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	Statement No.	WITN4282001
	Exhibits:	WITN4282002 to
		WITN4282005
	Dated:	16 1 April 120201
	INFECTED BLOOD INQ	UIRY
	WRITTEN WITNESS STATE	MENT OF
	GRO-B	
I, provide this stateme Rules, 2006 dated 14 <sup>th</sup>		ade under Rule 9 of The Inquiry
l, GRO-B	will say as follows:-	
1	d	
Section 1 - In	<u>itroduction</u>	t I prefer to be called GRO-B , I was
Section 1 - In	i <b>troduction</b> e is GRO-B bu	nt I prefer to be called GRO-B I was and currently live in North West
Section 1 - In  1. My full name born in GEngland.  2. GRO-B is a divorcee. I here	troduction  e is GRO-B but  RO-B On GRO-B 1959  my maiden name, but I have nave four children, three sons I two miscarriages, one eithe	

- 4. I intend to speak of my infection with Hepatitis C (also known or referred to as HcV and / or Hep' C) and in particular how I believe I became infected, the nature of the illness as it affected me, the treatment I received with a view to clearing me of this disease, and the impact it has had on my life.
- 5. I will also detail my engagement with my local member of parliament, whom I approached for assistance together with contact with the Skipton Fund, and their dismissal of an application I made for assistance.

# Section 2 - How Infected

6.	In about	1981, I suffered the first of two miscarriages. At the time I had been
	living at	GRO-B
	(my first	marital home), with the closest National Health Service hospital
	with an	accident and emergency department having been Lancaster
		At this time my General Practitioner (G.P.) service was provided,
į	by either	a Dr. GRO-B or Dr. GRO-B of the GRO-B
	GRO-E	<u> </u>

- 7. I suffered a haemorrhage and was bleeding heavily, so much so that an ambulance had to be called for me and I was rushed into Lancaster General for treatment.
- 8. Whilst *en route* to the hospital, I was found to have been bleeding so heavily that laying on my back, my legs were raised and a pillow placed beneath me in an effort to stem the flow.
- 9. Whereas I cannot remember too much of what took place, I know that I was taken through 'A & E' and straight into an operating theatre for emergency treatment. Everything took place in a great hurry, but I was given a general anaesthetic before any intervention took place, which may account for my memory of what occurred being somewhat vague.
- 10. This had been my first pregnancy, and the situation was very traumatic. Once in theatre, I had to have an emergency dilation and curettage operation (referred to more commonly as a 'D and C'), and lost the baby I had been carrying.
- 11. Despite the circumstances, I wasn't kept in hospital for any length of time, and was discharged the following day. Although I was young, and this had been my first pregnancy, I wasn't told a great deal by the hospital staff and wasn't offered any form of emotional support, advice or counselling.

- 12. I cannot now recall whether or not I was told if I had been given a blood transfusion whilst in the operating theatre or immediately thereafter, and as I was placed under anaesthetic almost as soon as I had arrived at the hospital have no recollection of this having taken place, but in some manner or form the amount of blood I had already lost, at home, and then in the ambulance, would have had to have been addressed.
- 13. Accordingly, whereas I do not know it for a fact myself, I have always believed that I was given a blood transfusion in Lancaster General Hospital at this time. I have discussed this with various others since, including other doctors and nursing staff who have been treating me, and they are all of the same opinion I had to have been given blood or I may well have either bled to death or suffered other complications for want of sufficient blood circulating within me.
- 14. I fell pregnant again, and in GRO-B gave birth to my son in the GRO-B GRO-B
- 15. The pregnancy did not progress well, and I suffered from pruritus (extreme 'itchiness' caused by an irritation of the skin) and jaundice. I also experienced water retention and bloating issues which gave rise to concerns as to the likelihood of pre-eclampsia. The itching used to drive me mad as at times it was unbearable.
- 16. The pregnancy ran its full term (in fact a little over the same), and after the birth I was found to be severely anaemic, which had to be treated. My blood was tested to assess my iron levels regarding my anaemic state, but I do not know, and was not told of anything else it may have been tested for.
- 17. I am pretty sure but can't be certain as it is now a long time ago that my blood was tested during the course of this pregnancy, as a matter of normal pregnancy monitoring, but I can't say what it may have been being tested for, or if anything other than my having been pregnant was suspected in light of my skin irritation, jaundice, water retention and bloating. I was never told anything of this nature by those treating me.
- 18. I gave birth to my second son in 1985, but in the period between these births, I again suffered incidents of ill health and my second miscarriage.
- 19. I developed gallstones, something which I considered to be very unusual I was young (only 24 years of age when diagnosed), kept myself generally fit, ate healthily and was slim, I simply didn't present myself as someone who would be likely to develop gallstones.

20. My. General Practitioners of the time. Dr. GRO-B and Dr. GRO-B of the GRO-B between gallstones and those using the contraceptive pill, and as I had been on 'the pill' since the age of fifteen (a result of my suffering with heavy periods), they believed that this could have been the reason the stones had developed.  21. On and off, I have taken both the combined pill and 'mini-pill' over many years.  22. I also had an issue with my appendix, and required surgery to remove it. Both my appendix and gall bladder were removed at the same time, by way of elective surgery conducted under a general anaesthetic.  23. The operation was conducted at Lancaster General Hospital, and I am unaware of my having been given any blood or any blood product as a result – in fact I was again told very little in formation, in particular nothing about living without a gallbladder, but I was nevertheless again prescribed the contraceptive pill by my G.P. despite their concerns as to its side-effects.  24. It wasn't too long after this surgery that I found myself pregnant again, but again miscarried. I remember what happened on this occasion far more than with the first, and recall that at the time we had builders working on our home when it occurred. I was then living in our second marital home at GRO-B GRO-B  25. I suffered a bleed, minor in nature when compared to the severe haemorrhaging experienced with the first miscarriage, but nevertheless significant. A doctor was called to the house, but only served to make a bad situation worse by saying, "Oh, you didn't last long!" I was only eight to nine weeks pregnant when it happened. Again I had to go to hospital for treatment but was far more with it' on this occasion and know that I did not receive any blood or blood products to assist me. My husband took me to the hospital.  26. In 1985, having again fallen pregnant, I gave birth to my second son at the GRO-B This was a full-term 'normal' pregnancy and passed without incident – no itchy skin, no jaundice, none of the symptoms I e		
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- 29. I had always been a fit and healthy woman, slim, someone who was mindful of what I ate, and with no underlying health issues until falling pregnant and suffering the first miscarriage. I had not been promiscuous, my husband of the time having been only my second boyfriend, and I did not use intravenous drugs or associate with those who did. Nor had I engaged in any hazardous activities such as having self-inflicted tattoos, I was what could be considered to have been a 'clean living' person.
- 30. The only background health issue which may be of any note is the fact that my mother had also apparently experienced what she described to me as having been a 'difficult' pregnancy but she survived my birth, as did I, without any complications.
- 31. I had always worked, but with young children to care for, whilst the children were young I became a stay-at-home mother looking after four young children. However, when my daughter was about a year old, I returned to work and created my own business which involved care of the elderly.
- 32. In 1997, my husband left us, and very shortly thereafter stopped providing any financial support for the children. It was an extremely stressful period of time as I found myself without a partner and having to both look after four children and run a business on my own, all at the same time. Financially, things were so difficult for us that I had to turn to income support for assistance.
- 33. In the summer of 1999 I entered into a new relationship. All was well for a while, but after about six months I learned that my new partner had been cheating on me, and although I remained with him, as partners, our relationship was stressful and awkward to manage.
- 34. My new partner had Asperger's Syndrome, which was undiagnosed, and found it very difficult to deal with various aspects of our relationship, and then found it even more challenging when I was diagnosed as having contracted Hepatitis C.
- 35. Before the HcV diagnosis (which happened in 2012), my first husband having left me in 1997, I had decided to retrain and pursue a different career path, something which could fit around my children's needs, and had been given a place at St. Martin's College, GRO-B to take a degree course in teacher training. Sadly, I had to stop when on 5th May, 2000 I suffered an Achilles Tendon rupture, which not only required me to undergo surgery, but saw one of my legs secured in a plaster cast for an appreciable period.

36. The tendon surgery took place in the	GRO-B
	use of a blood transfusion or any blood
products in so far as I am aware.	

- 37. I subsequently suffered a tear in the Achilles Tendon of the other leg in 2010 which caused further problems for me especially as I was then living with, and caring for, my mother. Taking these two issues together, I found myself unable to return to the teacher training course and had to seek employment, initially with a freely distributed local newspaper and then with a telecommunications company in GRO-B Lancashire, Telewest. Previously, my partner had bought a house in GRO-B I had always owned my own home, as he hadn't wanted to own a home with me, but in the summer of 2001 I had moved in with him.
- 38. It was at about this time that I began to suffer from successive bladder infections, Interstitial Cystitis, repeat infections I experienced over a protracted period. I was prescribed various treatments over a number of years, but none seemed to be effective.
- 39. Eventually, facing with what appeared to me to have been an incurable, painful bladder condition, I conducted some research online, and learned that my problem was caused by a biofilm infection, and further enquiries I made myself, led me to a doctor located in Stoke-On-Trent who helped me deal with the issue through a long-term course of antibiotics.
- 40. Sadly, in 2010 my father passed away following which I became my mother's primary carer. This was a difficult time as I was then working at the Lancaster University and living in GRO-B whilst my mother was resident in GRO-B, at least twenty-five miles away from home or work. I moved in with mum in March 2010, leaving my house in GRO-B although I did also spend some time with my partner.
- 41. As my condition had persisted unchecked for such an appreciable period of time, in an effort to find out exactly what was going on, I decided to go undergo tests in a Genito-Urinary Medicine Clinic (or 'GUM' Clinic for short). This was in 2012.

- 42. I had already decided that I would have to cease or at least substantially reduce my working and move in with my mother in order to become her full-time carer, so having moved in with her, I set about selling my home in GRO-B whilst trying to find somewhere else for both her and myself. At the same time, I additionally sought to renovate and decorate my mother's home so that too could be sold to facilitate our moving somewhere more suitable. It proved to be a very stressful time, not least because in 2011 my partner, GRO-B had been diagnosed as having bowel cancer which required surgery which he underwent in November, 2011. I stayed with him following the surgery, to care for him, and at the same time was travelling backwards and forwards between him and my mother as I provided her care as well.
- 43. By 2012, I had been suffering from depression and found that I felt absolutely exhausted almost all of the time. I found that with the tiredness, I was finding it difficult to work, and once had even fallen asleep, albeit only momentarily, whilst driving which really scared me.
- 44. My first G.P. blood tests were undertaken through the surgery in GRO-B GRO-B As I had been living with my mother at that time, I had transferred my care from GRO-B to GRO-B I went to see my G.P. at the GRO-B then Dr. GRO-B who took some blood for testing in order to determine what might have been going on. When the results came back, he called me in to tell me that the tests had revealed my liver function to have been impaired it had returned 'abnormal' test results. I was told that my condition would be monitored, but offered no intervention. Any form of a test for Hep' C was not suggested and HcV wasn't mentioned as having been a possible cause.
- 45. Whilst waiting to see what may happen, in August 2012 I decided to go to the GUM Clinic at the Lancaster General Hospital where I believed that I could secure a full blood screening. I was still suffering from the bladder infection and was additionally concerned that my problems may have been related to my partner and wondered, because of what had happened before, if he had passed anything on to me, such as a sexually transmitted disease (or 'STI'), as I knew that he had had an affair.
- 46. The clinic were very good, took my blood for testing without any fuss, and about a week later I received a call from a female doctor at the clinic outside of normal business hours. The doctor was cautious, and asked if I were alone or with anyone else at the time I told her that I was with my partner, and she asked if I could move to somewhere more private before taking matters any further.

- 47. I was very worried, as I didn't know what she was likely to say, but moved somewhere more private to listen to what she could tell me. The doctor then said that I had tested positive for Hepatitis C antibodies, and advised that I go as soon as possible to see my G.P. and have a PCR test conducted to check if I had been infected with HcV.
- 48. At the time, I had no idea what Hepatitis C was, how serious it may have been, or what infection meant for me. The doctor gave very scant information on the 'phone, basically that my test had been positive and no more, I was given to background information about it.
- 49. I went to my G.P.'s surgery where I was told to make an appointment with the practise nurse. When I saw her, and told her that I needed a PCR test, it became clear that she also knew nothing about Hep' C or what a PCR test may have been.
- 50. The nurse took blood, but there was no space on the blood test form they were using to accommodate a test for HcV as an option, so she wrote on the form that the blood had to be tested for Hepatitis C.
- 51. When the test results were returned, I was called by the surgery to be told that I had tested positive for HcV (which I already knew from the GUM Clinic test), but that as the incorrect firms had been used, and accordingly an incorrect test conducted in the laboratory, no PCR test had been performed.
- 52. I therefore had to return to the surgery, see the nurse, give blood and await the result of testing, again. On this occasion, the nurse spoke to a doctor, to ensure the right forms were used or the right thing was written on the form, but the doctor didn't appear to know either. The nurse therefore contacted the laboratory (in Preston) to find out just what she had to do.

53. A PCR test was the	n conducted and the	results sent to the surgery.	Dr.
GRO-B GRO-B	GRO-B	) then called me, by 'pho	one,
to tell me that I had to	ested positive for HcV	In doing so, he admitted to	me
that he knew nothing	of Hepatitis C or PCR	testing and consequently co	ould
offer me no guidance	, support or perhaps r	more importantly, any treatn	nent
for the condition. He	told me that he would	refer me to the Royal Lanca	ster
Infirmary and to a Dr.	GRO-D , but that ther	e would be a thirteen week	wait
-		· · · · · · · · · · · · · · · · · · ·	and
my G.P. care thereaf	ter was undertaken th	rough the GRO-B	in
GRO-B			

- 54. I found it all very difficult to accept, and decided to conduct some research myself, to learn of the condition and see what, if anything, could be done. Conducting my own research, I discovered the Hepatitis C Trust who provided me with details of a Samantha May with whom I would be able to liaise.
- 55. This lady and the charity she represents were brilliant and extremely helpful. She was someone whom I believed to have gone through the treatment process herself, and someone who proved to be a great support for me throughout the period beyond the initial diagnosis and throughout my subsequent treatment.
- 56. I also tried to get in touch with the British Liver Foundation, but I found them less approachable or 'user friendly,' so the Hep' C Trust became my 'go-to' group for any support and advice.
- 57.I believe that my G.P. failed me through ignorance of this condition, and should have been knowledgeable enough to have provided information, support and guidance or at the very least to have been able to place me with those who could, by urgent referral. I really should have been told about the risks I posed to others and how any such risks could have been mitigated.
- 58. I was also rather unhappy with the situation concerning the PCR test and the delays I had experienced, especially as I had instigated the whole thing by taking myself into the GUM Clinic whilst the surgery were merely 'monitoring' me. I raised these issues with Dr. GRO-B who told me that in any event, the laboratory would have required a second test, a new antibody test, to confirm the diagnosis as the single test conducted through the GUM Clinic could not have been relied upon in isolation.
- 59. He explained that some form of delay would have been inevitable, whatever the case with the PCR test having to have been repeated, but I disagree I find the delays to have been unacceptable and do not think that I should have been left for so long waiting to find out if I did or did not have the disease, especially where all I knew of if was that which I had been able to find out for myself.
- 60. With the diagnosis confirmed, I began to consider how I may have become infected. I was really worried, and told my ex-husband, former partners and even my children that they all needed to be tested for the disease. Fortunately they all accepted this and underwent tests, with all tests returning negative results they didn't have it, so I had neither passed it on to them, nor contracted it from them.

61. Looking at my lifestyle and conduct, and having eliminated all other possibilities, I believe that I can only have been infected as a result of my having been given blood on the occasion of my first miscarriage in around 1991 when I was treated, as an emergency case, having suffered not only a miscarriage but a significant haemorrhage.

# Section 3 - Other Infections

62. I do not believe that I have been infected with any disease other than Hepatitis C, but feel that the symptoms experienced during the course of my first successful pregnancy may indicate the presence of HcV from that point in time onwards.

## Section 4 - Consent

- 63. Consent was not an issue with my first miscarriage, as I was taken into hospital as an emergency case and shortly after arrival was sedated to provide for my comfort during surgery.
- 64. It was now so long ago, and I had been in such distress at the time, that I can now no longer recall whether or not I was asked to provide consent for any procedure performed, I may have been but equally I may not and to be honest, I would most probably have consented to anything at the time I was in such a poor condition.
- 65. Thereafter, where any form of invasive surgery has been required, it has been by way of elective surgery, and I have been aware of what was going to happen and consider it before it happened. I have to accept that I may have been given blood or blood products on other occasions, for example on the occasion of my second miscarriage, but I do not believe this to be the case and my recollection is better in those cases.
- 66. In so far as blood tests were concerned, until my diagnosis, I never really knew what my blood may have been being tested for, just that tests were required to either monitor a pregnancy and my condition or to look for the cause of a problem I was experiencing. I consented to the tests, but with the benefit of hindsight should, perhaps have been told what they were designed to achieve, but believe that I would have given my consent all the same.

- 67. I was treated for HcV infection (an issue which will be addressed later within this statement). Whereas I consented to receiving treatment for the infection, initially using a combination of Pegylated Interferon and Ribavirin weekly Pegylated Interferon injections and daily Ribavirin tablets.
- 68. I felt that I did not have much, if anything, of a say in my treatment plan and was not given the option to consent or decline treatment. I was told that I had Type 1b Hepatitis C, apparently the more serious type of the virus which posed a higher risk of my contracting cirrhosis of the liver, liver scarring and a greater risk of my developing liver cancer.
- 69. A Dr. GRO-D under whose care I was at that time, made all of the decisions as to my care and what course of action may or may not be in my best interests, without any input from me and I did not feel that I had been involved in the decision-making process at all.
- 70. I cannot say whether or not Dr. GRO-D was experimenting with treatments, and / or using me as part of some form of research programme, but I definitely felt as though I may have been being used as a human guinea pig. In particular, he kept amending my treatment plan and altering doses as things started to go wrong, and I felt that he was experimenting on me with no clear idea of how the changes made would affect the viral load.
- 71. Two weeks into my first course of treatment, and having become extremely unwell, Dr. GRO-D decided that I should introduce longer intervals between my injections and reduce the medication I was taking, which together then caused my viral load to rise.
- 72.1 couldn't help but feel that he was rather blindly experimenting with my treatment, a situation I was very unhappy with (and which again, I will detail later within this statement).

## Section 5 - Impact

- 73. As stated previously, I had become both exhausted and depressed which had caused me to first consult with my G.P., albeit that no answers were initially forthcoming. Then, having been diagnosed as having Hepatitis C, I realised that both my exhaustion and depression were symptoms of HcV.
- 74. With the benefit of hindsight, I also understood that the itching skin and jaundice, both experienced almost immediately following the blood transfusion I received following the first miscarriage, were also classic signs of Hep' C infection, but neither had been considered to have been hepatitis related at the time.

- 75. On 1st November, 2012, having received the HcV diagnosis, my G.P. Dr. GRO-B referred me to a Dr. GRO-D a Consultant Gastroenterologist at the Lancaster General Hospital. Despite the serious nature of the disease, the symptoms I had presented with, and the potential for progressive physical damage to me, in particular to my liver, I had to wait thirteen weeks for an appointment, which was both a very trying and anxious time for me.
- 76. I attempted to eat healthily and to improve my general lifestyle, but was at the same time trying to care for my mother which brought ab out its own stresses. As I waited, I experienced some bleeding, despite my having been post-menopausal, and had to undergo a colposcopy examination. Fortunately, all was well, but it nevertheless caused a great deal of worry over and above that I was already experiencing.
- 77. When I finally saw Dr. GRO-D I found that I was not impressed with his manner, but rarely actually got to see him more often than not I saw his nurse practitioner, an GRO-D but I did see Dr. GRO-D for my first appointment.
- 78. On that occasion, I met him with my daughter who had accompanied me. Neither of us were impressed by the manner in which he addressed us, feeling that he came across as being both rude, dismissive to a certain extent, and intimidating in nature. Throughout the consultation he stood in a corner of the room, arms folded across his chest and initially not saying a great deal at all.
- 79. He told us what the treatment which was available at that time would be, but was rather offhand in the way in which he did so, and did not give me the opportunity of asking him any questions about either the treatment or the condition in general. However, he did assure me that I would be quickly cured of the disease with the treatment on offer, which is what I wanted.
- 80. Dr GRO-D's approach to my daughter and I was of such a nature as to make me feel very uncomfortable and to a certain extent embarrassed at having HcV, and I felt a victim of the dreadful stigma which had by then become attached to the disease. I did not feel at all comfortable in his presence.
- 81. His nurse specialist GRO-D told us that she was actually a cancer nurse specialist who did not have a great deal of experience with treating Hep' C, which did not instil much confidence in the way I was likely to be handled thereafter, but she was much nicer and far more approachable that Dr. GRO-D although I nevertheless found that there was a lack of immediate support offered through her, and I still felt stigmatised through my condition.

- 82. I was so unhappy with the manner in which Dr. GRO-D had dealt with me that I made a complaint through the hospital PALS office (Patient Advice & Liaison Service). This resulted in my receiving an apology from the doctor, in person, Dr. GRO-D having taken the time to see me one day during his lunchbreak and whilst I was visiting his clinic for a check-up. In spite of the apology, I was worried that my complaint could adversely impact upon my treatment.
- 83. My treatment plan consisted of a combined therapy using Pegylated Interferon and Ribavirin. Taking these meant that I had to self-administer one, through a weekly injection and take daily tablets. I was shown how to self-administer (inject) at the clinic and was additionally given a pamphlet about it.
- 84. I was told that I was likely to experience what were described as being 'flulike' symptoms whilst taking this treatment, and that if I did, paracetamol
  could be taken to help nothing else, no further information and certainly
  nothing which prepared me for just how bad I was likely to feel and I was
  given a clinic appointment for six weeks following my first dose of
  medication.
- 85. The only information available beyond that which I was told, which was insufficient, came from the note which came with the medication. The lack of detailed information meant that I was wholly unprepared for the symptoms I experienced from the very first injection I took.
- 86. I had been told by Samantha May of the Hepatitis C Trust that I should have been seen weekly and monitored very closely as a monitoring and safeguarding measure, due to the nature of the medication I was being given, but the first 'follow-up' appointment had been scheduled for six weeks later.
- 87. Following my first injection, within a matter of hours I became very ill and ran a very high temperature. At the time, home for me was with my mother for whom I was caring and felt responsible, but there was no one to help me as I had been totally unprepared for just how unwell I was going to be.
- 88. Just a fortnight into the treatment I found myself extremely unwell. My ability and desire to eat had diminished to such an extent that I was losing weight, dramatically. I was out of breath and so tired that I found it almost impossible to rise from my sofa or even speak in full sentences. I was so weak that I was unable to raise my arms sufficiently to do simple things like drying my hair.

- 89. Unfortunately, I am also an asthmatic, my only underlying health issue, but something which had always been controlled and which had not hitherto presented as a health problem but the treatment I received seemed to affect this as well.
- 90. My pupils also shrank to a point where at times they were no more than pinpoints. Taking the side effects together, I became very worried as to what was going on and how I was being adversely affected, so I contacted Dr. GRO-D s clinic, only to discover that both he, and his nurse specialist were on holiday and that there was no medical professional from whom I could take advice or discuss the treatment I was having, and its dreadful side effects.
- 91. No one knew what was going on I had been put onto a course of treatment by Dr. GRO-D and his assistant, and having placed me onto this treatment plan, neither were available.
- 92. My daughter visited me and was shocked by what she found, I was suffering from far more than just a bad bout of the 'flu as I had been forewarned, this was something else, even my hair had started falling out, we were both frightened as to my health and what was actually going on.
- 93. Throughout this, the only person I found that I was able to speak to and take advice from was Samantha from the Hepatitis C Trust. She suggested that as I was so unwell, I needed to go to a hospital Accident & Emergency Department to have my blood levels checked.
- 94. My daughter and I, almost in a panic, decided to go to A&E, immediately, so on 29<sup>th</sup> May, 2013 we attended the Lancaster General Hospital where having explained what had been happening and how I was with the treatment, they took some blood for testing, and sent me home.
- 95. My G.P. care had by now changed to that provided by the GRO-B GRO-B in GRO-B On 30<sup>th</sup> May, 2013 a locum doctor from the surgery called me having received the blood test results. I was told that my white blood cell count was extremely low (I can recall the figure of '1.9' having been used) and that I should go straight to an A&E Department if I were to suffer so much as a sore throat or common cold.
- 96. The doctor didn't know anything about my condition or its treatment, and told me so, he didn't try to hide the situation, but contacted a Gastroenterologist Consultant at the GRO-B on my behalf, in particular to see if I should continue taking the combination therapy, or not. I was told to cease the Interferon and Ribavirin course until such time as I was able to consult with Dr GRO-D so I stopped taking it.

- 97. About a week later, once GRO-D had returned from her holiday, my daughter took me to see her in Dr. GRO-D s Clinic. My daughter had to accompany me, as by then I was too weak from the effects of the treatment to have taken myself she had to push me around the hospital using a wheelchair.
- 98. When she saw me, the specialist nurse looked terrified. As we spoke, she continually repeated the fact that she was in fact a cancer nurse specialist and *not* a hepatitis treatment specialist. For a while, we simply sat in silence while I think she tried to think of what to do next with me, or for me. She took my blood pressure and sent me for a chest X-Ray, but nothing else was done or prescribed to help me I was just told not to take the Interferon and Ribavirin until such time as Dr. GRO-D had returned to the clinic.
- 99. A fortnight later, I was called into the clinic to see Dr. GRO-D He told me that he was going to change my treatment reduce the frequency of the Interferon injections from weekly to two-weekly and drop the dosage level of the Ribavirin tablets. I was also to have weekly blood tests, to enable the clinic to monitor progress,
- 100. Dr. GRO-D on altering my treatment plan, told me that it would not change the overall result, in particular as over the few weeks when I had been taking the treatment, my viral load had actually decreased, so I would still be cleared of the disease.
- 101. The doctor also said that he was considering using a third drug in addition to Interferon and Ribavirin, something called Telaprevir. I couldn't understand how, being so ill taking two forms of treatment together, I could be cope with a third. He also told me of what he referred to as being a 'rescue injection' which I could be given in order to elevate my white blood cell count.
- 102. Dr. GRO-D appeared to be very enthusiastic as he spoke of this new treatment regime, but I felt that he was simply going to be experimenting with me and didn't actually know at the time what, if any, positive impact this new treatment plan would have.
- 103. I wasn't given the opportunity of commenting upon what was being proposed, or to question its need or effectiveness, I was just told what I was going to be taking and felt no better than a guinea-pig, unable to voice any concerns I may have had, and I had grave concerns.
- 104. Despite my fears I commenced the new treatment plan but after just a few weeks found that my viral load had risen (I believe that it was recorded at 6.9 log). Dr. GRO-D told me that the revised treatment programme wasn't working and told me to stop, which I did although I desperately wanted to be rid of the disease.

- 105. Dr. GRO-D left me feeling as if it had been my fault that his treatment wasn't working and that I was to blame as I had been unable to tolerate the side effects with the initial treatment plan. He told me that he, "... thought that this would work for you, " but his attitude towards me hadn't really changed from the time of our first meeting he made it feel that my having HcV was all if my own doing and that it was my fault that he couldn't rid me of it.
- 106. I subsequently learned from another doctor that the 'rescue injection' he had referred to would never have worked as it had been unsuitable for me. Having ceased with the multiple therapy he put me on, Dr. GRO-D never mentioned any new treatments, more advanced treatments that may have become available, monitoring apart I feel as though he placed me aside.
- 107. By June 2013 I had a new G.P. at GRO-B a Dr. GRO-B He was in my view a far better placed doctor than his predecessors as he at least had some knowledge of and experience of treating HcV as apparently, a nurse he had previously worked with had contracted the disease.
- 108. Dr. GRO-B was absolutely appalled by the treatment I had received, and came across as being far more supportive and proactive. By now, although my general blood test results including the white blood cell count were showing an improvement, the viral load was noted as being higher than when I had first started treatment through Dr. GRO-D 's clinic.
- 109. Dr. GRO-Breferred me to a Gastroenterologist Consultant at the Blackpool Victoria Hospital, a Dr. Tim Hendrickse. I had a consultation with Dr. Hendrickse where I met his specialist nurse, Mike Rolland. Prior to my having met with him I had been somewhat encouraged through my having heard that he was a 'good doctor' from another nurse who had been monitoring me.
- 110. Both Dr. Hendrickse and Nurse Rolland appeared to have had far more experience in treating Hepatitis C than either Dr. GRO-D and / or GRO-D GRO-D and my attending their clinic was a completely different experience for me as a patient. They were both far nicer to me and I never felt the stigma attached to the condition whilst in their company or department.
- 111. Mike Rolland, in particular, went to great lengths to explain things to me and I was invited to email him at any time with any concerns or worries that I may have had. Although I could have emailed GRO-D, I found Mike far more approachable and genuinely accessible.

- 112. Dr. Hendrickse told me that there were a lot of new hepatitis treatments on the horizon, alternatives to Interferon and Ribavirin, but that at that time they awaited approval for use. I was told that although I was effectively in a 'watch and wait' situation, he would monitor my condition through regular clinic appointments, and gave me the opportunity of having a FibroScan through which my liver condition could be assessed, something I had never been offered before.
- 113. The scan revealed some fibrosis of the liver, but although a biopsy was discussed, it was never undertaken as it was not considered necessary at that time, the scan would suffice.
- 114. As I awaited any new Hep' C treatment being made available for use, I decided to conduct some further research of my own, to help myself as best as I could in the interim. I was also still suffering with the bladder infection I have mentioned and wanted to lessen if not remove its effect.
- 115. As a result, I took up a vegan diet, stopped drinking any alcoholic beverages and started to take natural medication and supplements, including Lauricidin, Oil of Oregano and Colloidal Silver.
- 116. Having made these changes to my lifestyle and conduct, I went for a blood test at one of the regular clinic appointments which I had as a part of the monitoring process. The results were very encouraging as my viral load was noted as having decreased. A second FibroScan was conducted, twelve months after the first and I was told that my liver was again healthy.
- 117. However, with a liver that was being considered to be 'healthy,' came an added problem. Mike Rolland told me that because of the changes I had made and the resultant improvement in my health, I was no longer sufficiently unwell to be eligible to receive a newly authorised treatment which they may otherwise have been able to prescribe.
- 118. The new medication was known as Harvoni. The National Institute for Health and Care Excellence (NICE) had issued guidelines concerning the use of this drug, and whilst conducting my research I had read them, online. I therefore knew that Harvoni apparently worked well for people who had previously tried other treatments that had been unsuccessful, and also worked well for people who had not developed cirrhosis of the liver.
- 119. I met both conditions (as above), but was frustrated to find that I didn't qualify for treatment as I wasn't poorly enough the criteria then being used in Blackpool to decide who was or was not treated, as Harvoni was an expensive drug. I was even more frustrated when I learned that locally, people who had become infected by virtue of their being illegal drug users were to be given priority over what I would term to be 'normal' patients.

- 120. Had I lived elsewhere, where different qualification criteria had to be met, I may well have been prescribed Harvoni, but because of the geographical location of my home and the hospital, coupled to the hospital's fiscal constraint, it could not be given to me. I was outraged.
- 121. I wrote to my local Member of Parliament GRO-B MP (the MP for seeking his help and even threatened to go public with news of the apparent 'postcode lottery' I had been a victim of. I needed the treatment which was being unjustly withheld from me.
- 122. Although I never received anything other than an acknowledgement of my letters from Mr GRO-B a short time after my having written, Mike Rolland contacted me to offer a course of the Harvoni treatment, which I gratefully accepted. Whereas I do not know for a fact that the MP intervened on my behalf, I strongly suspect this to be the case.
- 123. Whereas I appreciate this political intervention, if it did indeed occur, it should not have come to that, anyone in my position, suffering from Hep' C and requiring treatment, and being a suitable candidate for treatment, should have been offered treatment. It should not have been withheld on financial grounds.
- 124. On 27<sup>th</sup> November 2016 I commenced Harvoni treatment. It was a twelve week course during the course of which I experienced hardly any side effects, although I did suffer some 'brain fog' on occasions. The side effects, when compared to Pegylated Interferon and Ribavirin were minimal and at no time was I rendered unable to function as I had been before.
- 125. I completed my course of treatment in January, 2017, and then in August 2017 I was told that I was clear of the infection I no longer had HcV.
- 126. During the course of my treatment I had enjoyed really good care from the team at Blackpool Victoria Hospital who had been treating me, and my local surgery. I did not have regular appointments with Dr. Hendrickse but had a far looser (and consequently convenient) arrangement through which I could contact either him or Mike Rolland as and when I may have needed to.

- 127. My progress was monitored not through the hospital, but through my local G.P.'s where a nurse (Jill Ralph) saw me, checked on my condition and any side-effects, and took blood for testing at 2, 4, 8 and 12 week intervals across the treatment programme. This was really helpful as Blackpool was quite a distance from where I was then living. Jill Ralph was affiliated to the Royal Lancaster Infirmary and Dr. GRO-D I had previously asked the staff in Blackpool if I could have the regular blood tests undertaken somewhere closer to home (as I didn't want to have to travel all of the time). I didn't want to see Dr. GRO-D again, and as a result, Jill had been assigned to my case.
- 128. Having been infected with HcV had a major impact upon my personal life. In part as a result of the delay in my diagnosis, from the point in time of my having become infected, I had to tell all of my family and former partners and then ask them to undertake an HcV test. It felt horrible finding myself having to do this, and finding myself thinking of how they may have considered I had come by the disease. I also told a few former colleagues, people I had worked with prior to my diagnosis.
- 129. I was very open with them all as I had absolutely nothing to hide, but knowing of the stigma then attached to the disease made it extremely embarrassing at times. Once single, it impacted upon my ability to develop new relationships as I felt, rightly or wrongly, that I needed to tell any dates I may have had about it but then found that I also had to tell them, how I had come by it.
- 130. My partner, as mentioned previously, did not deal at all well with my diagnosis. He had already had an affair, difficult enough to deal with, but then he effectively disappeared when I needed him most. I think that his having Asperger's made it even more difficult for him to 'be there' for me in the way in which I needed his support and companionship. The divisive impact it had upon our relationship made everything that much harder.
- 131. I also found that there was a major stigma as regards Hep' C infection across the healthcare community in part driven by an apparent lack of knowledge. There was no support or information provided to me, and no reassurance from the doctors I dealt with when first diagnosed. The actions of Dr. GRO-D merely served to reinforce the bad attitude many held towards those who had Hepatitis C and my time under his care was a terrible experience.

- 132. With no tangible assistance, sound advice or personal support available from the medical authorities, until I was placed under the care of Tim Hendrickse, through Dr. GRO-B I had found myself wholly reliant upon Samantha and the Hepatitis C Trust. I was frightened, worried that my diagnosis could have led to liver cancer, worried about its impact upon my family and I, worried about my mother and who'd care for her and I had no one to turn to but Samantha. She was the only person to whom I was able to talk of my concerns and advise me.
- 133. By the time I received my diagnosis, I had stopped working in order to be able to care for my mother. When I went through the first treatment, I was so ill that I simply couldn't care for her (I was unable to adequately look after myself), so the treatment also impacted upon her care and quality of life at that time.
- 134. It was so bad that on occasions we were wholly reliant upon my daughter travelling to look after my mother and I. Prior to my receiving the second HcV treatment, my mother had been diagnosed with Myeloma. I cared for her at home, offering 'end-of-life' care with the assistance of MacMillan Nurses, the St. John's Hospice and doctors from both the hospital and GP's surgery. It was an incredibly stressful time. She passed away in GRO-B 2016.

#### Section 6 - Treatment / Care / Support

135. Although I had suffered from depression, I was never offered any form of counselling or support, either following my diagnosis or during the course of the first treatment plan of Dr. GRO-D I believe that appropriate counselling may have helped me deal with all that was happening in my life at that time, but in its absence my daughter became my counsellor. The need for professional help should have recognised and would have proven beneficial to me.

#### Section 7 - Financial Assistance

136. When I first met Dr. Hendrickse and Nurse Specialist Rolland, we discussed how it was that I could have become infected with HcV. We discussed my history, and both formed the opinion that as a result of my haemorrhaging during the course of my first miscarriage, and the severity of that bleed, that it was highly probable that I had required a blood transfusion and that this had been the most likely source of Hepatitis C infection.

- 137. I also discussed the issue with my G.P., Dr. GRO-B who having discussed my medical history and lifestyle also came to the conclusion that a blood transfusion given at the time of the first miscarriage was the most probable source of my infection.
- 138. Mike Rolland told me about The Skipton Fund. He said that I could apply to the fund for financial assistance as it was highly likely that the blood transfusion given in 1981 following my miscarriage had been the source of my Hep' C infection. He told me that he would support the application, as did Dr. GRO-B when I spoke to him about it.
- 139. To support my application, I tried to get my medical records from both the Lancaster General Hospital and GRO-B However, both the surgery and G.P.'s practise told me that the records held for the relevant time were 'missing.' This seemed to me to imply that records of other things were available, but that the 1981 miscarriage records and any showing a blood transfusion given at that time were not.
- 140. No one in a position to do so could tell me why these notes were missing, or where they may have gone, but in any event they weren't accessible at least not by me. I suspected that someone may have disposed of the record, as did Dr. GRO-B who was equally suspicious of them having 'gone missing' whilst everything else remained.
- 141. I kept pushing both the GP's practise and hospital for the records, urging them to look a bit harder for them. This didn't take the matter any further with the GRO-B but the hospital eventually told me that they had viewed the records, as held on a microfiche, but that there was no record of any blood transfusion having been given to me.
- 142. Due to the lack of any supportive medical record, The Skipton Fund rejected my application, although a blood transfusion given under the circumstances described is the only likely source of my having become infected with Hepatitis C – all other likely possibilities having been eliminated.
- 143. Had my application been successful, some financial assistance, no matter how small, would have greatly assisted – I could have sought private counselling assistance and / or private healthcare and thus been given the Harvoni treatment earlier.
- 144. I have been made aware of a new scheme, the England Infected Blood Support Scheme (EIBSS) to whom I intend making a fresh application in connection with which I will again seek my medical records.

## Section 8 - Other

- 145. In order to assist the Infected Blood Inquiry, in advance of my meeting with the same on 9<sup>th</sup> October, 2020 in order to draft this statement, I prepared some brief notes (typed) of my recollections. These I now produce as my **Exhibit WITN4282002**.
- 146. I have also produced prints of email traffic between myself and Samantha May of the Hepatitis C Trust, again to assist the inquiry as they provide for a contemporaneous record of what was happening, how I felt about that and the knowledge and advice I received. These I now produce as my Exhibit WITN4282003.
- 147. The above also includes email traffic between myself and GRO-D

  GRO-B MP and Jill Ralph (hepatology nurse specialist re. blood test results).
- 148. I have also produced hard copies of email exchanges with the Skipton Fund (i.e. a Mr. Nick Fish, their Scheme Administrator). These I now produce as my **Exhibit WITN4282004**.
- 149. In connection with Mr. GRO-B MP, I have also produced a paper copy of an email dated 23<sup>rd</sup>. July 2015 in which I raise the question of my treatment with this MP and outline the manner in which I had been treated, the treatment being available in the U.S.A. but not in the U.K. and with it being prioritised for use by intravenous drug abusers. This I now produce as my Exhibit WITN4282005.
- 150. In order to further assist the inquiry I have produced a timeline which shows the chronology of the various events which I have detailed within this statement. This document I now produce as my **EXHIBIT WITN4282006**.

## **Statement Of Truth**

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

Signature:	GRO-B	***************************************
Name (printed):		
Dated:	16/4/21	
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