Witness Name:	GRO-B
Statement No.	WITN5605001
Exhibits:	Nil
Dated:	31,12,2022

INFECTED BLOOD INQUIRY

WRITTEN WITNESS STATEMENT

OF

GRO-B

I provide this statement in response to a request under Rule 9 of The Inquiry Rules, 2006 dated 11 th February, 2022.

I, GRO-B

will say as follows:-

Section One - Introduction

 1. My full name is
 GRO-B
 GRO-B
 but also once known

 as
 GRO-B
 and I was born on
 GRO-B
 1963 at
 GRO-B

 GRO-B
 in Manchester. I am a married woman, the mother of four children, and live at an address which is known to the Infected Blood Inquiry with my stepson who, like me, is also unwell.
 Inquiry with my stepson who, like me, is also unwell.

- 2. Through this witness statement, I intend telling the Inquiry of my infection with Hepatitis C (also referred to as Hep' C and / or HcV), how I came to be infected, and in particular the nature of this ailment as it impacted upon me, my treatment, and how Hep' C infection has directly affected my life and that of my family and friends.
- 3. I have the debilitating condition of Myopathy, and suffer from Continuing Depression. I am also Bipolar (first diagnosed in 2005, but I had been under the care of a psychologist for an appreciable period beforehand). Additional health issues I face include, but are not limited to, Adrenilanating Syndrome; nerve pain and sensory deprivation (particularly in my arms and feet); a constant feeling of my being 'unwell' (which has been everpresent since about 1999 2000); involuntary tremors and / or 'shakes' together with Restless Leg Syndrome; tiredness (but accompanied by an inability to sleep well); and anxiety, which means that I generally won't leave the house alone, as I simply cannot bring myself to do so.
- 4. As a result of some of the health issues I currently face, I am on various prescribed medications, including Lamotrigine and Prozac.
- 5. Significantly, in so far as my having contracted HcV is concerned, I have Haemophilia C, a condition through which my body is deficient in producing a particular blood clotting (in my case Factor XI).
- 6. Although I am not legally represented, and am quite content to have allowed the Inquiry to assist me with my providing this witness statement. I have engaged solicitors in the past in approximately 2004, as a direct result of my infection, I successfully took civil action against The Blood Transfusion Service, using consumer protection legislation and as a result of which, I received a financial award.

7. I have not provided evidence to any other investigations, tribunals, inquiries or litigation other than that mentioned above (Paragraph 6). I have been an applicant to the Skipton Fund, initially received financial assistance through them, and am now supported by the England Infected Blood Support Scheme (or 'EIBSS' as it is more commonly known or referred to).

Section Two - How Infected

- 8. I was born into a family with no known prior history of blood borne ailments or deficiencies, although my parents were apparently aware that some members of the family apparently *'bruised easily.'* Nowadays, this would most probably have been picked-up, or at the very least clinicians may have been alerted to a possibility of Haemophilia being present, although I was a girl, but back at the relevant time for me, it wasn't.
- 9. I was born as the eldest of two children, my parents going on to have a son, my younger brother GRO-B As a child, my mother noticed that I bruised quite easily, more so than could have otherwise been expected, and that I also bled a lot, again more than one would expect for example when I lost a tooth, when I could bleed for days afterwards, unlike other children of my age.
- 10. Eventually, when I was aged about nine or ten, I was taken to the GRO-D Hospital where, following tests, I was found to have a Factor XI deficiency. I was diagnosed as having Haemophilia C, an hereditary condition I had been born with and for which there was / is no known cure. It meant that my body struggled to stem the flow of blood and 'clot' should it be required to.

- 11. For me, at that time, the deficiency meant that I bled whenever I lost a tooth or had to have a dental extraction. As you will read, I also haemorrhaged each and every time I gave birth – before, during and after the same.
- 12. Having diagnosed Haemophilia C, the <u>GRO-D</u> Hospital referred me to The Haematology Department of the Manchester Royal Infirmary (more commonly known as 'the MRI'). Here, further tests were conducted, a detailed familial history obtained, and my Factor XI deficiency confirmed.
- 13. At that time, the doctors of the MRI attributed this hereditary condition to the fact that I was of <u>GRO-B</u> on my mother's side of the family, relying upon the fact that it was apparently common for bleeding disorders such as Haemophilia C to be found within people with this background. As part of their investigations , my mother was also tested at the hospital, and she too was found to have the same Factor XI deficiency, something she had never known.
- 14. My first Haematology Consultant at the MRI was a Dr Delaware. This later changed to a Dr. Wensley and then to Dr. Charles Hay (latterly, Professor Charles Hay). Under these specialists my condition was monitored bi-annually or annually (as time progressed), using blood tests.

15. As I grew up and entered my teenage years, my mother became worried about my having children, and sought to advise me against it, as there was a high probability of my suffering a significant bleed if I did; rather than her being concerned for the fact that there was a risk of my passing the condition on, as she had.

- 16. I remember her telling me that were I to have children, I should opt to give birth at GRO-B (also in Manchester) as it was the closest to the MRI and its haematology department who were monitoring me.
- 17. As I grew up, I learned that there was no treatment for my condition, so I simply had to get on with life as best as I could, and sought to do so; but haemophilia meant that my activities were somewhat limited compared to those of the other children of my age.
- 18. I wasn't allowed to go on school trips, or to participate in contact sports - as a pupil with haemophilia appeared to have been far too much 'hassle' than the school were prepared to cope with, especially as there was absolutely no guarantee that I would not suffer a bleed, so I was barred.
- 19. A good example of this, is that in my early years at school I found that I loved gymnastics, a sport which I very much wanted to progress with, but the school decided that the risks I faced were too high and consequently I had to stop.
- 20. In later years I had thought of following a career which my grandmother had enjoyed, by becoming a nurse, but my careers advisor felt that it would pose far too much of a risk to me, and I was dissuaded from pursuing my chosen career path. I was simply never allowed, or found myself unable to do, what I may have wanted to do of my own volition, which was not only frustrating but at times quite upsetting, and it served to marginalise me, especially within my peer group as I was growing up.
- 21. One day before my thirteenth birthday, on GRO-B 1976, I had to undergo a tonsillectomy. I remember it distinctly, as I was going to have to spend my 13th birthday in hospital and wasn't at all happy at that prospect.

- 22. As a direct result of the Factor XI deficiency, I had to be admitted to the MRI where I was to be given a transfusion of blood plasma both before and after my tonsils were removed. I understand that at least two transfusions were considered necessary, as the required Factor XI which I would receive from the first would apparently only had a relatively short 'shelf-life' within my body, so a second was required to maintain a suitable level covering the entire period over which I had been expected to bleed.
- 23. I received these transfusions, but any issues as to 'consent' (for either the transfusions themselves, and / or the tonsillectomy) would have been dealt with by my parents, most probably by my mother who tended to accompany me to any medical appointments I may have had to attend.
- 24. I do not know if my parents were given any particular warning as to any risk(s) which may have been associated with my being given blood plasma, but I honestly believe that had either of them been told anything, then at some point in time they themselves would have told me, which they did not.
- 25. In particular, my mother and I always had a very open relationship, especially as regards medical issues, and I am adamant that she would have told me of any conversations which she may have had with the clinicians, where any form of risk had been raised she told me nothing which leads me to believe that she herself was told nothing of any risk.

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26. My mother was also quite risk-averse. I am sure that had any form of risk been raised, as regards the clinicians giving me a blood transfusion, then she would have refused to allow them to perform the operation itself – again, as I had the operation, I cannot believe that she was told of any risks.

- 27. I fell pregnant with my first child at the age of seventeen. I did not require any treatment during the course of the pregnancy and had regular blood tests in order to check my Factor XI levels each and every time I went for an antenatal check-up, all of which I gave my consent for.
- 28. Towards the end of the pregnancy, I was informed that I had Toxaemia (now referred to as Pre-Eclampsia). I was admitted to GRO-B GRO-B as a result, and remained an inpatient for some three weeks before being discharged, having been told that as soon as I experienced any signs of labour, I was to immediately return.
- 29. Having been discharged, my labour commenced the very next day and I was immediately re-admitted (on GRO-B 1981). The birthing-plan before this had happened, was that I should have been given some Factor XI *prior* to the delivery, but this didn't take place, instead I received some post-delivery.
- 30. The birth was anything but straightforward. Having been released only to be readmitted within twenty-four hours, birthing-plans (including my being given Factor XI pre-delivery) were abandoned and I was effectively rushed into a delivery suite where, during the child's delivery, I was told that the baby was positioned face-to-pubis, and that as a result I would have to give birth by way of a Caesarean Section.
- 31. I lay worrying for the outcome, for both the child and myself, as a Caesarean birth was far from ideal for a person with a bleeding disorder, especially as I hadn't been given any plasma to facilitate this type of procedure going ahead, as there was certainty, not a mere possibility, that I would suffer a significant bleed.

- **32.** At one stage, a maternity doctor entered the room I was confined in, and angrily threw my medical notes onto my bed. Clearly annoyed, and showing his frustration through his actions, he told me that the MRI (with whom he had clearly been in contact), had told him that I *could not* give birth by way of a Caesarean Section, as I would bleed, and that I *would have to* give birth naturally. As such, requiring a natural delivery, he also told me that I could not have any form of pain relief.
- **33.** The birth saw the clinicians using forceps to deliver my child, and I tore as this took place, bleeding for many months afterwards, but the bleed was apparently insufficient in nature to have been classed as an actual haemorrhage. All the same, I had to be given some 136 sutures to secure the tear and could neither sit down with any degree of comfort, or use the lavatory without issue, for many weeks thereafter.
- 34. Even when I tried to sit, to feed my baby, I found it impossible to get comfortable because of the stitches and had additional problems just trying to walk properly – the whole experience left me absolutely devastated, disappointed, uncomfortable, and upset.
- **35.** Following the delivery, a Dr. GRO-B not the doctor who'd thrown my notes onto the bed but another maternity doctor, spoke to my mother about it all, and in telling her that I " *Should have had a Caesarean*," said that he'd be *"having words"* about it all. I do not know with whom he was going to 'have words' but clearly some of the clinical staff weren't happy with my treatment.

- 36. Having been expecting to be given plasma but receiving none, and then being told that I was to have a Caesarean only to be told that I had to give birth naturally, I tried my best to follow the directives being given to me by the maternity staff, but found myself (at least in their eyes), to be struggling to do so. I was a patient with haemophilia, fearful of suffering a significant bleed, and a patient who was just seventeen years old but carrying their first child.
- **37.** The midwife attending to me, I subsequently discovered, had not kept my notes updated. She acted awfully towards me, kept screaming at me to "*push*," and then after a while called for a doctor to whom she complained that I was being uncooperative.
- 38. Following this, the doctor examined me and then cut me open (performed an episiotomy). However, having done so, he found that I was then only about 9 cm dilated and not the requisite 10 cm.
- 39. He told me that, "you were not being uncooperative, you just couldn't do it (i.e. deliver the child), because you were not fully dilated." He put me on a drip in an effort to speed up the delivery process, but I was on it for about an hour. I don't know what the drip contained, but I know that it wasn't whole blood, plasma or a blood product.
- 40. I was so exhausted by the time of this taking place, that the doctor told me that he'd try to deliver my baby using forceps and without my having to push. However, with him seeking to do this, and trying to turn the child who was lying face up, the rough handling I experienced dislocated one of my hips and I was screaming in agony until it was 'clicked back in.'
- 41. Finally, my daughter was delivered, a healthy 8 lbs 1 oz in weight, and safe and sound, despite the trauma of her forceps delivery and the poor experience I had endured.

- **42.** Blood was taken from the umbilical cord, to test for any Factor Xi deficiency in the child, but I was told that any results from these could not be confirmed for sure until she had reached five years of age. Fortunately, I had not passed on my Factor XI deficiency.
- 43. Following her birth, I remained an inpatient of the hospital for seven days during which time I had to be given about twenty-eight units of plasma via intravenous transfusion.
- 44. As a result of the litigation I have previously mentioned (Paragraph 6), I requested, and was given access to, my maternity notes from this time. This is how I know that some omissions had occurred (Paragraph 37) and how much plasma I had been given. I also saw that a nurse had administered an intramuscular injection of Pethidine, despite the fact that I was not meant to be given any intramuscular injections due to my bleeding disorder, or had requested it.
- **45.** At that time, I assumed that the plasma I received had been sourced by the hospital from a National Health Service (NHS) blood bank, and as such had come from British donors. I had never been given any warnings as to any potential risk that may have been associated with this material, and certainly didn't expect it to have come from overseas and / or to have been contaminated in any manner or form.
- **46.** No explanations were given, it was just a case of a nurse or doctor turning up at my bedside and saying something like, "*Right* **GRO-B** *it's time for your drip*," and they'd then set it up and I'd receive the transfusion. I was never given any cause for concern, so I accepted what they were doing. I trusted those who were treating me and always had.

- **47.** My grandmother was a nurse and my mother never had any issues with questioning doctors, so if we had been confronted with any cause for concern we would have either dealt with it *'there and then'* through questions, or referred to Nanna who was more familiar with the medical process, terminology used, and so on, and she would have asked any appropriate questions on my behalf.
- 48. From careful consideration of my medical notes, I believe that over the years I have been given blood plasma, and at one point in time some Cryoprecipitate, but rarely, quite possibly never, whole blood.
- **49.** Following my daughter's birth and the subsequent week spent as an inpatient, I went back to my family to live with my baby. The child's father, my boyfriend of that time $\begin{bmatrix} GRO \\ B \end{bmatrix}$ was some twenty years older than me and married, so my parents were not at all comfortable with him being around.
- 50. I had been using a contraceptive pill when I fell pregnant, but this had clearly not worked, so my mother arranged for it to be changed, which it was, to prevent any recurrence, at least until I had fully recovered.
- 51. GRO-B and his wife eventually split up, and on GRO-B we married. I was GRO-B years old by then and we moved into a caravan together with our daughter GRO-B six weeks after she had been born. Some twelve to fourteen months later, we moved to an address in GRO-B and I then changed my General Practitioner (GP) from what had been our family doctor's of many years standing, to a group practice GRO-B GRO-B

- 52. For three years I was able to carry on with my life without the need for any form of medical intervention as regards haemophilia, no Factor XI, no further transfusions, and no annual check-ups with the MRI Haematology Department.
- 53. Having again become pregnant (another daughter, GRO-B I found that I spent a lot of time going in-and-out of GRO-B again suffering with Pre-Eclampsia and High Blood Pressure. For months I spent most of the week as an inpatient of the hospital, where I could be adequately monitored and medical support was readily available should I have needed it, with only my weekends being spent at home.
- 54. This situation went on from a time when I was about twenty-eight weeks pregnant until GRO-B s birth. Sadly, monitoring had revealed that the child did not appear to be growing as the clinicians would have liked to have seen, and I had to have complete bed-rest whilst hospitalised.
- 55. I had a couple of checks done regarding my Factor XI deficiency, but in the main, the MRI were in charge of that aspect of my care and liaised with GRO-B s, so both knew what may have been going on and the MRI could intervene or offer suitable advice if it proved necessary.
- 56. Whilst at home, I was visited by a midwife who conducted fairly standard observations of me and my condition, blood pressure readings and other minor checks. One day, I told my midwife of a vaginal discharge I had experienced, which I saw to have meconium in it. She asked me if my waters had broken, but I didn't know as I had just had a bath, so she examined me and found the baby's heart rate to be lower than she expected, so she called for an ambulance to take me to hospital.

- 57. Once at <u>GRO-B</u> further tests were undertaken and as a result I was admitted and given twenty units of plasma. This was immediately before my labour started, but although smaller than her sister had been (at 7lbs 5oz), she was born a healthy child and they did not conduct any Factor XI tests in her regard at that time (as they had done with her elder sister, GRO-B).
- 58. The Obstetric Consultant in whose care I had been placed, was a GRO-B GRO-B He apparently had the necessary expertise for dealing with problematic deliveries such as mine was expected to be, taking into account my haemophilia and the experience of GRO-B s birth.
- 59. Whereas the delivery itself went well, certainly nothing as traumatic an experience as I'd had with my first child, I haemorrhaged postdelivery and had to be given blood plasma in the delivery suite. Two days later I haemorrhaged again and had to be given a further transfusion whilst on the ward.
- 60. On this second occasion of haemorrhaging, I can recall that I told the nursing staff that I was 'feeling funny,' and a nurse then lifted up my bedclothes to find that there was blood everywhere and that I was lay in a pool of it.
- 61. All of a sudden, as I now recall, there were lights flashing and a buzzer going off and a lot of activity around me as they tried to stem the flow of blood, which included them trying to contract the womb in some manner or form. I don't know what I may have been given, in terms of medication, but I received more than one unit of blood. I again had to stay in hospital for seven days in all, but following my discharge there was no follow-up through the hospital.

- 62. I wasn't given any form of card or letter to say that I had been given a blood transfusion and nor was I warned, at anytime, of any risk(s) which may have been associated with the use of whole blood, blood plasma or blood products.
- 63. Between 1984 and 1986 I suffered a couple of minor accidents (one to a foot, another with a hand) each of which resulted in my having to be given some plasma. I cannot now recall too much of these incidents, or their dates, save to say that the foot injury was the result of my having dropped an ironing board onto my foot, and on each occasion I was treated using plasma at the GRO-D Hospital.
- 64. In 1985 I again fell pregnant, giving birth to my third child, a son GRO-B on GRO-B 1986 at GRO-B As before, I was diagnosed with Pre-Eclampsia, but not until quite late on in the pregnancy, and although the medical authorities wanted to admit me as they had before, as I had two young girls at home who needed their mother, I felt that I had to stay at home to care for them so I stayed out of the hospital (as an inpatient) for as long as possible.
- 65. I was monitored, and this revealed that the baby would apparently be smaller than my last, but as she had nevertheless been of a good size, I wasn't too concerned. However, I believe that the clinicians knew differently, and may have simply been trying not to alarm me, as when he arrived, GRO-B weighed in at 11 lbs, he was a very big baby.

- 66. Again, GRO-B worked in liaison with the MRI and the materials I may have required to assist me were made ready in advance of my entering hospital. When my due date arrived, I entered the hospital as an inpatient and was advised that I would need to be induced so that the delivery could be controlled, rather than them having to react to any problems which may arise.
- 67. I entered hospital on GRO-B 1986 but as the maternity department were apparently busy with other deliveries, I had to wait if I were to be induced. I duly waited, but on GRO-B I went into labour of my own accord, with the birth which followed being quite sudden in its timing, and severe in its nature.
- 68. After no more than two and a half hours in labour, quite possibly less, I delivered my son naturally, but haemorrhaged and bled out from 9.43 a.m. that morning until around 5.00 p.m. in the evening, almost eight hours later.
- **69.** To help me, my womb was again contracted and I was given a blood transfusion, plasma, and something else which was delivered to me via a drip, but which I cannot now recall (although it may have been glucose). At one stage, as they battled to stop my bleeding, a doctor told me that if they were unable to get the bleeding under control by 6.00 p.m., then they'd have to take me into theatre for a Hysterectomy.
- 70. This doctor also spoke to GRO-B about my situation, telling him in no uncertain terms that he did not want to see me there again, that is, "No more pregnancies!" as in his opinion, my body probably wouldn't be able to cope with it.
- 71. At one point in time I recall that I was lying in bed, with my legs agape, turned onto one side, with blood all over the bed and floor and people standing, staring and pointing at me in shock and disbelief at what they were witnessing.

- 72. Having had the baby, and with the bleeding finally under control, I can remember a midwife telling me that the placenta alone had been *"massive,"* and also a doctor telling me that there had been little or nothing he could suture as my *"downstairs had been totally wrecked."* He explained to me that I had, for some inexplicable reason, haemorrhaged behind the placenta which had clotted. I received several units of blood in the delivery suite and again once I was on a ward I was given plasma.
- 73. My son was found not to be breathing properly, and it was thought that he may have been born with some form of Asthma, but it was far too soon for any such diagnosis to be made. I am sure that the shock of my labour and his delivery is why he has Autism.
- 74. He has been diagnosed as having Attention Deficit Hyperactivity Disorder (more commonly referred to as ADHD), and has a borderline Personality Disorder. I am convinced that all of his issues arose as a result of his birth – not the blood or blood products I had been given, or the fact that I had Haemophilia, but his traumatic birth.
- 75. I remained in hospital for about a week, with no further information being provided as regards my having been given a blood transfusion and / or plasma, and nothing to show to any others in this regard thereafter (that is, no card or letter informing *'the reader'* of my status as someone who'd been given blood or plasma).

- 76. In so far as my having been given blood and / or plasma is concerned, I had been told from an early age, albeit that I cannot now remember when, or by whom, that I could not become a blood donor as a result of what I had been given or as a result of my being Factor XI deficient.
- 77. A few weeks after GRO-B s birth, I received a letter from the Haematology Department of the MRI in which they told me that a test had been conducted (on a sample of my blood) and that I was HIV Negative, I did not have the Human Immunodeficiency Virus.

- **78.** At the time, the risk of HIV and AIDS received prominent media coverage, but my husband and I understood very little of either, and didn't think that they necessarily concerned us, so the letter and its content came as a complete shock when it arrived, not least as I had been wholly unaware that any HIV Test had been conducted no one had told me, perhaps more importantly, no one had asked for my consent to an HIV test being conducted.
- **79.** GRO-B and I were left a little puzzled, but not particularly concerned by the news, as I didn't have HIV, but I wondered *why* they had tested me without even asking or explaining what they were doing and why?
- 80. My husband had no history of any bloodborne ailments himself or through his family line, and he had fathered four other children by his first wife, without issue. He was a fit and healthy man with no underlying health issues which he may have passed on to me or any of our children.
- 81. But our son GRO-B had been born a sickly child, who went in-andout of hospital with various problems, even spending his first birthday as an inpatient. One of my daughters went on to develop Wolff-Parkinson-White Syndrome whilst the other had a heart murmur. Between GRO-B GRO-B GRO-B and myself, life became one of medication, hospital visits, clinics, and care or caring.
- 82. In GRO-B and I separated and our divorce was finalised on GRO-B
- 83. In the same year GRO-B, I had to have four wisdom teeth extracted. This took place at the GRO-D Hospital as my dentist felt unable to adequately care for me due to my Factor XI deficiency which I had made him fully aware of.

- 84. I entered the hospital as an inpatient, was given a few units of plasma prior to the operation, and then again afterwards on a ward, before being discharged a day later. Again, I was not advised as to any risk(s) associated with the receipt of plasma and left the hospital with nothing to show that I had been given a transfusion should lever need to show anyone thereafter.
- 85. At discharge, the hospital advised me to return for more plasma, but at the time I did not have adequate childcare arrangements in place (my parents usually helped me in this regard, but they had had to return to work), so I had declined to stay any longer than was absolutely necessary, or to return.
- 86. As a result, I found that my teeth 'oozed' for a few days, but otherwise I was fine. I didn't really want to go back in to a hospital who had been quite happy to discharge me, even when they quite clearly knew that I needed more plasma and / or blood than I'd already been given. They should have either kept me in, to finish my treatment and monitoring post-op', or unconditionally discharged me.
- 87. Now with a new partner in my life, I again found myself pregnant but underwent a termination GRO-B I simply did not want another pregnancy at that time, with all of my children by GRO-B being unwell and my not wanting to 'push my luck' as a result of both the Factor XI deficiency and the doctors comments at the time of GRO-B s birth. I was also a single mother and was finding life difficult enough.
- 88. The termination took place at GRO-D Hospital and during the procedure I was given three units of plasma to assist with my factor deficiency. Initially, staff at this Hospital had been reluctant to give me any plasma, so I had contacted the MRI's Haematology Department to explain the situation to them and seek their assistance with the GRO-D Hospital's staff.

- 89. The MRI told me that I would have to undergo the termination at their hospital if I wanted plasma, but I argued against that, telling them that in my opinion it was simply a case of their job (MRI) being to liaise with GRO-D and arrange for me to be given whatever I may require there, not for me to have to travel to the MRI.
- 90. There were other problems too staff at the GRO-D Hospital refused to accept that I had Haemophilia, stating that it was an ailment only present in males, despite my trying to explain what Factor XI was and that a woman could indeed have haemophilia, albeit that it was rare. To emphasise this errant belief, when looking at my medical notes I saw a comment in a letter from a doctor at the GRO-D Hospital which read, "... claims to have haemophilia ..."
- 91. The matter was resolved and I had the termination, successfully, at GRO-D Hospital and fortunately did not haemorrhage. All the same, I was given blood products, and am firmly of the belief, based upon what happened thereafter, that it was the plasma I had been given on this occasion (three units) which had been contaminated with Hepatitis C, although I have to accept that it could have been present in any of the transfusions I had previously received, as detailed.
- 92. In 1989, the results of a regular Cervical Smear test revealed the presence of cancerous cells. As a result, I was due to have laser treatment, conducted at the MRI, and in advance of the procedure I was given some Factor XI concentrate.
- 93. This was the first time that I had received Factor IX Concentrate and the Clinical Nurse Specialist at the MRI (Olive Reading) explained to me that it was a new treatment which would replace the use of 'natural' plasma – it was apparently quicker than plasma use, meaning I'd spend less time in hospital.

- 94. What she *did not* tell me was that this blood product was then only available on a trial basis I was being used as a 'guinea-pig,' and didn't know it. The product was injected into me via my forearm and almost immediately I experienced heart palpitations in response, so the nurse had to slow the rate at which it was being administered.
- 95. My laser- treatment for the cancer being complete (which I am happy to say was successful), I was released from the hospital later the same day. I had been really worried about cancer, and had to a certain extent placed haemophilia aside as I could deal with that, but I had three young children and was worried about its implications for me, but especially for them. Cancer was then my prime concern, so I didn't stop to question anything else.
- 96. In 1990 I suffered a miscarriage and had to go into the <u>GRO-D</u> Hospital for a Dilation and Curettage Procedure (also know as a 'D and C'). I had been about five or six weeks into the pregnancy when I'd noticed some 'spotting' and went to see my GP. I was then referred to <u>GRO-D</u> for a scan to assess what was happening, and a miscarriage was confirmed. I was given three or four units of plasma at the time.
- 97. By GRO-B 1991 I had been seeing a new boyfriend for about seven months when I found myself pregnant again. This had not been a planned pregnancy and I wasn't particularly happy about it as we didn't even live together at the time, but my attitude was that it had happened sol just had to get on with it, deal with it, and move on.
- 98. My daughter GRO-B was born on GRO-B 1991 at GRO-B GRO-B through whom I had been monitored regularly throughout the pregnancy due to my past medical history and because of concerns which developed concerning the baby's development.

- 99. A few weeks before the baby's due date I experienced High Blood Pressure and the doctors dealing with me advised that I schedule an appointment to go in for an arranged induction. I was quite worried for this child as it had been some time since I had last had a baby and I'd also undergone a termination and then a miscarriage.
- 100. When I was about 5 cm dilated, the child was found to be positioned face-to-pubis, but fortunately she turned of her own accord and a very quick delivery followed where, after only about five minutes, I had moved from 5cm dilated to 10cm.
- 101. I haemorrhaged following the delivery, but the hospital staff moved quickly to get this under control, and although I can recall having been given something to help me with the blood loss, I cannot now recall what it may have been, blood, plasma or something else.
- 102. The baby weighed 7 lbs 5 oz at birth and appeared healthy, but when she was just six weeks old it was discovered that she had Pulmonary Stenosis, a hole in her heart. I believe the clinicians were aware of, or at the very least suspected this from birth, as they had always been asking me if she had been feeding properly.
- 103. As time progressed, she was diagnosed as having 'FTT' or Failure To Thrive, which is basically inadequate growth or an inability to sustain growth as a new-born on into infancy. At two years of age she weighed a mere 17lbs.
- 104. From the first time I had attended an antenatal clinic whilst carrying GRO-B I had decided that following her birth, I'd seek sterilisation. I followed this through, and on 7th September, 1991 I was sterilised in a procedure led by a Dr. GRO-B. To facilitate this operation, I was given either plasma or concentrate, both before and after surgery, but not blood.

- **105.** I had been adamant that I did not want to fall pregnant again, especially as with the three children I already had before GRO-B I had found myself feeling very tired and was concerned for any further children having health issues, which sadly proved to be the case.
- 106. I had first begun to notice my feeling tired in or around Christmas 1988, although it had probably been evident for some time before. It really became prominent when I was pregnant with GRO-B I wasn't just tired, or tired as some women can be when pregnant, but completely exhausted at times I was just twenty seven years old but felt too old to be having a baby as a direct result of my being tired-out all of the time.
- 107. I went to my GP who took blood for tests to be conducted, but nothing was found before I was eventually diagnosed as having Chronic Fatigue Syndrome. The doctor carried out further blood tests, in particular to see if I was anaemic, or needed some vitamins, but I don't believe that my blood was ever tested for Hepatitis C and / or HIV at this time.
- **108.** Following GRO-B is arrival, the tiredness and accompanying lethargy continued, but I just put it down to my having four children each of whom had health issues, and to my constantly having to go to-and-from hospital appointments with one or the other of them, whilst juggling with their childcare as may have been necessary, which meant that at times, various family members had to take time off from work to help me.

- 109. Matters weren't helped by our receiving absolutely no financial assistance from my ex-husband GRO-B and my living as a single mother of four. Although I had a boyfriend (GRO-B GRO-B S father), we weren't living together. The only financial support I had was through the benefits system housing benefit in particular, as I didn't receive anything in relation to my own health issues at that time (e.g. Disability Living Allowance).
- 110. GRO-B helped me with the children as best as he could, but he had a full-time job which limited the time he was able to dedicate to us. I myself found that I was unable to secure a job because once I had declared 'Haemophilia' on any application or health screening form, I found that I did not get offered any job I sought.
- 111. As a consequence, I stopped telling potential employers that I had haemophilia, and was able to get jobs, but once they found out, they let me go because I hadn't been open with them. On one occasion I recall an employer telling me that I was ' too much of a risk' for their insurance to cover.
- 112. There were 'peaks and troughs' with my tiredness and lethargy. Sometimes it was manageable and I could function, whilst at other times I found that I was unable to do anything. On occasions I found it a real battle just to stay awake, something which worsened in the winter, or darker months, like a seasonal affective disorder. I was tired to a truly unbelievable degree.
- 113. By 1994 I was experiencing really bad period cramps and pain. I found that I was also bleeding quite severely and was unable to go out until at least five days into a period as a result. I went to see my GP who diagnosed Endometriosis and referred me to GRO-B GRO-B where I was to have a Hysterectomy as an elective procedure.

- 114. Admitted to <u>GRO-B</u> for the hysterectomy, a blood sample was taken from me, with my consent, as an integral part of their preoperative assessment. I believe that this happened on either 27 th or 28 th March, 1994 and I was told that it would be tested to assess the Factor XI level in my blood. Other, more standard checks were also made, such as measuring my blood pressure.
- 115. I was given some Factor XI concentrate prior to surgery, and a further blood test was then conducted to assess my factor levels. I can remember talking to a nurse about it, telling her that provided the level was at 80 % (or higher), I didn't need anymore, but she told me that I did, and administered more to me all the same.
- 116. I had advised her that to give me too much would lead to my blood 'curdling,' but she simply ignored me. At one point, the levels were measured in the lower 100's, which is really high for me, as by then I knew from past experience and multiple treatments, that I was (am) fine with a reading of just 80.
- 117. Following the hysterectomy, which itself passed without incident, I developed a Deep Vein Thrombosis (or 'DVT') above my right knee. The hysterectomy had been conducted by a Dr. GRO-B under a general anaesthetic, so I do not and cannot recall a lot about it, but afterwards, with the DVT, found myself in a lot of pain and experiencing breathing difficulties I felt as if I'd been hit by a bus.
- **118.** On the day after my hysterectomy I had to have physiotherapy. As the physiotherapist was treating me, I found that I was coughing-up blood, but she explained this as most probably having been because I'd had some tubes placed down my throat in theatre. Fortunately, as this was happening, Dr. GRO-B was passing us on the ward and questioned what was happening.

- **119.** Dr. **GRO-B** suggested that I may have had a Pulmonary Embolism and caused further enquiries to be undertaken which led to the DVT above my right knee, and a Pulmonary Embolism being found in one of my lungs. As a result, I was put onto a pump which delivered Warfarin to me, to thin my blood, and given plasma. The doctor subsequently told me that the Factor XI Concentrate which I had been given prior to surgery had caused the DVT.
- 120. I was really ill at this time, so poorly that I cannot now remember too much of what happened, but I am sure that it was the doctor who told me of the DVT having been a result of the Factor XI concentrate used, and not a nurse.
- 121. Under what for me would be usual circumstances, I'd have been kept in hospital as an inpatient for about a week following a procedure such as this, but on this occasion I remained an inpatient for some two to three weeks.
- 122. Whilst I was an inpatient of GRO-B Dr. Bolton, one of the Haematology Department doctors at the MRI came to see me and explained that she wanted to take a blood sample from me to test for the safety of the Factor XI concentrate being used. She explained to me that Factor XI concentrate could contain contaminants, such as viruses, and that the concentrate was still only being used *"on a trial basis."*
- **123.** This was the first occasion upon which I had been told that Factor XI concentrate was only being used as part of a trial. I was outraged, and refused to consent to my blood being taken, arguing with her and demanding to know *why* I had not been told this on any previous occasion?

- 124. I would never have given my consent to be treated with trial medication had I have known, as I had young children and would not have taken the risk, any risk, as I had more to lose than gain if anything went wrong and as I knew full well that an alternative (plasma) was available.
- 125. Later that day, Professor Hay (then Dr. Hay), Dr. Bolton, and a nurse (someone whom I later learned was a Clinical Nurse Specialist dealing with patients who had HIV and / or HcV) came to see me on the ward. I was taken into a side room to speak with them.
- 126. I was questioned as to why I had declined to provide a blood sample for testing. I expressed my anger at not having been told of the trial nature of the concentrate, and that had I have known I would have insisted on being given plasma instead. I also told them that I knew that I did not have HIV (as a result of the earlier test conducted. which I have previously mentioned).
- **127.** Professor Hay, in a rather nonchalant manner, then told me, "I don't know what you are bothered about, you have already got Hepatitis C."
- 128. I was both angry and shocked, and asked them *when* they had found out that I had Hep' C. I knew little or nothing of HcV at that time, save for the fact that it wasn't a good thing to have from the little bits and pieces I had heard or seen. I panicked, and started to think of whether I was going to live or die.

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129. I thought of a woman whom I'd seen on the ward just a few days before, someone who was being treated with Interferon and who really wasn't well as a result. My mind passed across all of the things I'd seen, read or heard about Hepatitis and I started shouting at them, demanding to know when I'd been tested for Hep' C, when they'd found out, why I hadn't been told, why had I been tested without my knowledge, and where had it come from? I was outraged.

- 130. Looking back, the only occasion when I can recall my having given permission for a Factor XI blood test was when I'd been to hospital with my daughter GRO-B on 14 th January 1993. She was to have an operation at the MRI regarding her Wolff-Parkinson-White-Syndrome, and to kill some time whilst I was waiting, I went to the MRI Haematology Department, which I knew, and was being monitored through, to volunteer myself for blood testing Factor XI levels as haemophilia patients could at that time.
- 131. I hadn't actually needed a test as part of my regular bi-annual / annual blood testing regime, but submitted to a test all the same, just to 'kill some time.' I had gone there as much for a test as to see the staff there, most of whom I had known since childhood, doctors and nurses alike, most of whom were familiar to me, and had been looking to simply say, "hello."
- **132.** Professor Hay told me that he had not been with the MRI when the tests had taken place, and that they had *"nothing to do with him."* I told him and his colleagues off, telling them that no one had been doing their job properly, telling me that they wanted blood to check factor levels but then doing all sorts of other tests with it. I told him that his attitude was poor and I left the room.
- 133. I calmed down and returned to the room. They then told me that I would have to come back into the hospital for further tests and to have my Warfarin levels checked, but not long after this happened, in disgust and anger, I discharged myself.

- 134. Whereas I fully appreciate that it may not have been Professor Hay's fault that I had contracted Hepatitis C, he was nevertheless supposed to be professional and yet in my opinion he had not acted professionally in delivering the Hepatitis C diagnosis to me. He told me in such a manner as to assume that I knew, which I didn't. I was quite within my rights to decline the tests they sought, especially under the circumstances in which I did so.
- **135.** Having found out that I had Hep' C, I had that to deal with in addition to my haemophilia and the other health issues being faced by my children. I had to find out more about Hepatitis C, then deal with the implications it may have for both me and my family, and find a way to cope.
- 136. I had not been given any HcV information at the hospital no written information sheets or pamphlets, nothing verbally by the staff, no reference to any self-help groups or organisations, nothing, so I started asking people and trying to find out more by myself.
- 137. I tried using my local library as I was concerned for my chances of surviving this virus, so little did I then know, and my wanting to be a good mother to my children, not a burden upon them.
- 138. A few weeks later, I returned to the MRI Haematology Department where I was assigned an HIV Clinical Nurse Specialist (Meg' Openshaw). I queried her appointment, as an HIV specialist, when I had HcV, only to be told that they were basically the same and that consequently she dealt with both.

- 139. Meg' Openshaw came to visit me at home about a week later and explained that she had experienced some difficulty in finding me as she'd gone to the wrong address I had moved house and had changed my home address details on my medical records, but it hadn't apparently been passed on properly and she'd first been given an old address. I say more about my having moved home, later within this statement.
- 140. Meg' Openshaw had a number of different responsibilities, and appeared as much as a counsellor as she did as a nurse. She also took blood from me, with my consent, whenever I had to visit the hospital and came to my home every fortnight in her counselling capacity, for about a year. She monitored me, listened to me, heard my worries and concerns, and gave advice or helped fill in gaps in my knowledge.
- 141. She explained to me that the Hepatitis C virus was only spread through blood, as I had expressed concerns that I could have passed it on to my partner through sexual intercourse. She also advised against my having any tattoos or sharing needles with anyone, and suggested that I should keep my toothbrush and any razor I used separated from that of anyone else.
- 142. The nurse told me that were I to cut myself, then I should use bleach on any surfaces I may have bled onto. I was told that it was easier for a man to pass HcV on to a woman through sex, than it was for a woman to infect a man, but that a risk nevertheless existed and so condoms should be used as a preventative measure. She also advised me that I should not have sexual intercourse during a period.

- 143. During the course of my argument with Professor Hay and his colleagues, he had told me that I had *"most probably"* contracted Hepatitis C from a blood transfusion given to me in the 1970 's. Meg' subsequently supported this by telling me that I had contracted HcV through a transfusion, but she did not specify whether this had been from blood, plasma or concentrate
- **144.** As a result of what I had been told or learned, I had to advise both GRO-B and GRO-B to submit to HvC testing, which they both did, with each of their tests having been negative, something which came as a great relief to me.
- 145. Not long after Meg' first started visiting, sometime in around 1995 / 1996, I was advised that should my symptoms worsen then I could be placed onto a course of treatment using Interferon.
- 146. However, I do not think that my symptoms had worsened at all by the time Dr. Bolton offered to put me onto Interferon treatment. I was still feeling tired and may also have been suffering with depression, so I presumed that the results of liver function tests they had conducted had shown that the virus was taking hold.
- 147. I was told by Dr. Bolton that Interferon treatment for HcV was then only available on a trial basis and that as such the MRI would have to seek specific funding for my being given it. In explaining this to me, she also told me that there would be side effects, but she stated that these would be akin to my having nothing more than a bad cold.

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148. Although this was a trial, and I had already expressed my displeasure at having previously been used in a trial without my knowledge, my fear of death outweighed any concerns I held at being a trial participant, so I agreed to take part.

- 149. I believe that I commenced Interferon treatment in late 1995 or early 1996. The treatment involved my self-administering an injection, once every other day, over a period of six months. Another haematology nurse specialist (Lorraine) showed me how to use a syringe and administer the medication to myself.
- 150. It was awful. I had been told that I may feel as if I had a bad cold, but it was far, far worse than that. I suffered from headaches, had cold sores, and felt unwell all of the time it was like Covid-19 (which I have also experienced, albeit of more recent times), but was more severe. My depression worsened and I experienced suicidal thoughts with only the need to care for my children having prevented me from taking my own life.
- 151. I had to rely upon the help of neighbours to get my children to and from school whilst my parents looked after me and the children as I should have been doing. I simply could not function properly at all whilst I was taking Interferon.
- 152. I believe that I was monitored during the treatment, with blood tests being used to measure my viral load, but I cannot now remember too much about that, other than my having had to go to the hospital for regular check-ups.
- 153. Following the final test, having completed the six-month course, I was told that blood test results had shown that I was clear of the Hepatitis C virus, but that I had to go back three-months thereafter for further tests to confirm this finding.

- 154. I went back, submitted to a further test, and then saw Dr. Bolton who told me that although he initial results had been good, the treatment had been unsuccessful and that my viral load had increased again. This was devastating news for me, especially when I was told that there was nothing else, in terms of treatment for HcV, that could be done at that time. All they could do was monitor me and wait for something new to become available.
- 155. I only ever dealt with personnel of the Haematology Department of the MRI and was never referred on to a Hepatologist or to another hospital. I saw Professor Hay occasionally, but at one point, whilst in my view going nowhere with my treatment, and not feeling very happy about my past dealings with him, told him that I did not want to see him again.
- 156. Following the unsuccessful Interferon treatment, my visits from Meg' ceased, and I returned to a regime of six weekly monitoring through blood testing which continued until 1998. In 1999 I was offered a new means of treatment which involved Interferon again, combined with another drug, Ribavirin.
- **157.** At that time, I was suffering with depression and during the course of a severe depressive bout had attempted suicide. I had developed a phobia as regards any form of blood, even refusing to prepare raw meat, and had become paranoid about my accidentally transmitting the Hepatitis C virus to others, especially my children.
- 158. I had experienced sensory and visual hallucinations, and had begun to act both irrationally and erratically, whilst also experiencing extremely bad mood swings. I would take anti-depressants, to help me feel better, but as soon as I felt better, I stopped taking them, but would then become depressed again.

- 159. My condition impacted directly upon my relationship, and in 1997 GRO-B and I split up. This did nothing to help with my mental condition, but I found that I had to cope, for the sake of my children.
- 160. Meg' had previously mentioned an organisation called The Manor House, Beech Grove Action Group, as people who were then trying to take legal action against H.M. Government and / or The NHS, or both, as regards contaminated blood and blood products having been given to NHS patients.
- 161. At the time, I had not been at all interested in this, and was far more focussed upon finding a support group of similarly impacted individuals with whom I could share experiences and look at ways forward.
- 162. As a result of my having been so ill, I had lost friends, a relationship, and had even had to move home when my neighbours had started acting unpleasantly towards my family and I, not really knowing what I was going through (as I will later describe).
- 163. When I had been offered the combination treatment of Interferon and Ribavirin, I was told that it had achieved *some* positive results, but I was sceptical as that also meant that there had been some negative results and I was additionally fearful of what I may have to go through mentally and physically, but I was then also feeling quite desperate.
- 164. Despite reservations, I agreed to take the course, but again experienced some of the same side effects as before. I also had to be monitored *not just* to check the progress of the therapy, in terms of my viral load and how impactive it may have been upon it, but also to assess my iron levels as Ribavirin, apparently, could have had an adverse impact in that regard.

- 165. The course was scheduled to take place over an eighteen-month period through which I was to self-administer Interferon by weekly injections and take a daily Ribavirin tablet. I did not complete the course, and after only about six months it had to be stopped. It was also unsuccessful.
- 166. I found that I had been wholly unable to deal with the side effects of the treatment which were every bit as bad as they had been on the first course. The whole period was sheer torture for my children, who whilst wanting their mother to get better, also saw how ill she was becoming whilst being treated. GRO-B in particular, still very young, was most concerned but I promised them all that I would try again once they were older.
- 167. At the end of the first six months, a blood test, as it had before, revealed that I was actually clear of HcV, but this did not influence my decision to stop that was entirely due to the side effects I experienced, I had already decided to call it a day by then, unable to take any more. In October, 1999 further tests confirmed that the viral load was there again, down, but measurable.
- 168. I decided to take action against the hospital following all that I had endured, especially as I had become infected by the NHS and instructed solicitors - Perkins & Haddon of King Street, Manchester. The solicitors, acting on my behalf and with my full permission, requested copies of my medical records from the MRI, GRO-B and GRO-D. In supplying the records held, both my solicitors and I received a copy.
- 169. Upon examination, I found that there were a lot of gaps in the records, with all of the test results being omitted / missing from the time of my hysterectomy operation. The test results, showing my having been 'clear' of Hepatitis C in October, 1999 were also omitted / missing.

- **170.** Unfortunately, following a successful outcome to my claim, I have burned the majority of the documents it generated, including all of my medical records.
- 171. As an integral part of the litigation case, my solicitors advised that I seek a second opinion as regards my Hep' C status as it was at that time. As a result, I sought the assistance of a Dr. Steven Green of the Royal Hallamshire Hospital in Sheffield.
- **172.** Dr. Green conducted a blood test which confirmed that I was HcV negative. He explained that despite the earlier results, the nature of which he did not dispute, he had found that I was then 'clear.'
- **173.** He explained that the first round of Interferon may have initially sent me into remission, and that the gap between treatments may have assisted my body in becoming better equipped to deal with Hep' C once it had returned. The second round of treatment, although abandoned by me after six months, had also been effective to a point, and that I had most probably then spontaneously cleared the virus myself.

Section Three - Other Infections

- 173. I believe that I have also been infected with Hepatitis A at some point in time, again as a result of my having been given contaminated blood, blood plasma or Factor XI concentrate, but fortunately this is apparently far less serious and I was able to rid myself of the virus almost immediately.
- 174. At some point in time, which I cannot now recall, I received a letter informing me that during the course of my past treatment for haemophilia, I had been given blood, blood plasma, or a blood product which had exposed me to the risk of the new Variant Creutzfeldt-Jakob Disease (vCJD) which had been carried by a donor.

175. I believe that this was a generic letter, despatched to me and others who may have been similarly exposed to danger through use of material originating from the same batch.

Section Four - Consent

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176. As previously detailed, I believe that there were a number of occasions when I was either treated and or had my blood tested, without consent. In particular, I was treated and tested as a part of Factor XI product trials, matters which I did not consent to, and had no knowledge of until after they had occurred.

Section Five - Impact

- 177. I found myself in debt, as a result of my illnesses and a related inability to work or secure work as a person with haemophilia (as I have described). I also ended up in trouble when I had taken a cleaning job at the same time as I had been claiming benefits, which I should not have been. I wasn't thinking straight at the time, and was far more concerned with keeping a roof over our heads, food on the table and clothes on our backs – I was in a desperate position so I worked and claimed at the same time.
- 178. I have subsequently been found to be Bipolar, which may well have accounted for my actions, but at the time I was prosecuted, fined and had to wear a tag. I have always experienced difficulties with work and not only because of my health issues. In 1999 I held a job as a carer for about six months, something which I enjoyed doing and was good at, but after a car accident in which I suffered neck damage, I had to give it up.

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- 179. I married my second husband <u>GRO-B</u> in <u>GRO-B</u> We had started seeing one another in December, 1999 and I took the decision to tell him of my Hepatitis C infection just a few months into our relationship, which was quite difficult, but was something I recognised that I had to do and should perhaps have done sooner, but I feared disclosure would jeopardise our relationship, as could our telling other people.
- 180. We now own our own house, and I am in receipt of Disability Living Allowance. My children have all grown up and left home, so GRO-B and I live alone. However, his stepson has Cerebral Palsy and stays with us regularly, so we also care for him on occasions although he lives with his stepsister their mother having passed away (in GRO-B 2021). As a cerebral palsy sufferer, his care comes with a high level of responsibility.
- 181. In 2005, I was diagnosed as having Bipolar Disorder after I had been a patient of a psychologist for many years. Since having been diagnosed, I have experienced both high and low moments as regards my mental health, the legacy of long-lasting health issues which have also left me in considerable debt (thousands of pounds).
- 182. I have been diagnosed as having Myopathy and Demyelinating Syndrome which is attacking my optic nerves which in turn will lead to me losing my sight. I have already started to see white patches in my vision. I have lesions on my brain with some scarring.
- 183. I also suffer burning nerve pain in my legs, arms, hands and feet with the burning sensation in my hands, legs and feet being particularly painful. I still feel unwell, as if I am going down with flu, on a regular basis.
- **184.** Most of these health issues started in 1996, after the two periods of treatment with Interferon and are a direct result of my having been given Interferon.

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- 185. I suffer from spontaneous shakes, muscular tremors and at times sensory deprivation. The tremors can occasionally be wholly uncontrollable and manifest themselves in my neck, hands and feet. I can suffer pain at night which keeps me awake, and even when I am tired there can be periods when I cannot sleep at all for anything from a week to ten days.
- 186. In more recent times, I have been diagnosed as having Clinically Isolated Syndrome (or 'CIS') which uis a neurological disorder. I had no idea what this was when diagnosed, so I asked my clinician to write it down for me - so that I could look it up myself and tell others who may need to know. A copy of his note I now produce as my Documentary Exhibit WITN5605003.
- 187. At times I do not feel like going out and I have missed appointments when I get to my front door, ready to leave, and just find myself unable to go. I just cannot bring myself to do it. I am not as scared as I used to be before, when I heard 'voices in my head,' because I now know that it's an illness, I know what it is and can accept it, even where I cannot actually deal with it.
- 188. I have to take various medications each day, to assist with my ailments, including Lamotrigine (used for Epilepsy as a 'mood stabiliser'), Prozac and Aripiprazole for my Bipolar Disorder and Zapain and Oramorph for my CIS.
- **189.** When I had been diagnosed as having Hepatitis C, I did not know what this ailment was, and in my ignorance told neighbours that I had HcV, not that they knew what it was either. I believe, looking back, that they thought I had HIV, which had been well reported in the media alongside AIDS, and in their ignorance they started to gossip.

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- 190. On 26th. September 1996 I returned to our home in Manchester following a short holiday. On the morning of either 27th or 28th (I cannot now remember which), I found that overnight someone had used some form of weedkiller to burn the words 'FAT' and 'AIDS' into the grass at the front of our house.
- 191. I told Manchester City Council, and they sent someone out from their parks department, who cut the grass so the words were not removed entirely, but reduced in their visibility.
- **192.** Having got this sorted out, I went out into my back garden only to find that someone had paint-sprayed graffiti onto the rear wall of our home. They had painted "AIDS OUT GRASS" in large letters of bright red paint which covered a large area and which would be quite evident to anyone passing as the letters in the grass at the front had been.
- **193.** I found all of this really frightening and intimidating, and our neighbours' antagonism was a considerable cause of concern for my family and I. I called the Housing Officer who visited our home and saw what had happened. She arranged to get someone out to the house to use a jet-washer to remove the graffiti, but I felt that we needed to move, we were no longer safe living there, someone or some people were deliberately targeting us because of my HcV.
- **194.** The housing officer agreed, and so the children and I moved out the children going to my parents or their father's whilst a change of address was sorted out. I was actually offered one that very day, but had to decline, eventually moving to one that was more suitable on 4 th November, 1996 but it needed to be fitted out and coming right on top of Christmas, meant that it was a very hard time for me, and us as a family, financially that year.

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- **195.** I have a photograph of the painted graffiti, a copy of which I now produce as my **Documentary Exhibit WITN5605002.**
- **196.** My daughter GRO-B suffered badly, having got into a number of scraps with other pupils at school where she was being subjected to abuse which had come from what children had been told or heard about us from their parents. She ended up being charged with having committed a string of violent offences and I was left feeling extremely guilty for having told people of my having Hepatitis C. It was honesty which had serious repercussions and which meant that I was a lot more guarded thereafter.

- **197.** GRO-B because of the apparent notoriety of our family and the localised unpleasantness being experienced, GRO-B a local newspaper even approached me to tell 'my story' which I was told would appear anonymously, but it didn't. When the item was published, my name and face were plastered all over the article and it had a widespread impact many kind people were sympathetic, but far more just wanted to make trouble for my children and I.
- 198. I think the story appeared in <u>GRO-B</u> newspaper, but I cannot now remember for sure. I do not know how they found out about me, but they sought me out through the solicitors who had dealt with my civil claim, although I had expressly asked them not to provide details of my home address to anyone else.
- **199.** The guilt I have experienced also came from other sources. I feit terrible at having to ask both GRO-B and GRO-B to submit to HcV testing, and I found this even harder to do with the children. I made sure that my three elder children were tested first, and then saw to it that GRO-B was tested later, delaying it because of the health issues she faced. I was really worried that she may have had Hepatitis C, having been born with it, caught it directly through me whilst being carried, but fortunately all of the children's results were negative.
- 200. Another cause for relief was the fact that none of my children had inherited my Factor XI deficiency. I find it very difficult to talk about my past health issues with anyone and believe that as a result I most probably suffer from Post Traumatic Stress Disorder (or PTSD), as well.
- 201. I recently had to undergo a procedure which involved a needle or rod being inserted into my spine which saw me being given six units of plasma. I was very anxious going into this procedure, as in the back of my mind I kept thinking that I could catch something, again.

- 202. Some of the lasting issues I experience post Hep' C infection include my not being able to drink out of a cup if I am at all unsure of its cleanliness and I cannot use or even go near a sink if my husband has not first cleansed it with bleach. Sometimes it's not too bad, and I can cope, but at others it is awful. I can *smell* blood and feel sick if I have to go into a butcher's shop. I went to be with a niece when she gave birth, but the smell of blood only served to fill me with fear.
- 203. I do not trust many healthcare workers, when I used to trust them all, without question. Whilst on a holiday, I tripped, fell, cut myself and had a major bleed, but I refused to go to hospital whilst I was overseas. By the time I returned to the U.K. it was too late to receive any treatment for the bleed, and as a result, one of my knees has been so badly affected that I will have to have a complete knee replacement, an operation I am also quite fearful of.
- 204. I cannot get travel insurance. I recently travelled to the U.S.A. and had to declare that I had haemophilia and had been diagnosed as being bipolar, something I identify as being a direct result of my having had HcV taken together, I was unable to secure any form of insurance that I could afford. I am therefore left either not telling insurers of my true health situation, withholding it from them and 'hoping for the best,' or simply travelling whilst uninsured.

....)

205. I have never encountered any issues securing dental treatment, nor have I faced any stigma related issues from dentists, but I am nevertheless still obliged to complete medical screening forms and declare that I have had Hepatitis C despite no longer being infected and accordingly posing a risk to anyone.I find that having to repeatedly complete a screening form each time I go to a dentists or into hospital is a bit much, especially as my answers will not change. 206. I do not drink any alcohol, something I stopped once diagnosed as having Hepatitis C on medical advice. I believe that my liver is working well, but have never had a biopsy, no doubt due to the bleeding risk I pose through Haemophilia. I have had a Fibroscan, and believe the results were favourable, although I do experience pains in that area of my body on occasions.

Section Six - Treatment / Care / Support

- 204. I have received psychological support in relation to the mental health issues I have faced and continue to endure. None of this support has been provided through any of the doctors or departments who dealt with the Hepatitis C infection.
- 205. I have been discharged by my psychiatrist, as I missed an appointment, as a result of which he told my GP that he (the GP) could deal with my Bipolar Disorder and Psychogenic Epilepsy, which he does with the GP maintaining contact with the psychiatrist, for advice, if necessary. I used to have a support worker assigned to me, but as a result of cutbacks within the NHS, this service has been withdrawn. I do, however, have a paid carer to address my personal needs and who supports me with daily living.

Section Seven - Financial Support

206. None of the clinicians treating or monitoring me had told me about the Skipton Fund, and I only found out about them when I engaged with solicitors. The solicitors put me in touch with the Skipton Fund and sent me the necessary forms to make an application, which I completed and handed to my GP to provide the necessary additional medical information on my behalf.

- 207. I found the application process relatively straightforward, and within about a month I had been accepted into the scheme and received a first stage payment of £20,000- The England Infected Blood Support Scheme (EIBSS) subsequently contacted me, explaining that they had been given my details by the Skipton Fund, and they (EIBSS) then invited me to apply for financial support through them, which I did.
- 208. I was granted annual support of £3,000.00p, but I believe this may have been as I had claimed for the wrong things in the past. It has now been resolved and I receive a quarterly payment of £7,100- together with a free prescription payment certificate, something which I find particularly useful.
- 209. A copy of the initial correspondence for my application to The Skipton Fund I now produce as my Documentary Exhibit WITN5605004.

Section Eight - Other

- **209.** I should also state that in terms of my receiving treatment with whole blood or a blood products, in around 1998 my left ovary was surgically removed, and I was given plasma; in 2004 my gallbladder was removed and I received plasma; and in more recent times, 2017 I had a gastric sleeve operation for which plasma was again administered.
- 210. My son GRO-B was so upset by the effects which Hepatitis C treatment were having upon me, that he moved out of our home and went to live with his maternal grandmother, as he didn't want to be in the same house as me, with my being so ill. This would have been in around 1997 / 1998, but I continued to care for him, in so much as I could at that time, providing financial support, and he visited me each day for breakfast before leaving for school and then for his tea as my parents were then both working.

- 211. All the same, he didn't return home but at the age of just fourteen went to live with his elder sister GRO-B at which point I stopped claiming benefits and family allowance for him which his sister did instead. He was distanced from me as a direct result of my becoming so unwell whilst being treated.
- 212. Prior to this, one of my daughters GRO-B left home to live with her father, between around 1993 and 1997, as she too found herself unable to cope with my being both mentally and physically unwell. Her father (GRO-B then claimed benefits for her, but this all ended when his relationship at the time broke down and he found himself no longer able to adequately care for her, so she returned home.
- 213. I can remember having asked my mother whether, had she known of the risks involved, she would have allowed me to have been given blood and / or blood products. Her response was a distinct "No!"
- 214. It may be interesting for the Inquiry to note that whilst undergoing my second round of Hepatitis C treatment, I returned a negative Hep' C test, although a subsequent test came back positive. I queried this, and was told that I had returned a 'false positive.' This happened whilst had been under the care of Professor Steven Green at the Royal Hallamshire Hospital, Sheffield, and I was told about it by Dr Bolton (of the MRI). When subsequent enquiries were made (at the time of civil litigation), there was no trace of this test, false positive or otherwise, within my medical notes.

- 215. My General Practitioner has, for some time, been a Dr GRO-B of the GRO-B I can recall having received a telephone call from her in which she told me of a telephone call she had received from some blood donation centre or blood bank, in which she had been told that a 'look-back' operation had been conducted, to trace known contaminated donors, and that as a result they had information to send her.
- 216. Apparently, Dr GRO-B asked that the information held be passed on to the Haematology Department at the MRI, under whose care I was at that time). For some time I asked Dr Bolton about this information, and if she had ever received any information following the look-back exercise, but she always told me "No."
- 217. Later, whilst being treated by a different doctor at the MRI, I enquired about it. I wasn't told anything, but having been asked, the doctor simply slid my medical file to me across the desk, and left the room. I opened the file, rifled through the pages, and found the information it detailed a contaminated batch of plasma, by number, going back to 1988 when I had been given at least two transfusions, and clearly showed that a transfusion I had been given on 16 th September, 1988 had come from an infected batch.
- 218. The above information was passed to my solicitor of the time, and further, more formal enquiries were made, and all of the necessary information obtained. If my memory serves me correctly, the infected batch had originated from a donor centre / blood bank in Burnley (UK) and had been contaminated by an infected donor who had undergone both dental treatment and had tattoos inked on whilst overseas.

- 219. I place no blame upon this donor as he / she had acted in good faith whilst trying to help others, and I do not blame the donor for my subsequent infection and all that it has meant for me. This should have been avoided by the NHS using more exacting testing of blood and blood products before they were used.
- 220. Providing the Infected Blood Inquiry with a witness statement has not been easy for me, due to the various medical issues I have faced and those which are ongoing. I should add that I have mild dyslexia and on occasions can struggle with my mental health. I recently suffered a fall, the result of my having CIS, in which I hurt my back and pelvis, and following which I have found walking more difficult and have even struggled to get out of bed. I have to use as mobility scooter and various other 'aids' just to get by.
- 221. Clinically Isolated Syndrome (CIS) is one of four forms of the better known ailment Multiple Sclerosis, of 'MS.' I believe there to be a direct link between CIS / MS and treatment using Interferon and Ribavirin, such as I underwent. To better inform the Inquiry, I would now like to produce two additional documentary exhibits.
- 222. Documentary Exhibit WITN5605005 An extract from the National Multiple Sclerosis Society website, showing CIS as one of the four ways in which MS may present, but that it does not necessarily follow that someone with CIS will progress to full Multiple Sclerosis as time passes.
- 223. Documentary Exhibit WITN5605006 A published case study, sourced from the Journal of Clinical and Diagnostic Research, published in May, 2015 and entitled, *Multiple Sclerosis Like Condition In A Patient Of Hepatitis C After Treatment With Interferon Alpha: A Case Report* [J Clin Diagn Res, 2015 May: 9(5): OD14-)D15]

224. This paper shows that the use of Interferon and Ribavirin in the treatment of patients with Hepatitis C can lead to patients developing other medical issues, beyond such side effects as 'flu-like symptoms, anaemia and jaundice,' and including psychiatric issues, vision impairment, central nervous system related problems and that the latter may lead to MS.

Statement of Truth

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

Signed:	GRO-B
Dated:	31/12/22