Witness Name: **Denisia GRAY**
Statement No. : **WITN04040001**
Dated: 08/ 04/ **2019**

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

DENISIA GRAY

I provide this statement in response to a request under Rule 9 of The Inquiry Rules, 2006 dated 22nd November, 2018.

I, Denisia Gray, will say as follows:-

1. My name is Denisia Gray and I was born on GRO-C 1943. I live at an address in Essex that is known to The Infected Blood Inquiry. I am a married woman, living with my husband (a retired Consultant Radiologist) and have two adopted children who have long since left home, and are now living elsewhere. I have seven grandchildren, aged seven to fourteen years. My parents had two children, my sister and I, my sister having been adopted.

2. My father was a serviceman within the Royal Air Force (RAF) where he became a Wing Commander. As a result of his military service, as a family we moved around a lot, one result of which being that I attended no fewer than twenty three separate schools.

3. I am a State Registered Nurse (SRN). My maiden name was Dummer which, with other initials meant that the first letters of my name read 'D.E.A.D.' something that was not welcome from someone working in a hospital environment.

4. I intend to speak about my having been diagnosed as having contracted Hepatitis C following treatment for a bleeding disorder I had suffered with from childhood, most probably from birth.

5. In particular, I wish to tell the inquiry of the nature of my illness(es), how Hepatitis C impacted upon my family and I, the treatment I received, and the impact which treatment for Hepatitis C (also referred to as 'Hep C' or 'HcV') had upon us.

6. As a child I was found to bruise and bleed easily, far more so than other children, and I suffered frequent nose bleeds. However, as my father was then serving with the RAF, and we often relocated homes, my apparent bleeding disorder wasn't actually investigated for many years.

7. I recall that I bruised and / or bled easily, particularly around ages four and five, and haemorrhaged when I had to have my tonsils extracted when I was aged about eight or nine. None of this was tackled until I eventually began a career in nursing.

8. When I started conducting 'rounds' on the wards, I found that if I stood up for too long, I would be prone to fainting. Investigations were conducted, and it was found that I had deficiencies of Factor V, Factor VII and factor X, especially Factor X.

9. I don't know if my disorder was genetic, as my mother refused to provide a blood sample for testing and felt that it wasn't worth my upsetting her by insisting upon her providing one, so I never found out, but suspect this to have been the case.

10. My bruising and bleeding did not impact upon my ability to go into nursing, and I saw nursing as a career that was going to see me through my entire working life. For me, nursing was a vocation, a 'calling,' as opposed to something I did simply to pay my bills, it was far more than that, I loved it.

11. I went into initial training whilst my father was still serving with the air force, starting at St. Thomas' Hospital in London in around 1962 / 1963 when I was just nineteen. As my parents were then still abroad, I found myself having to live with an aunt. I subsequently went on to specialise in paediatric nursing, and as my career progressed, became a staff nurse.

12. My training was not without its issues, notwithstanding my bleeding problems. Whilst my father had been serving in Aden, I had an accident in a laboratory which left me with a scar on one of my arms. A matron at St. Thomas' found it unsightly, and decided that I couldn't continue training the as the patients may not have liked to see it.

13. However, I finished my training and went on to work at St. Thomas,' University College Hospital (UCH), Gt. Ormond Street, the Homerton Hospital in Hackney, where I met my husband and Colchester where I also worked in the private sector.

14. It was whilst working at Colchester that I found I had to stop working. I then worked in a private hospital, and hadn't particularly wanted to move into private nursing, but they also treated children so I could continue with my speciality there, and made sue that whenever they were treating child patients, I was there. I was a staff nurse.

15. Shortly after being diagnosed as having Hepatitis C, I was asked to leave. I found I was unable to continue as a result of people's attitudes towards me and my infection rather than my ability to perform, at least initially.

16. When it was revealed that I had contracted Hepatitis C, I was effectively 'shown the door.' I wasn't allowed to say 'goodbye' to anyone, not even my colleagues. I had been working for the GRO-D, and was deemed that I was medically unfit to be a nurse. I went to the trust, GRO-D who paid me for three months work, but that was it.

17. I missed nursing then, and I miss it now. I still find that if I watch nursing related programmes on the television, I find myself thinking 'what could have been?' had things been different. I had been a Gt. Ormond Street nurse when they performed the very first heart transplant on a child, I don't know if I could have been involved in that, but it's when I see things like this that I remember how much I loved and missed nursing.

18. As a nurse, I was acutely aware of my infection and how the condition could impact upon others. I was very aware that if I suffered a nose bleed, or anything similar, I couldn't let it impact upon anyone else – I wouldn't let anyone else clean it up and used to carry a small bottle of bleach around with me, just in case.

19. On one occasion, I had a nose bleed and found myself having to shout out 'keep away,' to anyone around me. It was at that point that I realised I couldn't continue nursing, I had a moral, ethical duty of care towards to patients in my care, and didn't think I could rightly sustain that.

20. There was I with Hepatitis C, trying my best to cope with the condition safely, but it would drive me mad to see other nurses coming into work with coughs and colds. We all had a duty of care to keep our patients safe, ensure they could get better, not give them other issues to deal with, and certainly not our own illnesses.

21. There was no obligation upon me to tell anyone that I had contracted Hepatitis C, but I saw it as my duty, as a nurse, to do so, and lost my job as a result.

22. I am still under no duty to tell anyone of my condition, but I choose to tell people as I only feel that sooner or later it will come out anyway, and I can't stand it when people start to 'whisper' about me, or think I am hiding something, which only makes it worse. I tell people, in part to educate them about the condition and the lives people with it.

23. As a child, despite the evidence, I received little or no treatment for my bleeding and bruising. As an adult, when my becoming faint became an issue alongside the bleeding and bruising, investigations were conducted and my various blood factor deficiencies were identified.

24. I was initially treated with a blood product called Cryoprecipitate (or 'Cryo' as it is occasionally referred to). However, having suffered a retro-peritoneal bleed, and being given Cryoprecipitate to assist me, I suffered an anaphylactic reaction to the Cryo I had been treated with, and didn't have it again.

25. Following this, I began using Factor VIII (concentrate), which I had to take prior to undergoing any form of surgery or other invasive procedure through which there was a likelihood that I may suffer a bleed. I took this alongside Tranexamic Acid which I am also currently taking as I await surgery on a shoulder.

26. Prior to being treated with it, I was told nothing of Factor VIII. The only thing I knew was that each phial of the concentrate had been created using approximately fifty units of blood. I can't remember anything I may have seen on its packaging, which may have indicated its country of origin or manufacturer. As a nurse, I would have been concerned with what was within a medicine phial, not where it may have come from, so I paid it no attention.

27. All the same, I do remember that something came from Elstree, from the blood laboratory there, so at least some of what I was given had been U.K. sourced, but I can't recall having been told whether or not it was a U.K. product.

28. Even if I had been told that it was not a U.K. product, I'm not sure if that would have bothered me at the time – I had no reason to believe that the Factor VIII I was taking was in any manner or form 'unsafe.'

29. Over the years, I have been treated for my blood disorder and subsequent Hepatitis C through various hospitals. The Churchill Hospital (where I was under the care of a Professor Ritza); The Royal Free Hospital (where I was under the care of a Dr. Dormandy at their Lawn Road site); Addenbrookes Hospital (under a Mr. Alexander); the Hackney Hospital (by Dr. Cardno); and latterly by the Colchester General Hospital (initially by a Dr. Boots, then Dr. Woods and now Dr. Mohan).

30. I used to suffer from tooth abscesses, and every time I had one, it had to be drained, and I had to take factor VIII. The situation worsened, to a point where a decision was taken to conduct a dental clearance operation to prevent any further recurrence. The surgery took place at Colchester in 1986.

31. The surgery was conducted by a consultant, Mr. Clark. The anaesthetist was a Dr. Griffin, and he gave me some Factor VIII (concentrate) pre-surgery. It was following this procedure that I became more unwell than I had previously been, and became jaundiced.

32. There was nothing to suggest that I had been infected with Hepatitis C before this time, and I did not have a lifestyle that would have left me vulnerable to such a disease. I immediately suspected that something was wrong, but didn't know what, although from the time of this dental clearance operation my health deteriorated and I became increasingly unwell.

33. However, it wasn't for another six years following this operation that my having been infected with Hepatitis C was diagnosed. By then, nothing else could have been responsible but the use of the Factor VIII blood product given to me by Dr. Griffin, it had been contaminated.

34. My diagnosis came about as a result of the intervention of a Dr. Woods at Colchester who caused me to undergo a liver biopsy in an effort to resolve my declining health. Following the biopsy, the consultant, a Mr. Roger Motson told me the result in person, that I had Hepatitis C. He apologised to me, then said that my condition was fatal and that I may only have had six months thereafter to live.

35. I was provided with some information about the disease, directly following the diagnosis, something which couldn't have happened any sooner.

36. Throughout the six year period following the dental clearance operation, I had sought help I knew that I was unwell, and was referred to a Gastroenterologist, Dr. GRO-D but throughout those six years he simply dismissed me, accusing me of having been fabricating the symptoms I found myself suffering. Having had the biopsy, and been given the diagnosis I was, I have refused to return to see this gastroenterologist.

37. Dr. GRO-D put me through hell throughout this period, telling me that I had nothing wrong with me and even referring me to a psychiatrist, telling my husband that I was 'mentally ill.'

38. I went to the psychiatrist, to address my 'mental problems,' and had to attend a mental health institution in order to do so, a hospital for the insane. The referral was made 'behind my back,' by the doctor speaking to my husband about me, but not with me – he never had the courtesy to tell me what he was doing, or why, he couldn't face me himself.

39. During this time of my unknowing what was happening with me, it never clicked that I could have had Hepatitis C, even though all it would have taken was a simple blood test. The doctors who saw me must have tried every other test that was available to them, except for that one.

40. Doctor GRO-D, the gastroenterologist who referred me to a mental hospital told me that he thought I would be happy that all of my tests were being returned as 'clear,' or 'negative,' but I was in a lot of pain, sometimes eating related, other times not and found that I was increasingly debilitated.

41. My gall bladder was removed, but that wasn't the problem as I still had the pain, and I had to have abscesses on my lungs drained. I told Mr. Motson that I wasn't making it up, that something was wrong, but only Dr. Woods and Mr. Motson appear to have believed me.

42. I was supported by a friend, someone who'd known me for many years and knew that it was not in my character to take time off of work, sick. Dr. GRO-D, who knew my husband, joked that I must be sick as I was married to my husband.

43. He wasn't very nice, and I would have taken civil proceedings against him had he not worked with my husband – that was his only saving grace. I have since blocked him from my memories as I was, and am still extremely angry and bitter with him and his treatment – or not – of me, especially as all that was required was a specific blood test.

44. Last year (2018), the year before Mr. Motson retired, he invited the friend who had supported me, and I to his retirement party. Dr. GRO-D was present and asked for an introduction which rather took me aback. I said, *"Excuse me? You nearly killed me and you don't know who I am?"*

45. Once diagnosed, I found that I had to keep up-to-date with information concerning my condition myself, by using information provided by The Haemophilia Society and more general press releases.

46. Shortly after I had been diagnosed as having Hepatitis C, a Professor Dusheiko appeared on a Panorama television programme. He was a Hepatology Specialist who said that Hepatitis C was the disease he himself would least like to have – I have never forgotten those words.

47. Dr. Wood, who had referred me for the liver biopsy provided some, albeit brief information, and suggested that I see Professor Dusheiko at The Royal Free Hospital. Prior to that, I only knew that which I had been able to find out myself, as I had only been given fairly routine information as to how to care for myself, in particular hygiene issues around my infected status and risk of passing on infection through blood or sexual contact.

48. I have also suffered from Buerger's Disease, Raynaud's Disease and Digital Ischaemia. In 2006 I had to spend time being treated in a hyperbaric chamber for the Raynaud's Disease, having had to undertake some thirty separate treatments over a six week period. These took place every weekday, and were completed in August 2006, having been temporarily delayed as I suffered a ruptured eardrum, during treatment, and had to wait for it to heal before continuing.

49. I had a child proof lock on a cupboard at home, something I caught my finger on, repeatedly. An ulcer developed on the finger, and it would not heal, so I was sent for hyperbaric chamber treatment. Here I made a friend who had an ulcer on one of her legs which like mine, wouldn't heal. At the same time, there was another lady on the ward who had Methicillin-Resistant Staphylococcus Aureus (MRSA).

50. I approached the hospital ward management and asked if the MRSA patient posed any threat to my friend or I, as I certainly didn't want any other conditions to have to deal with, and thought that it was quite negligent of the hospital at that time, to have put someone with a known MRSA status on the same ward as patients with open wounds like us.

51. Once referred to The Royal Free Hospital, I was initially offered a Hepatitis C treatment using Interferon. Unfortunately I found that I was a non-responder and my treatment was stopped after a period of just six months.

52. I had, initially been refused Interferon treatment, and was extremely disappointed as I really wanted to be rid of Hep C. Accordingly I spoke to Professor Dusheiko about my having been declined, and managed to persuade him to put me onto the treatment programme.

53. At this time, Interferon as a Hepatitis C combatant, was only a trial drug, not something you were routinely offered as an HcV patient, and apparently I hadn't met the strict criteria for acceptance. I knew, through the Haemophilia Society, that a couple of other people had been taking it, and that there was no other then treatment available. I begged Professor Dusheiko to accept me onto the programme, which he did, but sadly Interferon didn't work for me.

54. Each time I attended The Royal Free for Interferon treatment monitoring, they performed a lot of blood tests to check my response. I had a special fridge installed at home, to keep the Interferon as it was meant to be, but still had to travel to The Royal Free for the tests.

55. I wasn't given the option of continuing with this drug, once they found that I wasn't responding to treatment with it, but even had I been given that option I would have refused. I believe that had I carried on using it, I would have become genuinely mentally unwell.

56. I had to inject myself with Interferon three times per week, and it's effects were extremely unpleasant, so much so that taking it every other day meant that in every week, I only had one day (a Sunday) where I 'surfaced' from it.

57. Having injected myself, I found that I was completely out of action, unable to function, and felt so sick that even the following day I continued to feel the side effects. I looked forward to my Sundays as being the only day when I was unlikely to suffer as I hadn't had anything the day before. I found it increasingly more difficult to bring myself to administer the injections, as I knew that I would feel really unwell almost as soon as I had done so.

58. I do not know who this trial may have been sponsored by – the NHS or anyone else. It was potentially supported by a drug manufacturer, but I do not know. I don't recall having seen anything on the Interferon packaging that indicated who it may have been.

59. About six months after I had been taken off of the Interferon trial, a new treatment, again experimental (or so I believe) became available. This was a double treatment using Interferon combined with Ribavirin and had been developed as a means of treating Hepatitis C patients who hadn't responded to Interferon alone, like me.

60. I can only describe my reaction to the combined treatment as having been 'off of the scale.' It was far worse than my initial Interferon treatment. I had only agreed to undergo this treatment for the sake of my family and friends, and in many respects wish that I hadn't, so bad were the side effects I experienced. Again I was found to be a non-responder, but the treatment had to be discontinued in any event as I found the side effects too severe.

61. This was again only an experimental treatment at the time I was put on it, offered on a named patient only basis. I was disappointed, but at least felt that I had tried.

62. I wasn't offered any further treatment beyond this. I think that once you have been identified as a 'non-responder,' you are effectively ruled out of any further modes of treatment. Again, as with the Interferon alone, I do not think that I would have accepted any further treatments given the way my body reacted during these two trials.

63. Incredibly, I had to have a Hickman Line (a form of catheter) inserted as I had terrible veins for drawing blood from me, but despite my Hep' C status, I found that some nurses refused to use it.

64. Today, I would not accept any further treatment. This is now partly because of my age, but largely because I know my body better than anyone else; for example I know when I am going to experience a Hepatitis crisis as my hands go red immediately beforehand. I know when I am getting tired, and understand that I then have to stop whatever I may be doing.

65. My friends have become used to it now, and I find that I can't make any plans too far in advance, as I don't know how I may find myself feeling when I awake of a morning.

66. I am, therefore still infected with the condition of my liver deteriorating. My pancreas no longer works properly (Chronic Pancreatitis) and as a result I have to take a product called Creon just to be able to digest food. My overall health has continue to deteriorate, and I now find that I require assistance with the most mundane of household chores, although I try to keep myself as active as is practicable.

67. I used to enjoy sewing, but can't sew anymore, which I find extremely annoying. I have Chronic Obstructive Pulmonary Disease (COPD) for which I have to take steroids, but find that this conflicts with my Hepatitis C status – the COPD leaves me breathless, I have to take the steroids to assist my breathing, and find that it brings about an Hepatitis C crisis. If I don't take the steroids, I am left breathless, so there are little or no alternatives.

68. Each time I suffer an HcV crisis, I am bed-bound for at least three days at a time, or until it passes thereafter.

69. I suffer from Biliary Dyskinesia and have had Hepatic Septicaemia. My thyroid no longer works and I am accordingly required to take Thyroxine, permanently. I found myself having to be fed through a Nasojejenal Tube with Peptisorb for ten hour periods of the day, a situation which led to my losing a lot of weight as I wasn't receiving the required nutrition.

70. Each day I am in constant pain – pain to such an extent that I have to take 30mgs of Morphine, twice per day (which I self-administer, orally). I have very little immune system left functioning, so I find that I have to avoid people or situations where people may gather. This is particularly the case at the moment as I await shoulder surgery.

71. Throughout the period of my infection with Hepatitis C, I have felt alone, isolated from 'normal' people and 'normal' life, and still feel that way. There are certain aspects of my Hep C infection and its consequences which even with the passage of time I haven't found myself able to disclose to my family. I believe they would be absolutely devastated hearing of the things I have kept to myself, in order, as I have seen it, to protect them.

72. As a consequence, I have found that my having made this witness statement to the inquiry has been an extremely difficult thing to have done.

73. I find myself taking a stance that I have to work with that which I have, not that which I would have liked for myself to have, and live in an atmosphere where I never know how I may feel the following day.

74. Placing the physical aspects of this disease aside, mentally I have been destroyed, starting from the point in time when I lost the job I loved. My having been accused of having been mentally ill, by someone acting in complete ignorance of my condition, someone who didn't even offer an apology when the truth was revealed, really hurt then, and hurts to this day – I find his conduct to have been wholly unacceptable.

75. Ignorance of Hepatitis C, and in particular how it may be contracted or passed from one person to another has also been a major factor within my family. My parents disowned me, and even at my mother's funeral my father declared, before everyone present, that I had caught Hep' C as I was a drug addict and prostitute.

76. My parents lived in Stafford. I was only allowed to visit them if I travelled there after dark, when I wouldn't be seen, and on a Friday. Growing up, we had a very good neighbour. I remember that when my mother died, I went to visit this neighbour, someone I used to be very close to. She said to me, "Long time, no see," as if I was never there. I told her that I had visited many times before, but she had never seen me and my parents hadn't told her that I had called upon them.

77. On one occasion, I went to stay with my sister for a couple of weeks. I arranged to go and see my parents, but was told that I couldn't go until after 8.00p.m. or 'after dark,' and on Friday. I believe that on this occasion, if not others, they threw away any plates or cutlery I may have used, as I saw them placed outside of the house, to be thrown out.

78. Professor Dusheiko offered to intervene on my behalf, to call my father and explain the situation to him, to tell him that I had contracted Hep' C as a result of a contaminated transfusion, but I told him that there would be no point – my father came from a particular generation of people who would not change their views no matter what.

79. Some people now think that they know everything about Hepatitis C, but they don't, and they don't really want to know. I have offered to give talks, at my local support group within the hospice I attend, where you would think that people would be more inclined to listen and understand, if not to empathise, but it is unlikely to happen.

80. Two or three years ago, I applied for a mobility scooter from a company called Quango. I had to apply for insurance for it, before I could have one, and fill in a questionnaire. One of the questions asked, *"Do you have Hepatitis C?"* It went further, asking those who replied, *"Yes,"* how they came by the disease.

81. I refused to answer, and as such never got a scooter – the company representative had attended my home, in a van, with a scooter on board for me, but I never even got to sit on it. The company told me that although the machine was the 'on my drive,' as I had Hepatitis C I wasn't even allowed to sit on it.

82. I find that nothing is private in the NHS. My blood test results were once put through using a consultant's card number as opposed to my own identity.

83. Oddly, whilst undergoing the Interferon trial, and subsequently the combined Interferon – Ribavirin trial, I gained the distinct impression from senior hospital staff (with the sole exception of Professor Dusheiko), that they were being very judgmental of their patients, and only appeared interested in those (primarily drug users and / or alcoholics) in whom they held a special interest. People such as me were a very long way down their list of interests and priorities.

84. I didn't ask anyone else I met if they had gained the same impression as I, but one of the patients on my ward at the time was the late Peter Cook – he was there having a second liver transplant. We had been told that we couldn't have liver transplants, because of our hepatitis, but here he was having a second. Everyone seemed to go in to see him, to see what they could do for him, but us other patients never had the same treatment, there was no empathy, no fairness.

85. GRO-D

GRO-D

GRO-D

86. As a direct result of their approach, I asked for a transfer from GRO-D GRO-D, and as a result became a patient of the Addenbrookes Hospital in Cambridge. Here I immediately witnessed a marked change in approach and for once found it a very positive experience.

87. The inquiry may find it interesting to note that despite my having asked and I believe Addenbrookes Hospital having asked, GRO-D were unable to provide either of us with any of my medical notes or copies of the same. At the time, my doctor at Addenbrookes (Dr. Alexander) referred to GRO-D GRO-D as being *'St. Elsewhere.'*

88. GRO-D GRO-D GRO-D, but through a friend of one of my daughters, someone working within the hospital, who made independent inquiries on my behalf, I was able to source my X-Rays, so something was still held there. I made a formal application to GRO-D, but didn't even receive a reply.

89. I became an Addenbrookes inpatient for some four months. They eventually managed to stabilise my condition, but I had to be placed in a feeding tube for over a year. I can never thank Dr. Alexander and his staff enough, they treated me like a human being and not simply 'yet another diagnosis.' Dr. Alexander is a lovely man, he actually apologised for the way in which GRO-D had treated me, even though it had had absolutely nothing whatsoever to do with him or his hospital.

90. I have been treated differently, both medically and personally, because of my HcV infection, and have had to make some difficult decisions.

91. Nurses are supposed to wear gloves when they take blood from people, however there are people who say that they can feel your veins better if they don't wear them, so they leave them off. I have had to say, 'no,' and point out that if they aren't going to wear gloves, then I'm not going to let them take blood from me. I wouldn't want someone coming back to me five years hence and saying that they'd contracted X, Y or Z from me, as that would be grossly unfair. It's wrong that I have had to tell them to wear gloves and makes me really cross.

92. I feel that my immediate family were taken from me by my parents as a direct result of their attitude towards me and my illness, something I had contracted through absolutely no fault of my own. I became estranged from my sister, and when my father died I found that he had left everything of my parents to her. She in turn chose not to share anything, so I have nothing, and my children have nothing whatsoever to remember them by.

93. My husband and I wanted children, but made the decision to adopt rather than risk us passing any infection on to our children through natural childbirth. We adopted two girls, our daughters. Until I had been infected with Hepatitis C, I had enjoyed a good life. Once diagnosed I didn't initially have a bad life, I just gave myself an injection and got on with things – but I wasn't prepared to pass on this burden to our children and felt that I had a mora duty not to do so.

94. I have attended meetings of The Haemophilia Society where parents used to come in and proudly boast how many units of Factor VIII they may have given to their children, children who had inherited their condition. I used to come home fuming, as I felt that they could have stopped haemophilia in its tracks, rather than opting to poke a needle into a child every five minutes just so that they could walk.

95. Our eldest daughter also has a blood disorder, Von Willebrand's. It was discovered when she was fifteen years old. As a child, like me, she suffered horrendous nose bleeds and at times could fill three ice-cream containers with blood. I suspected that she had a blood disorder, before she had been tested, but the nurse we went to see was very rude. She said that 'just because I worked with children, and had a blood disorder myself, didn't mean that my daughter had one.' Accordingly I took our daughter to a doctor, and it was then that Von Willebrand's was diagnosed.

96. My husband and I saw the sexual side of our relationship stop, something we both found extremely hard in what had been a very loving, caring relationship. My infection served to destroy our relationship. We are now two people who live in the same house, but not 'together' in a husband - wife relationship. The steroids my COPD is being treated with have meant that I have been unable to sleep and accordingly I moved into the spare room of our house, which is where I have remained.

97. Sometimes I do not think that my husband fully understands how I feel, but at the same time, I don't want my husband to know how I feel, as I feel like rubbish and don't want to burden him with it all of the time.

98. I also hold a lot of resentment towards my husband. Why did he choose to believe GRO-D for six years and not me? I was telling everyone that I was sick, and how that sickness was presenting itself, but Dr. GRO-D couldn't diagnose the problem. I found it very hard to understand how my good friend fully understood that something was wrong, but my husband didn't.

99. There was a dreadful stigma associated with Hepatitis C. The reaction of the general public, and even amongst some of my friends was that it was what they considered to be a 'dirty' disease, associated with poor lifestyle choices. Their lack of appreciation for the disease was extremely hard to take, but nobody seemed to know, or care to know how my illness had actually been contracted.

100. Despite all of the information which has circulated throughout the press and other media over the years, there are still some people who believe that they may become infected from drinking out of your crockery, or using your lavatory.

101. In the beginning nobody knew what to say to me, or do, so naturally nothing happened. I think that to the greater extent people chose top simply protect themselves – it was a classic case of people burying their heads in the sand and hoping that things would go away, rather than facing up to it. But it didn't go away, it doesn't, and won't.

102. I also didn't want to upset people myself, so I too said nothing and found that as I did so, I was unable to talk openly about things and became increasingly more isolated as a result.

103. People were saying things like, "now you'll have to use condoms," which again broke my heart. My husband and I didn't need them for family planning as by then I had undergone an hysterectomy.

104. I am fortunate to have two very good friends, both of whom are good listeners, so I do have someone I can confide in, but it has been very hard. I long to be able to say to my family that it is ok to talk about it, but I don't, so we rather 'plod on,' but for me it's a case of just surviving rather than living.

105. At work, within the hospital where both my husband and I worked at the time, rumours circulated that my husband was a homosexual, that he had caught the disease as a result of his alleged homosexuality, and had then passed it on to me.

106. I contemplated suicide but found that I wasn't brave enough to take an overdose and end my life, so I have just had to deal with the situation I have been placed in, as best as I can. Even now, after the passage of so many years, I still find it very hard to deal with and find myself feeling desperate and alone. I can only ever plan for the twenty four hours immediately ahead of me, no further.

107. My feelings of isolation of being somehow 'different' to everyone else is heightened by the way in which you are treated as a Hepatitis C patient when seeking other forms of medicak assistance.

108. Any surgery I have had to undergo (e.g. cataracts and orthopaedic surgery) have seen me placed at the back of the queue for theatre listing – as all of the surgical instruments use would have to be destroyed following to their use, and the room 'deep cleansed,' to remove any likelihood of vCJD (variant Creutzfeldt-Jakob Disease) being transmitted to others.

109. I have been told that I was infected with hepatitis C as a direct result of my having been treated with a contaminated blood product (in my case, Factor VIII). On 20th September 2004 I received a letter from the NHS, through Colchester General Hospital, which informed me that I was now at high risk for having contracted vCJD. This is also known as 'mad cow disease,' something which made my children laugh as they'd always thought of me as a 'mad cow.'

110. This letter was the only one I had ever received regarding my infection, but was apparently sent to all who had been exposed to vCJD. I do not know if I have vCJD, there is apparently no test, but I have clearly been exposed to it.

111. My two daughters have always been very open about my condition. When I was diagnosed, I told my girls teachers about it. Their school called me, when they were going to provide sexual health classes, to check if it was ok for them to be taught about Hepatitis C. I told them that I didn't mind, and that if my daughters wanted to learn about it, they could.

112. Socially, the stigma is one thing which impacts upon you, but other issues are also apparent. People find it awkward to invite you to social gatherings as I have to be careful with what I may eat, and have to avoid alcohol – you would be quite surprised by how many things have alcohol in them or have been prepared using alcohol, and nearly all social gatherings additionally involve drinking, which again I have to avoid.

113. I attend a local hospice once per week. Many people think that I have or have had cancer as I go to a hospice, but they are not just for cancer sufferers, it's another misconception. One day they were serving leek and chicken pie with trifle for dessert. I questioned the ingredients only to find that one member of staff said that no alcohol had been used, whilst another told me that it had, it was in the pie ingredients – it turns up in many things, even some soups.

114. None of my family have ever been offered any form of counselling, despite the impact my suffering has had upon them all. I have been offered counselling, through the hospice, and attended one session but found that I didn't want to talk about things again, to have to relive the experience, and by so doing risk the stability I have tried hard to achieve.

115. Counselling scared me to a certain extent. I feared that if I opened the door to my 'dark place,' I wouldn't necessarily be able to close it again. It was a risk that I wasn't prepared to take, so I didn't go again.

116. My husband and children have been very understanding, but I am sure that they are saddened by my lack of interaction with them and in particular my seven grandchildren with whom I don't and won't fully engage, to keep them safe, something which I feel that I have to do but find extremely hard. We cope, as a family, as best as we can, but the future will always be uncertain.

117. We lost a grandson some eight years ago, aged just five months. It was a cot death. Once the family went through the grief of losing him, I distanced myself, as I couldn't risk infected them. I found it very hard to grieve myself. I hope that I haven't turned into a hard person, but I know that I have become an unemotional one. When he died I found myself worrying about everyone else rather than grieving myself. I am unable to fully let go, I can't let my feelings get to the stage where I expose everything I have gone through, so I hold back.

118. Having been diagnosed with Hep' C, I lost my job and found myself immediately unemployable. Whilst taking the Interferon, and again whilst being treated with the Interferon – Ribavirin combination, I was too ill from the side effects to work, I was too weak and had to spend most of the day confined to bed.

119. As a result, financially I found things very hard, especially during the early stages of my illness and treatment, but eventually I was awarded disability benefits. More recently, about five years ago, I received payments from The Skipton Fund, and more recently though their successor the EIBSS and SCM, both of which have made a significant difference to my life.

120. I have found the respective application processes frustrating at times, in particular as I have no paperwork to support my application(s), especially from GRO-D which would have greatly assisted. Having asked, and received no response, I feel that to GRO-D I simply do not exist.

121. In stark contrast to the obstruction and resultant delays caused by the inability or reluctance of GRO-D to provide me with the information I have sought, I have found the financial support providers to have been fair, albeit a little slow. I am very grateful for their assistance.

122. Some years ago I was advised to write to a firm of solicitors whom I believe were based in Newcastle-Upon-Tyne, telling them of my Hep' C infection and how it happened. I can't now recall their name, but I wrote to them, and they replied, but stated that they could take my case no further as I had no supportive paperwork (from GRO-D).

123. Because of the nature of the information both the solicitors and then financial assistance providers required, and my GRO-D, I had not applied for help as I saw there being little or no point in doing so. However, having a Mr. James Byers persuaded me otherwise, and I am extremely grateful to him as I am now in receipt of financial assistance.

124. This new finance allows me to visit friends, using a taxi which I was previously unable to afford, a lack of mobility having added to my sense of isolation. Our youngest daughter lives overseas, and once I find myself feeling a little better, I intend using some of the money I have received to visit her.

125. However, no amount of money could ever compensate for that which I have experienced as a direct result of my having been given a contaminated blood product, it has, all the same, made a significant difference to me, and I am sure many others.

126. I am not interested in compensation, as it won't serve to sure anything. It annoys me when I tell people of the inquiry, and all they can say to me is that I'll no doubt get some money out of it – that's not what this is all about, but as with so many aspects of my infection, they don't understand.

127. I have never pursued any form of civil litigation. I thought it too expensive an undertaking, with an uncertain outcome, and that I did not have the supportive information I would have required. I approached the solicitors in Newcastle, but they couldn't help me so I abandoned all thoughts of it. I had thought of taking action against Dr GRO-D, but as he worked with my husband, didn't do so.

128. I really resent the fact that I contracted this terrible disease through absolutely no fault of my own, and have, as a consequence, been condemned to live as I have. I am disgusted that those responsible appear wholly unable to tell the truth, or even apologise for their actions.

129. Whereas the money I have received has helped me, just one word, "*sorry*," would make such a difference to so many of us. It won't make us any better, or feel any better, but it may just make us appreciate that someone, somewhere in a position of authority actually cares.

130. The NHS have a duty of care to those patients who need blood or blood products, but this went out of the window. Using contaminated blood or blood products wasn't their decision to make, it was ours as to using it or not, we never had that choice. When people say to me, *"Oh, you're brave,"* I say that I'm not, I had no choice in the matter. I'm very much a person who believes in dealing with what you have, rather than what you may like to have.

131. To assist The Infected Blood Inquiry, I would like to produce as exhibits copies of three documents I hold:

<u>Exhibit WITN04040002</u>

132. A letter of the GRO-D dated 20.09.2004 addressed to 'Dear patient,' re. vCJD exposure through contaminated blood products (1 page), accompanied by a letter sent 'to all' NHS patients who may have been treated with 'clotting factors' and which was apparently sent in direct response to information provided by the Department of Health, to NHS Trusts on 10.9.2004

134. Patients receiving the above were invited to read a further letter (attached) addressed to the individual patient, or parent of a patient, with haemophilia, other bleeding disorders and / or Congenital Antithrombin III deficiency. The second letter addresses the possibility of exposure to vCJD between 1980 and

2001 and the need for precautionary healthcare measures being necessary following certain medical procedures and surgical operations (5 pages).

136. Both letters were accompanied by a 'Patient Reply Sheet' (1 page, also attached).

Exhibit WITN04040003

137. 'Information For Patients,' regarding vCJD and blood plasma products provided by / sponsored by The Health Protection Agency; The Scottish Centre For Infection And Environmental Health; NHS Services Scotland; The National Public Health Service For Wales; and the Department Of Health, Social Services and Public Safety (NI), dated 7.9.2004 (8 pages).

Exhibit WITN04040004

138. Typed notes I made in response to a request for information from an investigator of The Infected Blood Inquiry and now incorporated within the body of this statement.

Statement Of Truth

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

Signed: GRO-C

Dated: 8th April 2019