Witness Name: GRO-B
Statement No. **WITN5208001**
Exhibits: WITN5208002 – 009
Dated: 23 / 03 / 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 16th October, 2020.

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

Section 1 - Introduction

1. My full name is GRO-B and I was born on GRO-B 1986. I have been asked to provide this statement by my mother, GRO-B: M with whom I have discussed its content and inspected various documents to which I may refer.

2. My mother had, or possibly still has, Hepatitis C (also referred to as Hep' C and / or HcV), and has of recent years suffered poor health. She has undergone treatment for this condition (which I will detail later within this statement) and currently awaits a second test to ascertain whether or not that treatment has been successful (currently scheduled for January, 2021).

3. One aspect of her illness presents as memory lapses, hence our having discussed her problems together and my now making this statement on her behalf, although I have also dealt with a number of issues that have arisen, on her behalf, seen various items of correspondence she has received or which have been held by our family, and I have also accompanied her on numerous occasions when she attended medical appointments or underwent treatment and / or tests.

4. As such, much of what I will now detail is known personally by me, and where not, my mother has told me or I have found out information from other family members or medical professionals.

5. I am a married woman with a child, living with my family in North West England, and work full time in the nuclear power industry as an Environmental Health and Safety Manager.

6. My mother, M, in spite of recent ill health (albeit currently improving), is a full-time carer for my father, a role she has undertaken since he suffered a stroke in 2012. Prior to that, she had always been a hard-working, fit woman with no underlying health issues.

7. M was born on GRO-B 1956 in the North West where she has always lived and where she met my father. They married in GRO-B settled and worked in the same area, and went on to have a family – two sons and a daughter. My brothers are both older than I, the first having been born in 1978, another in 1983, and then I arrived in 1986.

8. I intend to talk about my mother and her infection with Hep' C and in particular the manner through which we believe she became infected, the nature of her infection and how it has affected her, the treatment she has received including what we believe to have been 'missed opportunities' for her to have been diagnosed earlier (and accordingly treated earlier), and the impact which HcV infection has had upon her and our family's lives.

9. Neither my mother nor I are legally represented. I make this statement of my own free will, to assist the Infected Blood Inquiry in their understanding of what occurred in my mother's case. We are not complainants against the NHS, are not engaged in any form of civil litigation and are not members or supporters of any particular body campaigning on the issues arising from the use of contaminated blood or blood products.

Section 2 - How Infected

10. In or around March / April, 2019 my mother started to become unwell. Initially her feet became swollen and she found herself aching all over her body, in both joints and muscles, and as this progressed found that she was experiencing difficulty in simply flexing the joints in her fingers. She suffered from repeated nose-bleeds, and experienced real problems sleeping at night.

11. For her General Practitioner service, my mother used a group practise, GRO-B Cumbria which meant that she didn't always see the same doctor when attending although she was assigned to the care of Dr. GRO-B

12. She didn't get to see a doctor, but was instead attended by one of the practise nurses, GRO-B who began monitoring her condition(s) and care and who sent her for tests – blood tests which were conducted at the CUMBERLAND INFIRMARY in Carlisle (about an hour by car from her home).

13. No medical or surgical intervention occurred, and there didn't appear to be any specific treatment plan, other than to monitor my mother and send her for tests – repeatedly. She was sent to Carlisle to provide blood for testing on a number of occasions, and we would have to telephone the surgery for the results, but all we were ever told was that she (my mother) *"was fine,"* and not to worry.

14. My mother had always been fit and healthy, rarely having taken any illness related time off of work throughout her life – having become poorly came as an exception in her case, and its rapid progression gave us all great cause for concern. Although she was sent for 'blood tests' each time she presented herself at the GP's surgery, we were never told what they may have been testing her blood for, so we didn't know and as her condition worsened so did our concerns.

15. Her condition worsened to such an extent that she was visiting the GRO-B two or three times per week – and did so for a couple of months, but each time blood was taken and each time no result was forthcoming as to what the problem(s) may have been.

16. In the end, my mother was referred through her GP to the WEST CUMBERLAND Hospital in Whitehaven, Cumbria for a scan (which I believe to have been an ultrasound scan) on her stomach.

17. By now, from the time when it first started to being sent for a scan, she had swollen to such an extent that her shoe size had moved from a size 5 to a size 7, she couldn't bend sufficiently to get in or out of her bath, and her skin had the appearance that it could easily split open at any moment. She couldn't climb the stairs and was experiencing great difficulties just walking with painful joints, muscles, and a great deal of swelling.

18. Even now, whereas blood was still being taken for testing, through the GP, she had received no medication or therapy to assist her and had not had a diagnosis as to what her condition may have been. Both my mother and our family were becoming increasingly more and more concerned about her, and about our disabled father for whom she was the sole carer.

19. The scan was performed, and a radiologist at the West Cumberland Hospital told my mother that her scan had revealed an enlarged spleen. This was subsequently confirmed by letter, and the GP referred my mother to a Haematology Consultant, Dr. SAYALA at the Cumberland Infirmary in Carlisle.

20. Although she'd been referred to a haematologist, and understood that there was some sort of issue with her spleen, she still had no idea what the problem may have been or why she had been sent to see a haematologist.

21. Her appointment had been set for 19th June 2019, and in order to ensure that she could get there and back, and that someone could be with her to help (especially as her mobility was so poor), I took time off of work to accompany her.

22. Upon arrival we found that Dr. Sayala's office / clinic was located in the cancer department of the hospital, and we could see patients sitting receiving what we believed to be chemotherapy treatment as we went in.

23. This really frightened my mother and worried that she was merely there to be given 'bad news,' i.e. that she had some form of cancer, she panicked and wanted to leave, to get out of the hospital and go home, immediately. She waited outside as I went in to confirm that we had in fact arrived at the correct place – which we had – and I then had to go back out and persuade her to go in and keep the appointment. I literally had to drag her in to the hospital.

24. Dr. Sayala examined my mother, but offered no explanation as to what her problem(s) may have been. He too took a blood sample from my mum, *'for tests,'* but didn't tell us what they would be looking for. Having taken the blood, we were sent home, none the wiser and still undiagnosed and with no treatment, no explanation, and no treatment plan in place.

25. Following this visit to Dr. Sayala, her GP again told my mother that the blood test results, *"were normal,"* but now added that her *"Bilirubin was creeping up."* We had no idea what 'Bilirubin' may have been or what it 'creeping up' may have meant for her, but were reassured by the GP's practise that the doctors were *"looking for everything"* – we just weren't told what 'everything' was or what implications it may have had for my mother. Hepatitis C, HcV and or Hep' C was not and never had been mentioned.

26. As time went on with her condition passing apparently undiagnosed and untreated, the symptoms she was experiencing became progressively worse. She became virtually unable to walk at all, and was bed bound as a result. On at least one occasion when visiting a hospital, I had to push her around in a wheelchair as she had become so immobile.

27. One of the GP's eventually prescribed a medicine which was meant to alleviate the swelling – sadly it only served to make matters worse. The doctors were still apparently monitoring her condition closely and looking for an explanation, as they were taking blood from her *'for testing'* two or sometimes three times a week, but this was often as they apparently *'lost'* samples, or samples became lost and had to be retaken.

28. Unfortunately by this time, she had swollen to such an extent and had provided so many previous samples, that problems were being experienced accessing a suitable vein from which to take blood from her.

29. Finally, with no diagnosis given to her, she was referred to a Gastroenterology Consultant at the West Cumberland Hospital, Dr. GRO-D, an appointment having been set for 28th January, 2020.

30. During the course of this consultation, Dr. GRO-D told us that my mother had developed an autoimmune condition known as Primary Biliary Cholangitis (or 'PBC' for short). He explained to us that this was an irreversible condition which impacted upon her liver and its functions and that *all* of the issues my mother had been experiencing were directly attributable to her having PBC.

31. The doctor tried to explain it better to us by drawing a diagram, but it wasn't either very good or very successful, looking something like a tree branch, so instead of explaining himself better providing us with any relevant literature, he told us to *'google it.´*

32. My aunt had accompanied us to this appointment, and when told that mum had PBC asked the doctor of it could have been the result of my mother having been born *"a blue baby?"* but the doctor replied, 'no.'

33. None the wiser, my aunt and I tried to research PBC through the Google search engine, but found very little information. A nurse practitioner at our mother's GP's practise also tried, but again found little or no information on PBC that could help us.

34. None of the website searches we conducted for PBC returned any mention of HcV, but even if they had done, I would have discounted it as anything she could have had, as we all believed that she'd been tested 'for everything,' and as such the doctors would have already looked for it – or so we thought.

35. My mother was prescribed medication, Ursodeoxyxcholic Acid. Unfortunately, this had an adverse effect on my mother, causing her to experience chronic diarrhoea. She took it for a week, but then called the practise nurse for help and was told to cease taking it, so she did, but she wasn't offered any form of alternative.

36. Her loose bowels had been so bad that I had been compelled to purchase incontinence pads for her, as at times she couldn't even sit down without 'leaking.' At this time I also found myself having to take on the bulk of the care for my father as she could no longer do it.

37. The purchase of incontinence pads for my mother was embarrassing, having to then bathe my father was not just embarrassing for me, but degrading for both of us and made my mother feel helpless and hopeless in equal measure as she believed that looking after him was very much her responsibility and he had come to rely solely upon her. It was very upsetting for all concerned.

38. As time passed, from my mother's initial issues through to the time of her being diagnosed with PBC, she had slowly but surely become more and more jaundiced in her appearance, was unable to flex muscles or joints without a great deal of pain being experienced and couldn't sleep at night – although during the day she always appeared lethargic and tired, frequently falling asleep in a chair. She became so jaundiced that I took a photo' of her – it was so bad that she looked like Marge, the cartoon character in The Simpsons.

39. At her GP's practise, my mother had yet more blood taken *'for tests'* on both 13th February, 2020 and 17th February. Again we had to call them for the results but weren't told much, in keeping with that which we had always been told – PBC aside, everything was normal but they were checking for everything.

40. Her GP, Dr. GRO-B told my mother and I that in respect of treatment, each of the symptoms she was suffering had to be addressed separately. She was then referred to an Ear, Nose and Throat (ENT) specialist at the West Cumberland Hospital as regards her frequent episodes of nose bleeding.

41. On 5th March 2020 she was seen by an ENT doctor, prescribed a cream to use, and asked to return in three months' time, however things changed dramatically from that point onwards.

42. On 6th March 2020, feeling breathless and extremely tired, my mother went to see her GP's practiise again – she was severely jaundiced, still having nose bleeds and her body was really badly swollen from fluid retention. She didn't see her own GP but a Dr GRO-B. My aunt accompanied my mother to the surgery where Dr. GRO-B said that she was to go to the West Cumberland Hospital as she needed to be admitted, immediately.

43. She wasn't told why, and doesn't remember having been given any form or letter to take with her, but we believe that Dr. GRO-B either sent something on ahead of her, or called the hospital ahead of her arriving, as her arrival had been expected and she was immediately admitted to a ward.

44. Here she was examined and given medication to reduce the swelling. The medication given was successful, bringing down the level of fluid retention to a point where she could actually walk, albeit in slippers only and those two sizes bigger than she would normally have worn.

45. She was discharged on 10th March 2020, but even though as a hospital inpatient she was readily accessible to those who could have been treating her for the various problems she had, she wasn't seen by any, in particular no liver or spleen or haematology specialist examined her.

46. Although she wasn't seen over this period by an appropriate specialist, she was nevertheless asked questions about her lifestyle – questions no doubt framed to ascertain how she may have become so poorly.

47. She was asked if she was a heavy drinker, so clearly they were concerned about the condition of her liver and its function, but my mother does not drink, and never has. She was also asked if she was or had been an intravenous drug abuser, again she was not and never had been. She did smoke, and always had done, and she told them that, but that aside held no vices.

48. On the day she had been diagnosed with PBC by Dr. GRO-D, she had also been asked these questions, and had given the same responses – my mother has always been a hard-working, clean living woman, but the questions caused me to ask questions of my mother outside of the consulting room, questions I never thought I'd find myself having to ask, but I too sought the source of her ailments and asked whether she had used drugs, been a drinker, or conducted herself promiscuously, although I knew the answer was 'no' on all counts, which she confirmed. It was extremely embarrassing for us both.

49. On the day of her hospital discharge, we were told that the condition of her liver was 'worsening,' and appointments were made for her to have undergo both endoscopy and sigmoidoscopy procedures on 19th March 2020 at the West Cumberland Hospital.

50. We were told that the sigmoidoscopy procedure was to examine her following the discovery of blood in her stools, bleeding which we knew to have started when she was placed on the medication aimed at tackling her PBC – which she had to stop taking after just a week.

51. My mother underwent both procedures, but was given no results at the time. Both procedures were conducted as 'day cases,' and she was released home to await the outcome. On 22nd April 2020, my mother was at home, alone (apart from my father), when she received a telephone call from Dr. GRO-D.

52. The doctor told my mother that her liver condition was such that it could not be treated and that the only way forward was a liver transplant. She was told that she was being referred to The FREEMAN HOSPITAL in Newcastle-Upon-Tyne for a consultation with a liver transplant specialist.

53. Apparently the doctor had been very blunt with my mother during the course of this call, brief and to the point with no explanation given beyond that I have mentioned above. In previous appointments whilst accompanying my mum, I had asked Dr. GRO-D to explain what was happening with her and outline the treatment options which may have been available, but he didn't offer any explanation or treatment plan.

54. I do not think that it was appropriate to deliver such grave news as this to my mother, by 'phone as opposed to 'in person,' and by means where it would not have been known if she had anyone with her to offer support. I subsequently queried this, only to be told that due to Covid-19 restrictions on surgery use and personal contact, this had been the only means available, but all the same my mother and I believe that this was wholly unsatisfactory under the circumstances.

55. My father knew that his wife was unwell, but did not know and hadn't been told the extent as we did not want to cause him any additional distress or alarm – he had been left disabled following his stroke, my mother was his sole carer and we felt that any additional worry could have had an adverse impact upon him, so he hadn't been told. We didn't tell him of the liver transplant requirement as we feared that had we have done so, he may have suffered another stroke.

56. My mother was given an appointment to see the transplant surgeon on 21st May, 2020 and received a letter to this effect showing that she had to attend The CRESTA CLINIC in Newcastle-Upon-Tyne (*not* The Freeman Hospital).

57. I accompanied her to this consultation having again taken a day off of work in order to do so – otherwise, my mother may not have been able to attend, she lived on the N.W. Coast of England and the clinic was in a city by the N.E. Coast on the other side of the country to her, a two and a half hour drive away. She was also really worried and still experiencing mobility problems.

58. We drive to Newcastle and found the Cresta Clinic, only to find out upon arrival that we had been sent to the wrong place – the letter was incorrect, the consultant didn't have a clinic at this location, we should have been directed to the Freeman Hospital as we had initially been told.

59. Neither of us knew Newcastle, or where we had to go, so we needed redirecting, then drive for 40 minutes across the city until we found the hospital. Consequently, she was late for her appointment. A lot more care needed to have been taken by those responsible for drafting the appointment letter to my mother – when you are at a low ebb, in particular worried as to your future, little things like can become major issues and my mother and I were not in a good place emotionally when we finally arrived at The Freeman Hospital.

60. Dr. Jessica DYSON was the gastroenterology and liver specialist under whose care my mother had been placed. She was brilliant, and from the very outset of our meeting apologised for the problems we had experienced travelling to see her. She also apologised for the length of time it had taken for my mother to have been referred to her, inferring that she should have been her patient much earlier than she now was.

61. She asked us if we had been given any explanations of my mother's condition. Telling her that she had received no information, the doctor explained to us that she had been referred following a diagnosis of PBC and that her liver damage was, as feared, irreversible and as such untreatable.

62. Dr. Dyson told us that my mother had cirrhosis of the liver which she described as having reached 'Stage 4.' We didn't know what Stage 4 was, but she explained its gravity and the fact that the organ was in what she described as having been the *"final stages of its life."*

63. The doctor said that the only option for my mother was for her to receive a liver transplant – otherwise her liver would fail causing problems which could not be treated. In short, she would die. She was very clear with the information she gave us, but not blunt in her manner and showed a very caring attitude towards my mother and I whilst delivering this shattering news – we had hoped that we'd be told something more positive, but that didn't happen.

64. Jessica Dyson explained that prospective liver transplant patients had to be screened prior to any surgery taking place, to ensure that they were fit and able to receive the organ and that the operation and its success would be viable. As such, my mother would have to attend for an assessment and she told us that this consisted of various parts, each of which she had to pass.

65. At this time, my mum was very unwell and in a poor physical condition, for example, her mobility had been reduced to a point where she was no longer able to climb stairs, and was sleeping on a sofa on the ground floor as a consequence.

66. I feared that she would fail the assessment, and as a consequence would not be a suitable candidate for a transplant and would therefore die. In worry, I asked Dr. Dyson if it were possible for her to receive just part of a liver – I understood that the liver was an organ that could regenerate after impairment, so I asked if it was possible that she could be given a healthy piece of liver to replace that of hers which was damaged?

67. I was so desperate that I offered the surgeon part of my liver to my mum. I was prepared to do anything to keep my mother alive even if that meant losing a part of my own liver. In any event, I was then due to undergo surgery myself, and felt that whilst I was being operated on, it would be relatively simple to remove some of my liver and transplant it into my mother, as both my remaining liver and that given to her would regenerate.

68. Sadly this wasn't possible, as the doctor explained to us during this meeting, but she let me down very gently – we were both left with a feeling of fear, fear that she would fail the assessment and of the consequences of her not receiving a transplant. We told other immediate family members, but didn't tell my father, perhaps he should have known but we had to weigh up his knowing, and what he may have understood of what was going on, against any adverse impact this may have had upon him. I genuinely feared that I could have lost both of my parents.

69. On 11th June 2020 my mother returned to Newcastle and Dr Dyson's clinic. At this time I was in hospital myself, undergoing surgery for an unrelated issue, so one of my brothers accompanied our mum. They were there for a considerable period of time, undertaking the assessment which I believe to have consisted of seven separate investigations or 'stations' around the hospital within each of which she was examined for different capabilities or conditions. These examinations included blood and urine samples being taken.

70. They were there from 8.00a.m. until 5.00p.m. which was an extremely long time for a lady in her condition, especially when adding on a two and a half hour journey to either side.

71. A few days after the assessment, the Freeman Hospital Transplant Co-Ordinator, Peter ROBINSON-SMITH telephoned my mother with the assessment results. Again, in my view this should have taken place 'in person,' but can understand why it wasn't – he told her that he had 'phoned to save her a five hour round trip just to receive bad news.

72. Mr. Robinson-Smith told my mother that she had failed two elements of the assessment and as such was not eligible for surgery. In giving her this news, he told her that one of the blood test results had shown that she had Hepatitis C, something which alone was a bar to any organ transplant.

73. We were all worried as to what would now happen, and when, and were rather taken aback by this new diagnosis of 'Hepatitis C,' something which had never been mentioned before – despite repeated blood tests having been conducted through the GP's and other hospitals, surely it should have been detected earlier?

74. We also received a telephone call from a Dr. GRO-B of my mother's G.P.'s surgery who told us that our mum had tested positive for HcV and that it had been one of the things those commissioning the tests had specifically looked for.

75. On 25th June 2020 we returned to the Freeman Hospital for a follow-up appointment (post-assessment) with Dr. Dyson. Again we had received a letter detailing the appointment date and time, and again it directed us to the wrong place (the Cresta Clinic), but having been misdirected once, we ignored it.

76. During the course of the consultation with Dr. Dyson I told her of my concerns for the manner in which my mother had been given the assessment results, by 'phone, for which she apologised, accepting that it was not ideal.

77. Jessica Dyson asked us if my mother had ever been an intravenous drug user and when she answered 'no,' if she had ever had a blood transfusion? We told her that she had been born a 'blue baby,' When she heard this, Dr. Dyson said that as a 'blue baby,' it was highly likely that she had been given a blood transfusion immediately post-delivery. She explained that back then (my mother was born in 1956), blood used for transfusion was not routinely screened, and said that she was surprised that my mother had not been checked for Hep' C previously.

78. I told her that we had told Dr. GRO-D of my mother having been born as a blue baby but that he had dismissed it as having anything to do with her illness(es). Dr. Dyson clearly disagreed, and told us that it should have sounded alarm bells from the outset.

79. We were told that Hepatitis C could be treated and that if treated my mother's health may improve, and could improve to a position where she would no longer require a liver transplant and emphasised the need for her to commence HcV treatment as soon as possible.

80. Dr Dyson also told us that my mother's fluid retention had been due to her taking fluids at a time when she had been prescribed fluid retention medication. Her intake should have been regulated and monitored as all that had happened was that she had inadvertently made matters worse – none of her previous doctors, in either hospital of GP settings had explained this to her (or us).

81. Dr Dyson prescribed a spray which she could use to moisten her mouth and lips rather than drink something as and whenever she became thirsty. It was from this point that we understood what was required to help my mother, and we began to start seeing results almost immediately.

82. We were also advised by Dr. Dyson that my brothers and I should all be tested for Hepatitis C infection. One of my brothers and I were tested – and both found to be negative, whilst my eldest brother has yet to submit to testing. We have not caused our father to be tested as we are unsure as to whether or not HcV can be passed on through intimate contact. He is not currently receiving any form of treatment, and as such it may not have become apparent through other means.

83. My mother had three children, all delivered without issue. She then underwent a sterilisation procedure at the West Cumberland Hospital, but these matters aside, had never required hospital treatment or care until this all started just a couple of years ago. She has no tattoos, does not drink, hasn't used drugs or led a promiscuous lifestyle.

84. Accordingly, my mother, brothers and I all believe that having been born as a 'blue baby,' as Dr. Dyson said, she was most probably given blood at birth, unscreened blood that was contaminated with Hepatitis C – something which lay dormant within my mother for many years and which was only uncovered at a point in time when it had already caused irreparable damage to her liver.

85. One more possibility exists, that her mother, my grandmother (GRO-B GRO-B) received a blood transfusion whilst pregnant with my mother, an issue I will discuss further within this statement as I have a document which tends to support this possibility.

86. Either my mother having been given blood at birth, or her mother having been given blood whilst carrying my mum are the only two possible sources of her HcV infection.

Section 3 - Other Infections

87. I do not believe that my mother has received any infection other than HcV as a result of her having been given infected blood, although with it having lain dormant for so many years, and then passed undetected despite medical examination and blood testing, I cannot rule out this likelihood.

Section 4 - Consent

88. My mother has always been treated with her consent, although she may not have known to what extent that consent was extended – she would willingly attend a GP or hospital appointment, and take whatever medication she may have been prescribed, but wasn't always given an adequate explanation of what any given medication may have been, what its use sought to achieve and how, or what any side effects may have been arising from its use

89. In so far as 'tests' are concerned, blood was regularly taken from my mother, on some occasions two or even three times per week – she willingly gave blood, as she wanted to help the doctors determine what may have been wrong with her, but she was never told what her blood was being tested for, even when it came to the liver transplant assessment, hence the HcV diagnosis having come as a surprise to us all.

90. Communication throughout her treatment, such as it was, was awful until such time as she came under the care of Dr. Dyson – there was a marked difference between the hospitals in Carlisle and Whitehaven and that in Newcastle, the latter being by far superior in the manner in which they dealt with patients and thee information patients were given.

91. I can only summarise by saying that consent was given, but not what could be considered to have been informed consent when it came to testing.

Section 5 - Impact

92. The past few years have proven to be extremely difficult for my mother, our family and I. A part of me wonders if it may have been easier to deal with had her various symptoms arisen gradually and over a more protracted period than they did. Everything seems to have happened so suddenly – at first I just thought it was my mum just getting older, becoming less able to cope, her physical fitness starting to drop and so on.

93. I also believed that she may have been becoming depressed with the situation she was in, having to care for my dad and him being disabled. I even began to doubt what she was telling me, or thought that she might have been 'putting it on,' at times. This has left me feeling terribly guilty, knowing what I do now, for having doubted her because it was actually quite evident that she was unwell and was getting progressively worse throughout.

94. Prior to her HcV diagnosis, we found that the almost constant trips to and from the GP's surgery or hospital(s) was becoming increasingly more frustrating – each time being sent away, each time blood being taken for testing, each time a result that was apparently 'normal,' when throughout her condition was deteriorating in the absence of any diagnosis or treatment plan.

95. We all found it very stressful and my mother was genuinely becoming depressed with the position she found herself in , at one time telling me that she felt like jumping off of a cliff 'to be done with it.'

96. Over the past eighteen months my mother has appeared so tired, from both the health perspective and with life. I became genuinely worried that we would lose her and was desperate to ensure that she remained very much alive, but it was very hard watching her deteriorate before you and frustrating that no one seemed to know why.

97. My parents had always been a sociable couple until dad suffered his stroke, but even then mum remained socially active, seeing friends, going to bingo once a week to socialise and enjoy herself – she had to give all of this up, lost her social circle and had to satisfy herself with contact from immediate family and friends only as her health went downhill and then once she was confirmed as having Hepatitis C.

98. It isolated her at a time when she really needed the release of a social life as she had given up work to care for dad, and he was needing increasingly more attention, all of which she provided as his sole carer without any external support.

99. My brothers and I and our respective families are fairly tight-knit and private in our ways, so we only ever told immediate family or very close friends – people tend to gossip, especially where they don't know what's going on, but we tried to keep ourselves to ourselves, especially as once diagnosed with HcV my mother didn't want people to know as she felt it was somehow 'dirty.'

100. Even so, we experienced situations where people noticed my mum, saw the condition she was in, bloated, jaundiced, immobile and would pass comments such as, *"What's happened to* GRO-B*?"* and *"She looks bloody awful."*

101. There's little worse than someone staring at you and passing adverse comment on your appearance and my mother found it very hard to deal with and as time passed by and she worsened, only went out to go to the surgery or for a hospital visit.

102. I believe that I was extremely fortunate throughout this period – not only was I blessed with a supportive husband and family, but my employers were fantastic. I had to take a lot of time off in order to accompany mum to appointments, but they never once said 'no,' and my boss never asked for too much detail, they understood that I had a lot on my plate and were happy to help where they could, which made things a little easier for me. I dread to think what it would be like for those with less sympathetic employers.

103. As I stated earlier, whilst this was all happening with my mother, I was experiencing my own health issues and had to undergo kidney surgery whilst looking after my mother and father – attending to my father's needs as my mothers' health waned and then caring for both. I was taking both for medical appointments, cooking and cleaning for them and all the time looking after my own family whilst being in full time employment and a mother myself. It was an extremely taxing, debilitating time and came when I was myself, unwell.

104. The care for our parents wasn't equitably addressed, the bulk falling to me as I lived the closest and my brothers weren't inclined to assist to any great extent. As I was closest to her, when mum fell ill they all came to me with their questions, but I simply didn't have any answers and she didn't know anymore than I did – we'd been given very little information (until she came under the care of Dr. Dyson) and didn't know where to look for more. I had been unable to find anything of any real use on the internet re. PBC and didn't have any other condition to research until she was told of her HcV infection. It was a very frustrating time for us all.

105. I've also incurred costs a well as having lost time at work, driving to and from the various appointments she had, cooking additional food and so on, but I don't really mind, it's all been for my parents and for the good of us all and I am fortunate to have a husband in full time employment and I have a well-paid job myself.

106. There has also been an impact upon my ability to function as I may otherwise have liked, as quite often I have to rise early and have been unable to retire until 11.00p.m. to midnight, which leaves me quite tired, something which along with the kidney operation has been less than ideal.

107. My husband and I have a young daughter who is very close to her grandparents, in particular as they cared for her when she was very young and I went back to work having had her. She could tell that her grandmother was gravely ill, but my husband and I didn't tell her the extent of her illness or the possibility of her having to have a transplant. It upset her and she showed her worry by asking to sleepover at their house all of the time. This progressed to her not wanting to go to school, as she wanted to stay with her grandmother.

108. I found this very difficult to deal with and to find an adequate explanation of what was happening for her. It made me think of how I would address the situation if she lost her grandmother, how I would tell her, what I could say. It all served to provide for an additional worry for me at what was an already very worrying time.

109. However, since my mother commenced treatment for HcV, we have at last some hope, hope which has lifted our spirits and for the first time offered the possibility of a positive end to it all. She has done her bit – stopped smoking and knuckled down to exercising each day whilst sticking rigidly to the treatment plan.

110. In just a short period of time we have noticed improvements, her physical and mental health have each improved to a point where she recently walked the mile from her house to mine, then a further mile taking our dog for a walk, something which would have been impossible just a short time ago. She has also started to see people again socially, albeit on a limited scale.

111. Having told my mother that she needed to start the HcV treatment straight away, Dr. Dyson called a halt to our consultation and directed us into another room in which we saw a Hepatitis C Nurse Specialist, Carolyn MILLER. This lady explained to us what medication was available for my mother to take to treat her Hepatitis C, and the potential side-effects she may experience from their use.

112. The nurse was brilliant - caring and clear in her explanation leaving us knowing exactly what to expect. She was told that the treatment was a thirteen week course and she created a table for my mother to follow showing what needed to be taken and when, tailored to mum's needs. She additionally explained how the Hep' C treatment tablets would interact with water tablets she was then taking, and how to avoid any unwarranted complications from taking both. She also gave dietary advice and was generally very helpful, knowledgeable and kind.

113. Carolyn Miller also provided details of an emergency contact and aftercare, putting us in touch with another specialist nurse, Ruth HARRINGTON who worked at the hospital in Whitehaven – GRO-B GRO-B. We were told that whilst on the treatment course, progress would be monitored through Whitehaven by Ruth Harrington by way of fortnightly blood tests – to ensure that the treatment wasn't having an adverse impact upon mother's liver or immune system.

114. We left the hospital in a very positive, if anxious mood, hoping that the drugs would work but not knowing of they would or not. She then commenced a course of Epclusa and Ribavirin as a combination treatment.

115. Within about a month and a half of commencing treatment, we all began to see a marked improvement in her health. Her jaundice had reduced considerably, as had the swelling and she could move a lot better. She could now target 10,000 steps per day as an exercise goal, something she very quickly began to achieve.

116. She was fortunate not to experience the more impactive side effects we had been warned of, although she did find herself feeling nauseous and often found herself feeling cold.

117. The feeling of wanting to be sick was the worst of the side effects she experienced, and after about two months on the combination treatment, caused her to question if she could, or should carry on as it made her feel quite unwell, but she was reassured and carried on, being told that if she were sick in the morning, then to take the dose again – unfortunately she was ok in the mornings, but felt more and more nauseous as the day went on, often feeling the worst at tea time.

118. The main issue, feelings of cold and nausea aside, was with her condition being monitored. We had been extremely well cared for in Newcastle, but once the monitoring aspect of her treatment was transferred to the West Cumberland Hospital (Whitehaven) and to Ruth Harrington, things were less efficient.

119. My mother was meant to have been monitored every two weeks, with blood taken for testing through Whitehaven and her care managed by Specialist Nurse Harrington. However, perhaps due to Covid-19 restrictions on people attending the hospital (which I do not know for a fact), this didn't happen. Her appointments were frequently cancelled by Ruth Harrington, so she didn't see her at all during the course of her treatment. She did attend the hospital for one appointment, where she saw Dr. GRO-D, and another nurse saw my mum on an outpatient basis, but that was it, no one was monitoring her progress or otherwise.

120. We were all very worried by this and didn't want her to be taking medication that wasn't working or which could have been making matters worse for her, none of us wanted her to end up having to be admitted, but we were all reassured by what we could see even if we didn't have medical confirmation of it – we could see that she was getting better.

121. When Dr. Dyson referred us for HcV treatment and passed us on to Carolyn Miller, she had also referred my mother to a Dr. Stuart Mc.PHERSON, a Consultant Haematologist at the Freeman Hospital. This was because she discharged my mother from 'her list' (as she was no longer a candidate for liver surgery) and had passed her care to a colleague specialising in the treatment of blood disorders such as Hep' C.

122. Her first appointment with Dr. McPherson coincided with the last week of her Epclusa – Ribavirin treatment. I again accompanied her to Newcastle where she was examined by Dr. McPherson who told us that he was generally pleased with her physical appearance but that she remained a little jaundiced still. Compared to how 'yellow' she had been, this was such an improvement that I was barely able to see any evidence of jaundice at all.

123. She had an Ultrasound Scan (which I presume to have been on her liver), an Electrocardiogram (ECG) and blood was taken for testing. Two further appointments were made: for her to be seen on 5.1.2021 to see a specialist hepatology nurse and then Dr. McPherson on 14th January. We were told that blood would be taken, tested and the results known by the time she saw Dr. McPherson. This was to assess whether or not she was clear of HcV. Apparently tests conducted at the appointment time were encouraging, but that a further test would be required for confirmation, or not.

124. The whole affair has been emotionally draining and traumatic for my family and I, let alone my mother. However, the treatment she was given appears to have worked so there is hope – hope that she is now clear of Hepatitis C, and hope that if that is the case then her overall improving health condition may make her a suitable candidate for a liver transplant. It may be the case that if she *is* clear of HcV, then the medication she received may have caused improvements to her liver which could negate the need for a transplant, but these are all unknown points at this time.

Section 6 - Treatment / Care / Support

125. My mother never received and was never offered any form of psychological support through counselling – either when eventually diagnosed, whilst undertaking HcV treatment, or in the period she now finds herself in, between treatment and finding out whether or not she has actually been cleared of infection.

126. We feel that access to counselling would have helped, but that it is now most probably too late for us, as we have learned a lot over a relatively short period and support one another. However, our not yet knowing the outcome of her treatment, and even then whether or not that may be favourable, or not and what the future may hold for my mother (i.e. does she still need a transplant or not), may mean that she would benefit from some support of this nature – only time will tell.

Section 7 - Financial Assistance

127. Dr. Dyson copied my mother into a letter sent to her G.P. in which she summarised her care to the point of her being referred for treatment through Dr. McPherson. Within the letter she mentioned that as a result of the manner in which my mum had been infected (in her opinion, when given blood at birth as a 'blue baby'), she may have been entitled to compensation through the England Infected Blood Support Scheme (or EIBSS).

128. I researched the scheme, downloaded the application forms available through their internet site, and sent them to Dr. McPherson to complete in so far as the medical aspects of the application were concerned. Unfortunately, he only completed the forms for a Stage Two Application, and as we hadn't submitted a Stage One Application we haven't yet submitted what we have – as we are confused as to what is actually required of us at this point in time.

129. We have been given details of those who may be able to assist us, e.g. the Hepatitis C Trust, and will pursue this further, but at this moment in time, no applications have been submitted and no payment(s) received.

Section 8 - Other Issues

130. The EIBSS application forms stated that we had to find out how my mother had contracted Hepatitis C, and so I contacted The Cumberland Infirmary (Carlisle) to request copies of my mother's medical record, but the hospital told us that not only did no records exist for my mother, but they had none for my maternal grandmother either. In their eyes, it appeared that neither person actually existed.

131. Having been told this, together with an aunt I started doing some digging myself, and submitted a Freedom Of Information (FOI) request to the hospital in Carlisle re. both my mother and grandmothers records and on 2nd October, 2020 submitted an FOI request to my mum's G.P.' practise – we await the result of all applications at the time of this statement having been made.

132. Whilst searching various items of correspondence which may have proven helpful, we found the certificate / letter / card of the National Blood Transfusion Service which we believe shows that my grandmother (GRO-B GRO-B), whilst pregnant with my mother (when about 5 months into the pregnancy) had received blood.

133. This card appeared to be one that she had to carry, showing her blood group, the fact that she had been given a blood transfusion (we believe on 19th May, 1956) and alerting any other medical professionals who may have needed to know thereafter, that this is what had happened.

134. Finding this card, and my mother understanding that she could have been infected prior to having even been born, had a devastating impact upon my mum, and she finds it extremely hard to talk about it, or of her having been a 'blue baby,' breaking down in tears. She finds it extremely upsetting to think that her mother may have been the source of her infection, through no fault of her own.

135. She is also distressed to know that she had been infected for such a long time, a period during which she met and married her husband and in which she went on to have three children. She worries that she may have exposed our dad and us to infection, but she simply wasn't to know and I doubt very much if her mother was aware of what had happened. All the same, in some manner or form *she* feels that *she* is the guilty party.

136. The worries she has had caused her to think of other things which may have happened, and this caused her to consider HIV / AIDS, and her having possibly been infected with this ailment – she had no cause to worry about this on account of her lifestyle, but she came to understand through the research we conducted as regards the issue of infected blood, that she could well have become infected. It plays on her mind.

137. The entire issue has let me feeling extremely frustrated, angry and disappointed – we rely upon so called specialists to care for us when problems arise, but at no point over numerous visits to her GP or hospital was HcV mentioned, let alone considered as a possible problem, or diagnosed. It took many months, and a referral to a different hospital in a different part of the country to finally find out what was affecting my mother so badly.

138. Had my mother not been referred to a specialist at the Freeman Hospital, in Newcastle-Upon-Tyne, her condition would have deteriorated further and she may well have died. It seemed to me that the service provided by the National Health Service in the North West was inferior to that available in the North East which I find wholly unacceptable.

139. Whereas I cannot fault the care I have myself received through my G.P. or particularly at the Cumberland Infirmary, I am unable to say the same for my mother. Sadly, the West Cumberland Hospital in Whitehaven had developed such a poor reputation of recent years that when it came to my having to select a hospital in which to undergo surgery myself, I opted for a hospital in Blackburn, three hours away from my home by car, rather than GRO-B GRO-B the West Cumberland, due to its declining reputation and the experiences of my mother.

140. I believe that had my mother's HcV infection been detected sooner, then her liver may not have been subjected to the degree of damage as later became evident it had – it would have saved us all a lot of worry, heartache and the continuing concerns we have for her future. I feel that opportunities to diagnose Hepatitis C infection were missed, repeatedly whilst her blood was being tested and especially as she began to present herself before the doctors with a progressively more jaundiced appearance.

141. A lack of confidence in the NHS, arising from the way in which she initially became infected, and then as a result of how she has been treated (until coming under the care of Dr. Dyson) leave me with a major concern - that if declared 'clear' of HcV, and hopefully with a recovering liver, appropriate monitoring may cease. I'd like to see a programme put in place through which she will be monitored to ensure that any recurrence may be detected at the earliest opportunity and dealt with as quickly as possible.

142. In order to assist The Infected Blood Inquiry, I now produce as exhibits, copies of documents related to my mother and her treatment, and my grandmother GRO-B, these items being:-

143. **EXHIBIT WITN5208002** - A copy of the birth certificate regarding my maternal grandmother, GRO-B (GRO-B) and her death certificate in the name of GRO-B GRO-B (GRO-B).

144. **EXHIBIT WITN5208003** - A copy of a National Blood Transfusion Service card, issued to my grandmother, GRO-B, and dated 19.05.1956, showing that she was of blood group A Rh Negative and had received a blood transfusion or been tested on that date – this being at a time when she would have been in mid-pregnancy, carrying my mother.

145. **EXHIBIT WITN5208004** - Four pages of typed notes I prepared, in consultation with my mother and through inspection of documents re. her health and treatment which she has retained, which contains information used for the purposes of responding to a Rule 9 Notice with which she had been served by the Infected Blood Inquiry.

146. **EXHIBIT WITN5208005** - A copy of a letter dated 13th May, 2020 from the Appointments Officer, Newcastle Upon Tyne Hospitals, directing my mother GRO-B to an appointment at the Cresta Clinic (Newcastle Biomedical Research Building, Campus for Ageing and Vitality, Westgate Road, NE4 6BE) at 11.30a.m. on 21st May, 2020. This was the wrong location – she should have been directed to the clinic of Gastroenterology & Liver Consultant, Dr. Jessica DYSON at the Freeman Hospital (Freeman Road, High Heaton, NE7 7DN).

147. **EXHIBIT WITN5208006** - A copy of a letter originating from a consultation held on 21st May 2020 (i.e. that mentioned above) with Dr. Dyson, addressed to Dr. GRO-D (Locum Consultant Gastroenterologist at the Cumberland Infirmary, Carlisle) and copied to Dr. GRO-B (of GRO-B GRO-B – my mother's general practitioner) and my mother herself.

148. This exhibit includes a summary of the issues my mother had faced leading into this appointment, their treatment and enquiries made of her condition together with the results. It also includes comment by Dr. Dyson that, *"She does not seem to have any other significant past medical history of note. There is no history of alcohol excess ….."*

149. **EXHIBIT WITN5208007** - A copy of a letter originating from a consultation held on 25th June, 2020 with Dr. Dyson, addressed to Dr. GRO-B and copied to Dr. GRO-D, my mother, and Sister Ruth HARRINGTON, Specialist Viral Nurse of the Cumberland Infirmary, Carlisle

150. This letter includes a summary of my mothers' condition at the time of examination and leading into that time, showing past investigations conducted and the results of tests undertaken as part of the consultation with Dr. Dyson held on 21st May 2020 and as an integral part of a liver transplant assessment my mother underwent.

151. This letter, at its item numbered '19' shows a *"New diagnosis of Hepatitis C at a time of transplant assessment (serology not previously checked) – genotype 1B and pre-treatment viral load of 116,700."* At item '20' the author notes that my mother had returned test results as Hepatitis B and HIV negative.

152. Dr. Dyson also writes that fluid retention issues she was experiencing had improved through use of Furosemide (since the date of the previous consultation), with increased mobility a result – this having been a course of treatment she had not previously been offered whilst being treated elsewhere.

153. Two major issues, each acting as a barrier to her receiving a liver transplant were apparent and noted, her overall health and mobility, and the fact that she had been found to have Hepatitis C.

154. The consultant, in detailing her findings, states that, *"I suspect she has had Hepatitis C for a long time, but it has just not been checked previously. In terms of possible routes of acquisition, the only thing we could come up with was that she describes having 'blue blood' at birth and had some form of exchange of her own blood. I do not know if this is a transfusion at birth, before the time of blood being screened for Hepatitis C. This potentially will mean they are entitled to compensation if this was a blood transfusion acquired infection. She has no other obvious risk factors for Hepatitis C."*

155. As a result of the Hepatitis C diagnosis, the letter details how my mother was then to be seen by the viral specialist nurse, Ruth Harrington and that she would then commence treatment with Epclusa And Ribavirin.

156. Dr Dyson commented that, *"She has a good chance of being cured from Hepatitis C with the direct acting antivirals that are now available. This will be a twelve week course with somewhere in the region of a 90% cure rate. We may see an improvement in her liver synthetic function with treatment, which is to be hoped, but it may be unlikely that we will see improvement enough to remove the need for liver transplantation."*

157. My mother and I now understand that Hepatitis C has been present over such a protracted period, undetected, to have caused irreversible liver damage, with her liver function having deteriorated to such an extent that the only way forward for her is through a transplant. However, in order to have the transplant she needs to be both fitter and clear of Hepatitis C.

158. The letter also shows that following this consultation, my mother was referred on to a Dr. McPHERSON, a hepatitis specialist for 'follow-up.'

159. **EXHIBIT WITN5208008** - A copy of a letter dated 26th June 2020 showing that Epclusa and Ribavirin treatment commenced on 29th June 2020. The text notes that Epclusa consists of either Sofosbuvir and / or Velpatasvir and shows how the drugs are to be administered and possible side effects. It came from Dr. Dyson and was addressed to Dr. GRO-B (being copied to my mother and Ruth Harrington, the specialist nurse at the Cumberland Infirmary).

160. I have included within this exhibit, a copy of an email dated 1st July 2020 showing my mother having been discharged by Dr. Dyson and referred on to Dr McPherson (referred to as 'Stuart').

161. **EXHIBIT WITN5208009** - A copy of a letter originating from a consultation held on 25th September, 2020 with Dr. McPherson (Consultant Hepatologist, Freeman Hospital) in which he details his review of my mother as she completed her twelve week course of Epclusa and Ribavirin treatment.

162. The content of this letter at last offered some hope to my mother, as it suggested that the treatment had been successful and cleared her of Hepatitis C, but that this would have to be further assessed some three months hence through further tests – to confirm this suspicion.

163. It also showed increased mobility and improvements with her fluid retention (a result of other medication being taken) and the possibility that her liver was re-compensating as a result of the anti-viral therapy given. Dr. McPherson suggested that were the re-compensation to continue, a liver transplant may no longer be necessary – but that this would be assessed once the result of the further tests were known and the results of a liver ultrasound scan were known (to be conducted with the further tests). These will be undertaken in 2021.

Statement Of Truth:

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

Signed: GRO-B

Dated: 23.03.2021