ANONYMOUS

Witness Name GRO-B
Statement No.: WITN3205001
Exhibits: WITN3205002 - WITN3205010
Dated: February 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:-

Section 1: Introduction

1. My name is GRO-B and my date of birth is GRO-B 1963. My address is GRO-B I am married to my wife GRO-B: W. I am 57 years old and my wife W is 56 years old. We both retired in September 2019. I have three daughters from my previous marriage and two step-children from my second marriage.

2. I live just outside of GRO-B and my Haemophilia Centre is Manchester Royal Infirmary. My clinician was Dr Boulton and Dr Lucas was also based there. Whenever I attended I would see either of them.

Section 2: How Infected

3. I have haemophilia A which is known as the common one. I received my treatment on demand at either the Manchester Children's Hospital up until I was 18 years old and then the Manchester Royal Infirmary until the age of 56. Since September 2019, I have received prophylaxis treatment at home which is administered by my wife.

4. When I was two years old I used my dad's razor to have a shave and caught my lip quite badly. My parents took me to hospital because it would not stop bleeding. I was treated at the Manchester Children's Hospital, Pendlebury where the hospital stitched up my lip. I later picked the stitches out and ended up back in hospital for a week because it would not stop bleeding. At that point the hospital thought that I may have been anaemic, however my medical records show a recorded time for clotting and notes that everything was a bit slow. When I was around six years old I was out playing football and hurt my ankle. I ended up in hospital again and I was put in plaster and kept in hospital for a week. The hospital then diagnosed haemophilia, which would have been sometime in 1969. My first memory of being given blood products was when I was about 11 years old in about 1974 and I recall being given lots of it. I recall the hospital having large syringes of yellow fluid. It was defrosted and then injected.

5. It does appear from my medical records that it took the hospital a while to realise what was going on with my bloods. Back then there was little in the way of treatment for haemophilia and there was certainly no prophylaxis. I think it was a very slow process and was just a case of "we will keep an eye on you" type of process.

6. Whenever I had a bump, I would have gone to the Manchester Children's Hospital with my mum because it would have usually happened during working hours and my father would have been at work. I am not aware that my parents were provided with any advice in relation to the blood products that were being given

to me. I do remember the hospital informing my parents that I was a haemophiliac because that made me feel quite special, like a bit of a super hero.

7. Once the treatment started it was very matter of fact. I recall treatment for a bleed when I was 11 years old, I went to the hospital and explained the circumstances, the doctor had a look, the hospital then defrosted some blood products and I then lay on a bed and the doctor gave me the injection.

8. I am a little bit of an anomaly in the fact that I can be a severe haemophiliac on paper. Therefore, when the hospital takes a Factor VIII reading, it can move around a little bit. Everyone has a mean number and you know roughly where you sit and mine seems to fluctuate between slightly under 1 to about 2. I do not understand the science behind it, but there are other functions and mechanisms within the body that help you clot and heal aside from Factor VIII and mine must be pretty good because I do not behave like a severe or almost severe haemophiliac. My trips to the hospital were probably less frequent than expected, but at no time do I recall anybody saying "*right I'm going to give you this to help you*", or "*you need to be aware of the risk of A, B and C*".

9. At a young age I learnt, courtesy of my father, to ignore an issue. It was not that he did not care but quite the opposite, he possibly cared too much. He struggled to deal with the consequences of having a haemophiliac son and his anger surfaced whenever I hurt myself, possibly through a sense of hopelessness that his little boy was suffering. As such, I learnt to hide bruises and bleeds as best I could to avoid his anger and sadness, rather than have treatment. For his sake I had to appear to be fit and well at all times and ignore any problem.

HIV

10. In 1984 when I became a graduate entrant at a firm of chartered accountants I became aware of the of the impact of HIV and AIDS on the community. Initially this had been in relation to the gay community, but very soon the issue included

haemophiliacs. I remember the media coverage in newspapers and on TV and the level of saturation was frightening, but rather than dealing with the issue, my learnt behaviour surfaced. Therefore, at that point in time, I chose not to have a test for HIV and my bleeds went untreated. I was afraid of the diagnosis and to me ignorance was the answer. I felt that if I became ill, I would learn of the virus at the point it impacted my life. I did not see the point in knowing you were going to die so far in advance.

11. I met my now ex-wife in January 1984 and she was fully aware of the HIV issue and as I appeared "well" she accepted my decision to avoid a HIV test. We got married in GRO-B and I still did not have a test. It was only when we started thinking about having children that we felt we should have a test. My medical records show that I attended Manchester Royal Infirmary in November 1990 and had discussed having the HIV test, WITN3205002. The first document is a handwritten note which notes severe haemophilia and that I was treated with cryoprecipitate in 1982 and should therefore be HIV tested. The second document is a note which states the doctors had discussed this with me and that I would think about it. My wife and I both took the test and in January 1992 we received the news that the results were negative. The news was a huge relief. During this period of time I do not recall being invited for a test prior to the discussion in 1990. I was aware that I could have a HIV test, as probably anybody in the public could have a test at that time.

12. There is nothing in my notes prior to this time in relation to AIDS and I do not recall attending the Haemophilia Centre at the Manchester Royal Infirmary and being told anything about HIV. However, that may be due to me because I did not attend the hospital from the Summer of 1982 through to about 1988. During this period of six years I did not go for a check-up and I think I just fell off their list in terms of the MRI requiring at least an annual visit from me. To corroborate this point, the hospital and GP notes do not include any letters inviting me for an annual check-up and likewise, there are no letters that discuss non-attendance.

13. Also during that period I did not have much wrong with me, I probably had the odd bleed, but I chose not to go to the hospital for treatment. At a certain point in time in about 1985 I was quite conscious of HIV and thought "*there's no way I'm going near that place, I don't want any treatment thank you very much*". During this six year gap the hospital could have been informing other haemophiliacs of the HIV issue, as they attended for their regular checks. However, as I was not attending I was not informed of the risks involved. The hospital did of course have my address and I was one of their patients, but I did not receive anything from them.

Hepatitis C

14. I can see from my medical records that when I had last attended for treatment at the Manchester Royal Infirmary in July 1982, that my LFTs were within the normal range. The hospital had tested them at that point in 1982, for whatever reason they chose to do that, however, I was not aware they were doing so. The blood results are dated February and July 1982 and relate to both haematology and biochemistry. The biochemistry results show ALT and AST readings that were within the normal parameters, WITN3205003.

15. When I attended the hospital in July1982 I received cryoprecipitate. I attach a copy of a periodic summary from my medical records which details the treatment received and which confirms that the ALT result was normal, WITN3205004.

16. In around April 1988, the hospital called me in and I had a blood test. I did not know at the time what this was for. However, I can see from my medical records that they had tested my liver function. The biochemistry results indicate elevated ALT and AST readings and the document has been marked with a request to repeat the test in three months' time. The readings are marked with an asterisk and I assume this is when results fall outside the normal parameters, WITN3205005. I do not recall being retested and there is no evidence of this in

my medical records. In November 1990 my notes again show that the AST reading remained elevated and is again marked with an asterisk, WITN3205006.

17. Following the negative test result for HIV my wife and I started a family and our first daughter was born in GRO-B 1993. Shortly after this I had a problem with my shin on my left leg and so I attended the centre voluntarily in relation to that and to discuss a letter received from the Manchester Royal Infirmary informing me that in all probability I had a hepatitis virus, as yet unnamed. Whilst at the Manchester Royal Infirmary I had a blood test and was asked to make an appointment to discuss the results.

18. I duly made an appointment and on 13 October 1993 I saw Dr Lucas who made me aware of the diagnosis of Hepatitis C, WITN3205007. During this time, I also saw Dr Bolton again and it is her words concerning my diagnosis that will never leave me – "*Don't worry, you don't have to write your will just yet*". The escape from HIV some fifteen months earlier now seemed irrelevant as, to my mind, I was now facing a very real death sentence, this time with a different name.

19. I believe the provision of treatment for haemophilia was administered at a time when it was known there was a risk of contracting HIV or Hepatitis C. Following this treatment that could have knowingly infected me, there had been no follow up to check whether I had been infected. There was a lack of consideration by the NHS in relation to possible cross-contamination to family members and my unborn child in the period that the NHS knew of my likely infection.

20. There is a letter from GRO-D in Manchester, to my GP dated January 1995 in my medical records. The letter states "*his LFTs have been consistently abnormal since 1988 and is hepatitis C PCR positive*". The time gap between the NHS being aware of the LFT abnormality and me being informed of an issue was five and half years, WITN3205008.

21. The letter from GRO-D in January 1995 informed my GP that my liver function tests had been elevated since 1988. The medical teams knew they were elevated and they did nothing about that until I was informed in October 1993. This is more than a five year gap. During that time my wife could have contracted Hepatitis C, my youngest daughter could have contracted Hepatitis C, workmates could have contracted Hepatitis C. Not informing somebody about a virus that was transmissible I believe is negligent.

22. Before my current wife retired she was a GRO-B for the NHS. She had carried out a lot of work in relation to intervention for patients and so she was used to looking at blood results and what had to be requested if bloods were not right. She was horrified when she saw my blood results in my medical notes. These results show dates where my liver function results were not just high, but grossly elevated results. My wife and I know that times have changed and that processes are different now, however, we both struggle to understand how blood results could come back that looked like that and nothing done about it. No one said we need to admit this patient and find out what is going on. Because of this I believe that they knew exactly what was going on. The tests were repeated at intervals that my wife said she would expect to see when patients were being monitored and this was before anything was even mentioned to me.

Section 3: Other Infections

23. I did not have any other infections.

Section 4: Consent

24. I was not aware that my liver function tests were ongoing, however, I had not attended the hospital for a number of years. When I did eventually go to the

hospital I believe I would have been informed of the blood tests, but I do not recall being told what they were for.

25. When I started the treatment trials I was provided with some information which is at WITN3205009 which I believe is classed as informed consent. The information included in my medical notes appears to me to be entirely insufficient. It did not include risks or benefits, nor is there evidence of my signed copy in the medical records. This cannot be considered as "informed" consent.

26. Prior to retirement my current wife had also carried out a lot of work with the Health Research Authority "HRA" and also with other regulatory bodies regarding patient consent and intervention for clinical trials. She worked at an oncology hospital. She was shocked at what constituted informed consent as discussed above.

27. My medical records show that I had attended the haemophilia centre on 2 February 1994 and saw Dr Lucas. At that appointment Dr Lucas informed me of continuing "deranged" LFTs from a blood test on 27 January 1994. Dr Lucas then wrote to Dr T Warnes, a Consultant Gastroenterologist, on 3 February 1994 asking if I could be seen and advised in relation interferon treatment which Dr Lucas had already discussed with me. I attended this appointment on 15 March 1994.

28. On 23 March 1994 Dr Warnes wrote to Dr Lucas regarding my visit and stated that an ultra sound scan was to be arranged and the letter also mentions the possibility of alpha-interferon treatment and the difficulties of the provision of this therapy for haemophiliacs. Dr A Hawthorne, Senior Registrar, wrote to my GP on 7 July 1994, copying in Dr Lucas, which refers to my visit to the liver clinic on 1 June 1994 and states that the ultra sound was normal. The letter goes on to say that "*No decision has been made yet about interferon treatment for these haemophiliac patients*" and "*We will see him in six months so that once a*

formulation of the management plan and funding has been arranged we can take things further."

29. I attended the liver clinic on 12 December 1994 and on 13 December 1994 Clive Goddard, Research Registrar, wrote to Dr Lucas and stated "*I have told him there are still discussions in progress regarding Interferon treatment in this group of patients. However, I feel that he would be an ideal candidate for it should the opportunity arise.*" Dr Lucas has written on this letter "*Charlie Your thoughts? Guy*" which is a question to Dr Hay. Following this I met with Dr Hay on 23 January 1995, following that meeting he wrote to my GP to confirm that I would be starting on the Interferon treatment.

Section 5: Impact

30. I recall in 1985 there was a football match, Liverpool playing Juventus at the Heysel Stadium, there was a disaster and people were killed. However, I was studying and I was not watching the game. I was studying upstairs because I had some professional exams coming up and I just remember this overwhelming feeling of being anxious in relation to HIV. I reached a point where I felt as though my head was going to explode. I felt that anxious I had to stop studying. I did not know it at the time, but I think that it was a panic attack. Around that time, I had a feeling of complete anxiety which stayed with me from 1985 until December 1991 when I had my HIV test. There was nowhere to put it, it did not seem to go away and I could not put it in a box or hide it away.

31. In GRO-B the anxiety was still there, however, at that point in time I was about to get married, about to start my job with what is now GRO-B and my wife at the time and I were buying a house. There was a lot happening at the time that individually could have resulted in a little bit of tension, but when combined with the anxiety concerning HIV it was probably a bit too much for me and that

manifested itself. I went to see my GP who said that I had got this silly head cold. I knew I had not. I then went back and explained to my GP that it was still there and he asked if there was anything going on in my life. I explained to him what was happening and the GP said that I was suffering from stress. I understood then and I think more than anything that started with the HIV back in 1985. Before that I had no history of stress, anxiety or anything like that, I was always quite positive. I knew I had haemophilia and that I had to be careful, but that was my daily life which was like putting on your glasses every day and I had grown up with that.

32. I believe HIV was the catalyst which set off my chain of anxiety. I was not in control anymore, it controlled me. The anxiety defined me and I could not get on top of it at all. I lived with it and tried not to think about it all the time and went about my business as best I could. Later, I thought to myself, "it is 1989 now, those adverts were four years ago, so I am probably going to be okay". I had not had an HIV test. Looking back now I could have perhaps put it to bed by having the test, but I chose not to because I thought what is the point in knowing. I did not want to live the next ten years knowing that I was going to die someday, I will find out a couple of weeks before I die.

33. As stated above, when my ex-wife and I decided to have children we felt that the sensible thing to do was to have a HIV test. However, it was just two months later I was informed that I had Hepatitis C. Again I went through all the morose and negative thoughts and did not know where life was taking me.

34. I recall the day I was told and remember coming home with the doctor's words still in my head. My wife was still at work and so I walked up there to talk to her. I told her what the doctor had said and she responded "*well you look okay, so don't worry about it*". And that was that. Everybody reacts differently and you cannot blame somebody for the way that they think.

35. After the diagnosis of Hepatitis C I recall attempting to find out some information about the virus. This was pre-internet and meant visits to libraries and book shops, but this was futile as there was nothing of note. My anxiety remained. My thoughts also turned to my daughter and of leaving her when I died, of missing those important occasions in her life and how she might lead her life without me. I also felt guilty which was associated with failing those that needed me.

36. Following the diagnosis of Hepatitis C my liver function test results remained abnormal. They were taken every six months and the visits to the hospital did not seem so bad and I eventually became accustomed to them. In my mind I had received the worst of the news when I was diagnosed and from that point on I thought of the possibility of a cure, which the doctors had discussed with me.

37. Over the next few years my wife and I had another daughter, born in 1995, the same year that I began the Interferon trial which I refer to later. This trial failed and I then began another trial and in 1998 I became Hepatitis C negative. At this point my mind-set changed. I had everything to lose again. I dreaded each hospital visit in case the result reversed. Thankfully it did not.

38. I think it was in 1996 or 1997 when my wife first said that she was really struggling and that she did not think she loved me anymore. It had never been like that before and it followed my initial treatment and anxiety. We attended marriage guidance counselling around that time.

39. From that time, during the 1998/99 trial, it became obvious to me that my mental health had suffered further. This was a gradual decline and my relationship with my wife and children altered. I had also started to make mistakes at work. My work had always been important to me and I did not want to let anyone down. I was seen as dependable and a strong performer for the twelve years I had been with GRO-B and I began to feel that I was becoming a liability.

40. I recall having a meeting with my employer at which my performance was discussed. I agreed to have counselling in connection with workplace stress.

This was in 2001 and I was free of Hepatitis C and so I felt that that was what it must have been. I had no inkling at this time that my mental health may have been associated with my earlier treatment. I completed the counselling and I tried to carry on and around this time our third daughter was born.

41. In April 2002 I could not carry on. I arrived at work that morning and requested a meeting with a Partner of the firm and left the building an hour later. I did not return to work until February 2004, an absence of 22 months. I was diagnosed with depression on account of work-related stress. Again, there was no connection between my mind-set at that time and the treatment I had received earlier.

42. This period away from work was difficult with each day feeling empty and void of anything meaningful. I felt helpless and anxious of any return to work. Different anti-depressants were prescribed and further counselling was sought. After six months of being off work my wife had informed me of a loss of respect at me not being at work. The timing of this coincided with a 40% drop in my salary under the terms of the long-term sickness benefit offered by my employer. After this my decline intensified to the point that on Christmas Day 2002 my wife told me that she no longer loved me. My wife left me in June 2003 and we were divorced in November of that year.

43. My marriage had failed, I was not in work and I felt that I had failed my children. They no longer had a stable and loving unified family. This was my lowest point, but one from which I was determined to recover.

44. It was a few months after my wife had left when I decided that the only way forward was to try and return to work. I was on the internet and I was looking at haemophilia websites and I came across one in the US. I could not believe what I was reading. I read about people losing their jobs, I was off work; marriages failing, my marriage had failed; suicide, thankfully not. When I read on it became apparent that their members were suffering with depression arising from the

treatment they had received for Hepatitis C. They were being treated with Interferon and Ribavirin the same as me.

45. I got straight onto the phone to Manchester Royal Infirmary and spoke to a nurse who I know very well and explained what I had read on the US Haemophilia website and asked if it were true. She said "*oh yes, to the point now we have to give out Interferon, Ribavirin and Prozac or some people can't stand it and they prefer to have life with Hepatitis C and not have the treatment at all because they can't tolerate it*". I did ask her if they had a policy of informing their patients or checking with them that they were ok, but that conversation did not go anywhere.

Impact on my children

46. There would undoubtedly have been an impact on my children. My biggest regret in life was bringing up my children in a broken marriage. I did not want that to happen. If you are lucky enough to have children, you want them in a secure family unit with all the love and everything that you can bring to them and push them into their lives with. That did not happen. When my wife left I wanted joint custody, which I got, so they were with me as much as they were with their mum. But undoubtedly it did impact them emotionally. When this happened in 2003, they were ten years old, eight years old and two years old. My two-year-old probably did not know a lot different, but certainly for the eight year old and the ten year old there would have been a significant impact on their lives at that time.

47. I had the children for half of the time. I could not afford to take them on holidays. I lived on an overdraft and that was just the way it was. I could not avoid that from month to month. I do not recall worrying about it. However, it did not stop us having fun times but our lives were not what they had been.

Financial and career impact

48. I joined GRO-B in January 1989 and it did not come up in interview that I was a haemophiliac. It did come up within a couple of years though because I had to take a few days off. I started to get a troublesome ankle, arthritis through bleeds and I had a flare up and was unable to walk and I had to explain that to GRO-B When I informed them they were absolutely horrified that I was a haemophiliac and that they had not known. Looking back now I think this was because they believed I needed extra care, but there was absolute shock and horror from them. I could not believe the reaction when I told them. I did think at the time what has it got to do with them, my sickness record was better than 90% of the department. I never took time off and I did not have bleeds. All I had was a little bit of arthritis. I remember feeling quite upset about it at the time. I do not know why they reacted in the way they did as nothing was said, but it was such an extreme reaction from a few people. Nothing changed after this that altered the way I worked. I cannot discount the reaction being down to all of the press in relation to HIV and AIDS, but I do not know. I did not know anything about Hepatitis C at this point and I had not had a test for HIV but I may have informed them that I was not interested in getting a HIV test that could have caused the reaction. I do not recall the full conversation.

49. In April 2002 I was signed off work with work-related stress. At that time my salary was £48,000 and also cash taken instead of a company car. I received six months on full pay when I was signed off and then it reduced to 60%. There had been two incomes coming into the house, one went when my wife left, and the other one was reduced to 60%. I still had a mortgage to pay and still looking after three children, albeit for half a week. It was quite tough mentally and financially whilst I was off sick. Fortunately, my mum and dad helped in buying out my ex-wife from our family home at a cost to them of £30,000. I wanted to ensure that I retained the family home for the sake of the children as I thought it would provide at least some degree of continuity for them.

50. In early 2004 I had various meetings with my employer GRO-B to discuss my return to work. My employers would welcome me back full time subject to two provisos. My employer said that I could not just walk back into the same level of responsibility that I had had previously. I was a Senior Manager at that time. I was therefore demoted to Supervisor, which was two grades lower than I had been originally. They did pay me the highest they could pay someone on that grade, however, that was £36,000 which was a loss immediately of £12,000. I accepted this at the time and found myself working for staff who had previously reported to me. Despite me now knowing that my depression had been initiated by the treatment for hepatitis, no one at work knew this. It had therefore been, and continued to be, presumed that I had been off with work related stress and they had made a decision that I would not be able to return at the same level as they did not want me to have the added pressure of that role.

51. I do not know whether it's humility or being humble, but I did not explain the fact that I had depression caused by the treatment I had for Hepatitis C. I did not see the point. I believed I was lucky to be there and saw it as an opportunity to start again. However, I was left with the stigma of depression but did not feel it appropriate to share my explanation. I had been on a difficult journey and had come through the other side and was proud of that.

52. I then had to work my way back up the career ladder. I worked long hours and also carried out some of the duties of my previous role, even though I was being paid the lower grade. Through hard work and determination, I was promoted to Manager and then to my previous position of Senior Manager which took two years. I believe that is because they considered I had suffered worked related stress and this therefore impacted my career progression. The next position up at that time would have been Director and then Partner. I recall having a discussion with one of the Partners about career progression. He informed me that he did not want to put me through that process because it has its own levels of stress and anxiety. The process would have involved preparing for panel interviews and so that was where my career stopped.

53. When you are depressed you do not function that well. When you do not function well that might mean you do not brush your teeth as well as you normally would or it might mean you do not do your job quite as well.

54. In 2018 there were around 70 people employed in Manchester and Liverpool. I was made employee of the year. This was the first time they had given this award. I believe it was because I was probably over performing in the grade I was in, Senior Manager.

Impact on social life

55. After my wife left I did not go out. I would just stare at four walls all day. I also had the children to look after for half of the week. I had a two-year-old to look after and I had to make myself put her in the pram and take her for a walk. Beyond that I did not go out.

56. Shared custody of the children continued until they left home to lead their own lives. In 2008 I met my current wife and we married in GRO-B

Section 6: Treatment/Care/Support

Dental Treatment

57. I have always had difficulty in obtaining dental appointments. An appointment would be made and would then be postponed or deferred and excuses made such as the dentist was poorly. It was quite difficult to get a dentist and in the end I just gave up. Due to that I was eventually treated at Manchester Royal Infirmary. I went to the Manchester Royal Infirmary for quite a number of years. About four years ago my wife found me a dentist because I needed an awful lot of work. It took nearly two years between the dentist informing me "*you need a tooth removing but I can't do it*" to "*it needs to be done at Manchester Royal,*

there's a dental department I'll sort it all out" and the tooth being taken out, that I just do not go now. I recall on two separate occasions that we went to France and I attended the French doctors for treatment for a tooth abscess. Unfortunately, this has led me to what my wife would say is an unhealthy level of self-neglect when it comes to dental care.

Treatment for Hepatitis C

58. I recall Dr Bolton explaining to me at our meeting in October 1993 that the liver is a large organ and I remember her specifically saying that it can wear out after 25 years. I do not recall being offered counselling but I do recall seeing an office with the word Counselling on it and thought to myself that that was unusual as at the time the doctors had said that they did not know anything about it, it had not even got a name. They did say that it could be fatal. I recall some commentary about lifestyle but there was no counselling or treatment at that time. My counselling came later and was provided by my employer.

59. Following the diagnosis, I had regular trips to the hospital specifically for giving blood samples. I was not asked how I was, how life was generally and if I had any support. It was a trip to give a blood sample to check my LFTs and to talk about any possible treatment. I would attend the hospital; they would then write to my GP in relation to what treatment was discussed or if there was an update on what they knew about the Hepatitis virus rather than being patient orientated. It was ticking the boxes.

60. With Hepatitis C my issue was not the disease itself as I was asymptomatic. My liver function tests were elevated, but physically I was okay. I sometimes felt as though I had a toothache type pain in my side at times, but I was physically okay. All of my issues came from the treatment given to me for Hepatitis C and that impacted my life more than anything else.

61. A Clinical Assessment [WITN3205010] was carried out prior to starting any trials. The first trial I undertook was for Interferon in isolation. An entry in my medical records states that they will need funding and there is then a 12 month delay before Interferon is given, I do not know whether it was off licence and I do not know what the patient group directive was for the patients who were given Interferon. For the patient group that I was in they waited and waited as there was no funding and then it was given as a clinic trial. I am aware from my wife that in oncology medicine there are various drugs which have had approval for use, however the National Institute for Health and Care Excellence ("NICE") will not authorise them because of cost.

62. The trial lasted for six months from January 1995. I did have regular checks up with my GP and my medical records show that during this trial I suffered with lethargy. This treatment was unsuccessful.

63. In March 1998 I was called back to discuss a second trial. This was referred to as a new treatment and Ribavirin was described as an unlicensed drug. I was informed that I would be on a trial of 20 patients. I recall I had to sign a waiver to sign away all rights against the hospital, however a copy of the waiver is not in my medical records. I was advised not to have children within six months of coming off the treatment and they provided me with a start date. The trial was a combination of Interferon and Ribavirin. I was advised of the technique for injecting Interferon which was like a little needle into the tummy. Ribavirin was a tablet. That was all I was told at the time and asked to come back in a few months so that they could test LFTs.

64. I grabbed the opportunity to join the trials because it was a treatment and you trust in the doctors and hospitals. You take their advice and believe in what they are saying and that this treatment could help me. The second treatment helped.

65. At the time of the second trial we had been advised not to conceive as there may be abnormalities. I cannot recall if there were any other warnings. That trial

ended in March 1999. My daughter, GRO-B: D, was conceived in GRO-B 2000 which was around 14 months later. D was born with a cleft lip and I have always wondered whether there is any connection with the treatment I received. I am not sure if this was pure accident or something that was driven from the treatment. I do not know. The concern that you may be responsible stays with you.

Section 7: Financial Assistance

66. In 2003 I received a payment of £20,000 from the Skipton Fund. I have also received a basic payment from the English Infected Blood Support Scheme ("EBISS"). These payments are monthly and commenced in November 2017. At that time the payment was £252.50. From April 2018 the payments increased to £333.33. At the announcement of the Inquiry payments were increased to £1538.16 per month and were backdated. The payments have recently increased to £1564.33 per month. I have also received a winter fuel bill payment each year. I found each application process straightforward.

Section 8: Additional Information

67. Once I had been informed I had Hepatitis C I did then start to talk to the doctors and they wrote to my GP to discuss a plan of action. The letter states for this "group of patients". I then received my treatment through a trial. This treatment was not through regular NHS funds and therefore you had to be on a trial to be treated. Is that fair?

68. We were categorised as a group of patients. The doctors knew I had got Hepatitis C through blood products, but they categorised me as "this group of patients" and that they were going to have to come up with a plan as to how to treat this group. This was in a liver clinic that treats all liver complaints and so why was I different

with my liver complaint? Why did I have to wait for a trial? I do not know if there were any other treatments other than a trial, however the way the language comes across it seems that I was ring fenced and set aside and looked for some plan as they talk about funding in the letter which states "*how are we going to fund this?*" Did this hold up treatment? How many others like me are not here today because they were not informed of the condition or treatment was delayed due to funding?

69. Another point to make is duty of care. Despite the NHS having clear evidence of the causal link of Hepatitis C treatment and depression they did not contact me at any time to ask if I was having any issues. To find out later that they knew of this side effect felt almost as devastating as the news that I had Hepatitis C and I believe this can also be construed as negligent.

70. Knowing a little about how the NHS and other government bodies work with healthcare I believe we need openness and transparency in relation to funding of drugs and clinical trials.

71. I believe the government ministers are responsible ultimately. It is not a case of each individual centre deciding what they are going to do, what their policies are going to be for this group of patients who have been infected. The decisions made at the time in relation to continuing to treat patients with contaminated blood products would have come from very high. I believe that Dr Hay would have taken his instructions from elsewhere and I would like to see the chain of command in that regard.

72. I am sure that the medical staff did their best; they would not want a patient to come to harm and I would like to think that any treatment plan was offered based on best practice at the time it was given. I also hope that none of the doctors chose to ignore recommended best practice at any time in treating my haemophilia. If there is to be an assertion of blame, then I assume that the Inquiry

will look to identify any element of negligence at a higher level. In this regard I have a number of questions:

- As an authoritative medical body, there would be an expectation on the NHS of continuing excellence in all fields of practice. Was the NHS sufficiently active in its internal assessment of the potential for HIV and Hepatitis C to be transmitted in blood products?
- Was this duty of care ongoing such that the transmission of viruses could have been identified at the earliest opportunity?
- Did the NHS receive notice of transmission from overseas medical institutions and at what date?
- At what date did the NHS mandate the heat treatment of Factor VIII?
- Was it a blanket mandate provided to all treatment centres?
- Was the mandate communicated to all treatment centres on the same date?
- How does the mandated NHS date for heat treatment compare to the date advised by other leading countries?

Statement of Truth

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

Signed ... GRO-B ....

Dated.............7\2\2021..............................