liver function test results
3. Follow-up arrangements
4. Synergistic effect of alcohol consumption
5. Risk of transmission to sexual partners
6. Treatment options (WITN192200)

The patient was already aware of his result' (**WITN1922008**).

Section 3. Other Infections

24. After being infected with HCV I was vaccinated against Hepatitis A and Hepatitis B.

25. In 1997 I was informed by letter that even though the factor I had received previously had been heat treated to prevent HIV infection there was a risk I may also have been exposed to vCJD implicated products. I understand I have been exposed to 7,000 units of vCJD Factor. There is no test available for vCJD. I went to a meeting about it in Oxford held by the haematologist doctors. I told them that though I would be willing to risk eating a beef burger I was not willing to risk ten thousand people eating a beef burger. That is how I saw the risk of the factor I had been given. As a result, I told them I would go on treatment strike and would not take any more factor. I said I would not have any treatment unless I was going to bleed to death. I continued the strike from 1997 to 2004 when factor became synthetic and therefore safe from viruses. I also refused to have a liver biopsy as I did not want to take factor in order to undergo a biopsy. **WITN1922009** is the letter I received in 1997 regarding the risk of vCJD.

26. **WITN1922010** is a record from my medical notes clearly marking me as a vCJD risk, negative for HIV, and cleared of HCV. **WITN1922011** is a 'Patient vCJD Exposure Assessment Form' giving details of batches of 8Y I received in 1991 with the total dose. I have not seen the document at WITN1922011 before. I note the document says it is to be shared with UKHCDO (United Kingdom Doctors' Haemophilia Organisation), and was unaware that information about me was being shared in this way.

27. My notes contain an entry on 15 December 1997 as follows, 'GRO-B came to speak to me after the patient meeting re CJD & Blood product. GRO-B still under the impression that he had had the recalled batches of 8Y. Very worried about continuing to use factor. Works as a carpenter – goes through bouts of needing to treat several bleeds, then spell of none. Reluctant to treat unless absolutely necessary. Decided to change job – as carpenter – thinks may alleviate possibility of bleeds. Wants to retrain doing office work. Wanted support in letter from me – I offered to support him in this way'. The signature is illegible. (**WITN1922012**).

28. Since the introduction of recombinant factor from 2004 I have had some concerns about its use. The first time I was treated with recombinant factor was after I had had a filling. I felt very unwell and sick afterwards and got in touch with the centre who said it was all in my mind and nothing to do with the Factor VIII. My grandson also has haemophilia and he too has experienced symptoms after receiving recombinant factor. He had intussusception at six months old, where one portion of the bowel slides into the next, and was given recombinant factor. The warning on the factor says not to use if you are allergic to rodents, but my grandson had not been tested for allergies at that stage, though the centre assured us it was safe. I remain concerned about the long term use of recombinant factor.

Section 4. Consent

29. I do not know whether I have been treated or tested without my knowledge or consent or for the purposes of research. As a haemophiliac who was infected with HCV I would not be surprised if my blood tests were used to research vCJD. However, I went on treatment strike as soon as they mentioned there was a theoretical risk of vCJD from treatment factor.

30. **WITN1922013** is a medical record from 1983 with entries stating 'blood taken for virology, LFTs, ALT. It appears my blood was being routinely checked. I was unaware in 1983 that my blood was being tested in this way and had thought the tests were haemophilia tests only (factor levels).

Section 5. Impact

31. When I was first diagnosed with HCV I buried my head in the sand and carried on living my life and working as best I could.

32. In terms of further medical complications and conditions which have resulted from the infection, I have suffered with Barrett's oesophagus and hiatus hernia

and am on omeprazole as a result. I do not know whether either condition is linked to HCV and have not been told this by my doctors.

33. In 2004, when synthetic factor became available, I thought I would try to get my teeth sorted out. As part of this process I went to see the haematologist at the centre and saw a liver specialist at the same time. I had an ultrasound and they told me my liver had a funny texture but it seemed alright. They discussed treatment for HCV with me and said that because I was under 40 I had a 50:50 chance of clearing the HCV. They asked if I wanted to try treatment and I said yes.

34. I started 48 weeks of treatment with Interferon and Ribavirin in 2004, ending in June 2005. For the first week I was still able to work, but after only a week on treatment my wife was taken seriously ill and rushed into hospital. We never found out what was wrong with her but whilst she was away I found I could hardly cope on my own and could no longer work. My mental health went downhill when treatment started and I suffered with anxiety and depression. I have been on and off anti-depressants ever since I began treatment and I know these have made me very angry and difficult to live with. Combined with the strain of campaigning for victims of HCV (see below) and also the bullying I suffered at work in relation to my HCV status (also below), my mental health has never fully recovered.

35. The information leaflet you are given when you start treatment describes the possible side effects and mentions flu like symptoms. I feel this is not an accurate description at all. I suffered with flu like symptoms and spent the next year of treatment unable to work. My skin dried out and my hair stopped growing. By the end of treatment I had thrush in my mouth and was spitting out lumps of skin. My youngest daughter said at the end of treatment that she thought I was dying, something I too believed. Our children found it very difficult to cope whilst I was on treatment.

36. After completing the treatment I was told that I was clear of the infection. I had an ultrasound scan before my treatment began in 2004 and then, a few years ago, I had another test, though not an ultrasound, where a sound was passed through my ribcage and echoed back. I was told by the liver specialist that my liver was healthy. I have had no further follow-up at all.

37. Since treatment ended I have continued to have skin problems and my lips split on the sides. I told my GP I seemed to suffer with restless leg syndrome and, after routine blood tests, the GP said I was very anaemic and prescribed iron tablets. Within a few days my restless legs were much better. I now take multivitamins with iron every day. I think my iron deficiency is linked to the HCV. My teeth have suffered badly and I understand from others that their teeth have suffered after having HCV. I thought I would get better after treatment ended but it seemed to knock the stuffing out of me both physically and mentally. I wish I had never had the treatment.

38. In 2004, when I discussed treatment with the doctors, they suggested my wife should be tested for HCV too. However, they said they could not test her as they had limited funding and they were only testing haemophiliacs. They said she would need to be tested by her own GP so she had to make those arrangements herself. Thankfully, her results came back negative.

39. The only difficulties I faced in accessing treatment as a result of my infection was with the dentist. During my treatment strike from 1998 to 2004 I needed to have some teeth removed. The dentist told me he would not do it without factor and I asked him to pull the tooth out anyway, saying that if he broke my jaw he could give me factor at that point. He refused to do it so I went home and pulled the tooth out myself and just waited for the bleeding to stop. I have had to do this twice in my life. On another occasion when a dentist did carry out a tooth extraction he said he would not be able to give the tooth to me afterwards because of the risk of vCJD. The tooth had to be incinerated and all the dental equipment used had to be disposed of.

40. The stigma associated with the infection has impacted on my social life. Although I did not tell people I had HCV, they just presumed I had HIV because of my haemophilia. People were scared of catching AIDS from a known haemophiliac. Around the time I was diagnosed with HCV old school friends decided I must have HIV. Rumours went around, with friends saying not to visit our house, and not to share our cups. It was upsetting at the time and we lost friends as a result. The stigma of the diagnosis means people make assumptions about you as a person. Some think I am a junkie, or question how I got the infection. There is a lot of ignorance about HCV.

41. The work-related effects of the disease for me were considerable. Over the years I have had to change careers, retrain, and take on different work as a result of my haemophilia, HCV and the decision I took to go on treatment strike because of the on-going risk presented by infected blood over many years.

42. In around 1986 shortly after I had first been diagnosed with HCV my employer found out I was a haemophiliac. I was working on a farm at the time and had told my employer I had been infected with HCV and he asked why I had had blood products, so I had to tell him I was a haemophiliac. He was fine about it as long as I got on with my work, which was farming arable and beef cattle.

43. A few years later, November 1988, we moved to GRO-B and I changed jobs and started working in a factory. After having worked outside for many years I found I didn't enjoy factory work and so I retrained as a carpenter. I did not tell employers I had haemophilia or HCV, I was too scared to as I would not be able to work if anyone knew I was a haemophiliac. I lived as if I was not a haemophiliac and didn't have any problems with work. I worked as a carpenter until 1997.

44. In 1998 I decided I no longer wanted to do carpentry because of the risks of the job combined with my treatment strike: I no longer had factor on tap. I decided

on a career change and retrained in IT. I did a course at the local college and, when I completed the course in 2000, the college kept me on by offering me a job. I told my employers I had haemophilia and HCV. During my treatment for HCV in 2004 I was unable to work. My employer was very good and I received some sick pay, and they kept my job open for me to return to. When I was told I was clear of HCV after the treatment in around 2005 we decided to go to try to find my wife's family in GRO-B and spent six months there. I was unable to get health insurance but we went anyway. We tried to forget about the HCV and haemophilia and just enjoy ourselves.

45. When we returned home in 2006 I found a job in a school doing IT support. I worked there until 2010. My employer knew about my HCV status. They had known from the start and my first boss was sympathetic. However, my boss was replaced by a man who did not seem to like me. From that time on I was never again asked to fix the headmaster's computer and I didn't see him for the next three years. I felt I was treated as a leper and my mental health deteriorated rapidly. I was campaigning at the time (see below) and I think the school was worried about parents finding out about my HCV and the school's reputation suffering as a result.

46. In the end I decided I had to leave. I took my employer to tribunal for disability discrimination. As the hearing date approached I found I could no longer withstand the mental pressure and accepted an out of court settlement. I did not return to work with that employer and was off work for a few years.

47. A few years later a friend asked me to work with him, promising there would be no stress. I had been on and off anti-depressants for a few years. I accepted his offer and tried to go back to work, but I couldn't handle it and, after five months, I left. I found that other people's problems now affected me in a way that they had never done before.

48. I gave up work and tried to sign on for Employment Support Allowance but failed. I applied for the Personal Independent Payment, but this application also failed. I went through the appeals process for ESA and PIP and both matters were heard on the same day. A person from the Caxton Fund, Neil Bateman, who was supposed to support me during the ESA appeal did not turn up. I was asked whether I wanted to continue without my support worker and said yes. I was told the evidence I had been given to hand in to the tribunal about HCV was irrelevant and they said I had failed the reassessment. My PIP was due to start immediately afterwards but I walked out of the appeal because I couldn't handle the stress. Three years later I had a call out of the blue from a PIP assessor asking to reassess me. They asked me some questions about my haemophilia and the next day I was told I was entitled to basic PIP, mobility allowance and backdated to the date when I first claimed, which was three years previously.

49. The impact of HCV on my life has had severe financial consequences as I have had to change employment many times as a result of my haemophilia, HCV and resulting treatment strike. I believe I have not been able to progress in any particular career due to my health and am now unable to work at all and am reliant on benefits and financial assistance through the EIBSS.

Section 6. Treatment/Care/Support

50. Over the years I have faced difficulties and obstacles in obtaining treatment, care and support in consequence of being infected with HCV, as it set out throughout this statement. I have very little trust in doctors as a result of what has happened to me. Though I have now registered with a new GP surgery since moving, I have not been to see a GP here. I am dreading trying to find a new dentist as I will need haemophilia cover to access dental care as ordinary dentists will not take me on.

51. Counselling or psychological support has never been made available to me in consequence of being infected. I went to see my GP about my depression in

around 2012 but she said that there was six month waiting list. I asked the GP for recommendations for local counsellors and chose one of them, asking the Hepatitis C Trust to fund it, which they did. I attended four of the five sessions but found my counsellor wasn't particularly helpful as she didn't seem to believe me.

Section 7. Financial Assistance

52. I found out about the financial assistance available through online research. In 2004 I received £20,000 from the Skipton Fund and until that point had only been eligible for free prescriptions. We also received financial assistance from the Caxton Fund in the form of a carpet and a new bed for our rented accommodation.

53. When my wife's father passed away he left us his house, which we moved into. When we moved in we had nothing and the house had no central heating or carpets. We applied to the Caxton Fund for support to carpet the house. It was very difficult to get financial assistance from the Caxton Fund: we had to supply three quotes and they chose the cheapest and then gave us half that amount. We bought a cheaper carpet and we fitted it ourselves as we could not afford a fitter. I asked for help to install central heating but the Caxton Fund refused our request. We lived there for two years with just a wood burning stove in one room. My wife worked to pay the bills and buy our food.

54. Through the EIBSS I now receive Stage 1 payments of £3,000 per year and, with the SCM payment, this has increased to £18,500 per year.

55. The process of applying for financial assistance is difficult. When I initially applied for the SCM I asked the GP to fill in the form about how HCV had affected me. The GP completed the statement and explained how HCV was affecting me and that she was treating me for depression and anxiety. The GP was very honest on the forms and when asked whether my problems were due

to HCV she said she was a GP not a HCV expert so she could not answer. The application failed. When I reapplied I asked my haemophilia consultant to write a letter in support to back up the GP statement and in the end the payment was granted. I thought the application would not be a problem and I did not expect to be refused. When they told me they had turned my application down because they thought I had not been affected by the HCV I had an anxiety breakdown.

56. **WITN1922014** is a letter from my consultant haematologist in 2018 written in support of my EIBSS application. The letter usefully summarises what I have set out in this statement.

Section 8. Other Issues

57. In 2010 GRO-B David Cameron, became Prime Minister. I decided I would go and see him at his surgery and ask him if he would hold a public inquiry about contaminated factor. When I met with him I told him people were dying from HCV having been told it was a benign virus. I explained the financial disparity between HIV and HCV suffers. He said that he didn't want to hold an inquiry and talked about the Bloody Sunday Inquiry taking such a long time and costing such a lot of money: he said he would rather give the money to the victims. I spoke about it on Radio Oxford and the BBC. David Cameron then announced that those with HCV deserved some ex gratia payment and, six months later, he said he would give £250million to haemophiliac victims.

58. Despite this announcement, at that time all I received was free prescriptions, so I went to see Mr Cameron again. He seemed quite angry and spoke very loudly about the amount of money he had made available for those with HCV. I felt he was suggesting I was just coming back for more. His last sentence was, 'what have you had out of it?' so I told him that all I received was free prescriptions. He turned to his advisors to ask what was going on and they explained there were a lot of widows to pay, together with Stage 1 and Stage 2

payments. I left the meeting telling him I was still not satisfied and he said he would do the best he could.

59. I carried on campaigning. GRO-B GRO-B Although I looked everywhere for other victims, no one came forward. I wondered whether they had already died. I wrote to Mr Cameron asking to see him again because nothing was happening. He refused, saying he had seen me twice already and they were doing the best they could and it was all being sorted out. I responded to say that I would hold a demonstration if he would not meet with me.

60. We planned the demonstration outside Mr Cameron's constituency office in Witney and secured the necessary permissions from the police. The day before the demonstration was due to be held Mr Cameron emailed asking to see me. We held the demonstration outside his office in Witney and I met with him shortly afterwards. Demonstrating was a very upsetting experience: the stigma at that time was as bad as it had been in the 1980s. Once the local people in Witney realised what we were demonstrating about and that some of the demonstrators had AIDS they started moaning at us and took all the chairs away that they had initially let us use.

61. I suffered criticism for speaking out over the years and have taken a step back from campaigning, particularly given David Cameron has now resigned which means I no longer have the ears I used to have. My wife and I have now moved away and it has been an opportunity to make a fresh start.

62. I would like the Inquiry to address why potentially infectious treatment was used on mild and moderate haemophiliacs. The rationale for treatment was always that haemophiliacs would be dead by the ages of 15 or 16, but my grandfather, who was a haemophiliac and died before Factor VIII was invented, lived until he was 72. Mild and moderate haemophiliacs had a good life expectancy and did not need life threatening treatment. Such haemophiliacs should have received better monitoring and only been treated if necessary, rather than preventatively.

If I had been told that the treatment I was receiving possibly contained life shortening viruses then I might have opted out of treatment altogether. Instead, I recall Dr GRO-D telling me there was no proof Factor VIII was spreading AIDS.

63. I hope the Inquiry will get to the truth and prevent anything like this from happening ever again.

Statement of Truth

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

GRO-B

Signed

Dated …17 December 2019…