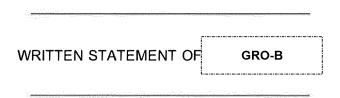
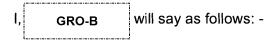
Witness Name GRO-B
Statement No.: WITN4995001
Exhibits: Nil
Dated: ✓ 1≤/6/22

#### INFECTED BLOOD INQUIRY



I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 November 2021.



# Section 1. Introduction

- 1. My name is GRO-B I was born on **GRO-B** and my address is known to the Inquiry. I work in GRO-B GRO-B I am married with and I live **GRO-B** and I intend to discuss my infection with between GRO-B GRO-B Hepatitis C (HCV) which I contracted from blood products used for treatment of my Haemophilia.
- 2. This witness statement has been provided without the benefit of access to my full medical records.
- 3. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. I would like to remain anonymous in order to protect myself and my family.

- 4. I can also confirm that the Inquiry Investigator has explained the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they may have the right to reply to that criticism.
- 5. I wish to acknowledge that naturally as time passes, memories can fade. I have therefore been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.
- 6. I have never been part of any action against NHS or group action litigation.

## Section 2. How Infected

- 7. I was diagnosed with severe Haemophilia A as a baby. I believe I have 0.02% clotting factor.
- 8. There was no record of haemophilia in my family, so my diagnosis came as quite a shock to my parents.
- 9. When I was 6 months old, GRO-B My parents immediately sought medical attention, and the doctors thought it was cancer.

10.	GRO-B		I
	in fact had severe haemophilia which had caused a bad bleed	GRO-B	

- 11. When I was a child, my haemophilia care was managed by GRO-B Hospital. My treatment was later moved on to the Hallamshire Hospital when I was aged 15.
- 12. Both hospitals provided great care, and I had good relationships with the staff, particularly the haemophilia nurses.

- 13. However as a child, I felt that the hospital was the worst place in the world. It involved pain, it often meant staying there for extended periods of time and being away from home, and it meant being with other sick kids. I hated it.
- 14. We had little jotter books, and my mum had to write down every time I had a bleed. I used to have 2-3 bleeds a week, and I went through many of these books.
- 15. I was initially treated with cryoprecipitate (cryo). When I was around 5 or 6 years old, at the GRO-B hospital, I had a dodgy reaction to the cryo.
- 16. I had had a bleed, and had been at the hospital for treatment. We had to get 3 buses to and from the hospital and it was an ordeal just getting there for my mum. I had a big pram I had to go in. I remember this because I found it embarrassing as I was older than the usual age to be in a pram but it was to keep me safe.
- 17. They had given me cryo for the bleed, and then we were told we could go home. It was dark and we went to the bus stop opposite the hospital, which was full of people queuing. I started itching, going hot and feeling funny. I started losing it, I was scared and didn't know what was happening. People around helped my mum to get me back to the hospital.
- 18. They said it was a reaction to the cryo. There were concerns that I wouldn't be able to be treated with anything going forward due to the bad reaction.
- 19. Following this incident, I graduated onto Factor VIII.
- 20. When I was first put on home treatment, the selling point was that I wouldn't have to stay at hospital, which I was very pleased about. Though in reality, I did still have to go to hospital quite frequently anyway.
- 21. My mum was taught what to do in order to inject me at home but she was very concerned about hurting me, so it made things very difficult.

- 22. It was not an easy task to inject me, and mum sometimes missed or went through the vein. She would have two attempts at the injection, and if neither was successful, we would have to go to hospital for a doctor to do it.
- 23. I remember the days of having a bleed, getting up at in the early hours of the morning, crying and having to go to hospital, then sitting and waiting for them to mix treatment. My dad would often have to go straight to work from there to do 12 hour shift.
- 24. We'd be in a room sometimes with 6 doctors, and they would all be having a go at injecting me and having difficulty. I would think; what chance has my mum got when the doctors can't even find a vein?
- 25. I started hiding bleeds as I didn't want to go to the hospital. I was internalising things, keeping a lot bottled up. I still have an issue with my elbow because of the number of times I hid bleeds.
- 26. The nurses helped my mum with her technique and eventually she got really good at injecting me. It was a good job as I was a typical lad and had quite a few bleeds over the years.
- 27. When I was around 15-16 years old, I started injecting myself. By this point, I had developed a fear of needles because of the number of times there has been problems.
- 28. My bleeds continued as I got older, more so than most. The nurses used to joke I was a nightmare as I didn't go to all my hospital appointments.
- 29. I now inject myself but I still have issues, I'm not very good at it. My best vein is my left arm and I am left handed, so I find it all very awkward.
- 30. Sometime in 1985, when I was around 9 years old, I was called in to the Hallamshire Hospital. This was unusual as my care was still under the

been to the Hallamshire; the first time had been for a possible biopsy. That was to be some kind of trial where we were told it would help others but mum and dad were not too keen and, in any case, it was stopped before it started which in a way, I was glad about.

- 31. I was taken to a meeting with Professor GRO-B and some others. I remember it clearly, especially the weirdness of being in a different hospital.
- 32. They said there was something not right and they thought they knew what it was. That's when I was diagnosed with hepatitis.
- 33. At first, I was diagnosed with non-A, non-B hepatitis, and this later became known as hepatitis C. I was young and I did not really understand. It was told to us in a matter-of-fact way not a big deal. I don't think anyone actually knew what it meant. I don't recall any information being given although my mum and dad may have been spoken to separately about it.
- 34. I have never used intravenous drugs, and I do not have any tattoos or piercings. I have been happily married since my 20s, and I have never been medically treated overseas. Furthermore, I was very young when I was diagnosed with HCV. There are therefore no other ways I could have acquired the HCV infection.

#### Section 3. Other Infections

- 35. I have had tests for HIV tests which were negative.
- 36. At some point, I received a letter about the risk of vCJD. This was after having been told problems with blood products wouldn't happen again.
- 37. I was in my mid 20s when the letter came. It said they had reason to believe a product I had been given may have been infected with vCJD.

- 38. I decided I did want to know more. I was told there was a good chance the blood products were infected. I was told they cannot prove it; there is no test and no cure. Why tell us about it then?
- 39. It just seemed like they were saying if it comes it comes. Essentially, they gave us this information but were saying we just needed to crack on.
- 40. My mum got the same letter, as she had had blood products a couple of times for operations as she is classed as a mild sufferer herself. Her clotting factor is around 70%.

# Section 4. Consent

- 41. I was unaware of the testing for HCV, and I think they were probably testing before I was found to be positive, but I was not made aware.
- 42. I would usually have blood tests every time I went to hospital, but I didn't know I was being tested for viruses. My mum and dad may have known but I'm not sure although I think they would have mentioned it by now.
- 43.1 don't think there were any discussions about risk from cryoprecipitate or Factor VIII.
- 44. We used to go to Scotland a lot when I was a child. On one occasion, when I was about 10 years old, I was treated in Wick in Scotland, and I went funny after treatment. I remember my dad asking if it was out of date.
- 45. At that time, something was mentioned then about the stuff being 'dodgy', but generally, there was never a mention of risk of infection.
- 46. We were only told of the risks after it was too late.

# Section 5. Impact

- 47. My haemophilia had a big impact on my early life and schooling, and then things got even worse with my HCV diagnosis.
- 48. My life was like Jenga, and the HCV was like the final thing to put on top of a multitude of other issues, and it felt like the HCV was going to topple it all down.
- 49. From when I was very young, my life seemed to be destined for me to be dependent on my parents. My parents were unbelievable in their care of me, and I appreciate them more all the time.
- 50. We have all had to fight for me to have the level of independence I was capable of.
- 51. I went to visit a special school, but Dr GRO-B, who was my main haematology doctor at the time, said I wasn't going there. He said I should be going to a mainstream school.
- 52. So my parents fought to get me into mainstream schools. My mum even became a dinner lady from when I was 3 years old, working at my schools to facilitate me being there.
- 53. When I got to secondary school age, my local comprehensive school didn't want me to go there, but my mum fought again for me to go there. They finally agreed to take me but on the condition that I wasn't allowed to participate in sports or anything high risk as they didn't want responsibility for any bleeds.
- 54. They didn't even know I had HCV. We didn't tell them as that would have been yet another reason for them to refuse me entry.

- 55. I always felt I had to do better than everyone else to justify myself. This is why I work such long hours now, as that feeling has been long-lasting.
- 56. By the time I left school, I hated people. I didn't feel college or university was for me as I lacked so much self-confidence. I felt like those options were for popular, good looking, 'normal' people. I thought people would ask what was I doing there, so I didn't go.
- 57.I did end up going to college when I was 31 to obtain qualifications, which I completed part-time. However I feel like I am about 10 years behind with everything.
- 58. I have always had a worry the HCV could lead me to be dismissed or pushed out of my job. People always say this wouldn't happen but realistically, if I am causing grief or not performing well, they would want me to go. I have seen people got rid of for less.
- 59. If it was a choice out of a 'normal' kid or me, they are going to employ the 'normal' kid every time.
- 60. I always try to get any health issues sorted in the school holidays. If something comes up, I will wait as long as possible to avoid time off in term time.
- 61. I feel that my haemophilia and HCV has undoubtedly curtailed opportunities.
- 62. My dad often says 'if you didn't have to deal with all of this you'd be a force to be reckoned with. We'd struggle to hold onto you.'
- 63. I have inherited a lot of drive from my parents; I always want to do new things and push myself.

- 64. Physically, as a result of the HCV, I was always tired and fatigued. Just a day at school or doing some walking would cause me to become exhausted. Even now, I still feel tired a lot of the time a residual effect.
- 65. I always felt like it shouldn't be this hard. I felt like I hadn't done a lot but I was so tired. I always feel like I've got my hands tied behind my back.
- 66. The HCV meant I needed to sleep a lot. It was and still is a feeling like I had been drugged up. I could sleep anywhere; I could sleep on the floor, on chairs, anywhere.
- 67. I also experienced night sweats, and I would wake up drenched. I am hot all the time, I'm like a 'Ready Brek kid'.
- 68. The issue with my sleeping actually only came to light when doing my Skipton application. Carol, one of the nurses who was helping me with the form, said sleeping for 14 hours isn't normal and that's when I realised the extent of the issue.
- 69. Since treatment, I can't sleep. I have severe insomnia, so I have gone the other way around. I struggle to sleep in my bed now, I end up sleeping on the sofa a lot.
- 70. I have to have a blanket over my elbow and internal organs due to bleeds, but at the same time I'm really hot. It's a dichotomy, and is very difficult for me to manage.
- 71. Regarding the stigma, I didn't want to tell people about the HCV or, later, about my treatment for it.
- 72. I was diagnosed around the time of the AIDS adverts and everything. I knew the fact that my HCV infection was caused by infected blood tied me to that stigma.

- 73. AIDS was being talked about and was being used as a tool to knock someone or to bully people at school. People used to say 'you've got AIDS' as an insult. With that going on, I was very anxious about my HCV coming out and people knowing I had it.
- 74. I didn't want to say anything to anyone, as I didn't want to be bullied. The only thing in my head when I was first diagnosed with HCV was not to tell anybody.
- 75. So nobody spoke about it. My family knew but also kept it quiet. Only about four people who know me are aware I have had HCV. This is in a box and I keep it that way.
- 76. I always felt like I stuck out enough as it was because of GRO-B and my haemophilia.

77. GRO-В

- 78. My ethos was to be at the back of the crowd. I just wanted to be low key and to fit in.
- 79. I don't like having any connection to HCV and I don't like people asking questions.
- 80. So the information was kept within my immediate family. I most definitely have not shouted it from the rooftops.
- 81. With respect to my social life, most of my friends are people I have known since I was 3 years old. I have always restricted friendship groups for fear of stigma. I have needed that stability. I struggle with anything new.

- 82. Even my close friends don't know about the HCV. They know something was wrong with me and have somewhat pieced it together, but I haven't told them. They know I have stopped drinking and have asked some questions as a result of that.
- 83. My wife and I have never had alcohol in the house. We would drink at weddings or birthdays or special occasions. But I have never been one for getting tanked up. I was always a cheap date; 3 pints and I'm done. This was possibly the HCV.
- 84. So I have never been a big or habitual drinker, as I was always affected quickly. However I decided to stop drinking altogether just prior to my treatment.
- 85. The HCV and treatment undoubtedly curtailed my social life, and that of my wife.
- 86.1 always feel I am the weak link, and the experience with HCV exacerbated this.
- 87. I haven't tended to go to my children's parents' evenings, as I have wanted to avoid being seen by the other children. I also tend to go out when their friends come over. Yet another indicator of my low self-esteem.
- 88. Even now I have cleared the virus, I still suffer some effects of it, including tiredness, fatigue, and sleep issues.
- 89. I have to have certain type of socks and shoes as otherwise my feet get set off. I have to wear tops with sleeves, and I can't have draught on my back or kidneys, due to old bleeds.
- 90. I still worry that my liver is likely to be damaged, even though I have now cleared the virus.

- 91.I don't think I can have had HCV in my system for as long as I did without there being a long-term effect on my liver. In my experience, you don't get away with anything in life.
- 92. That's why I want to do as much as possible while I can, such as travel.
- 93. Fortunately, despite my health concerns, my family and I have manged to travel quite extensively, and I think the experience with HCV has encouraged me to do as many of the things I enjoy as possible. I love to travel and create memories with my family, so this has always been a priority.
- 94. For example, we went on one particular holiday to Tasmania. During the trip, I felt tired and hot all the time, but really want to go to a particular island. My wife said we'll go next time, but for me, there is no next time. I always feel I'm on borrowed time. I feel I could drop dead at any moment.
- 95. I have what I call existence guilt, which is similar to survivors' guilt. I feel it is my obligation to do things. It is a privilege to be able to do things others in the community can't do. Every day is like a fight. I think it's that that keeps me going.
- 96. However due to the haemophilia and HCV, travel insurance has been very difficult, which has made things more complicated than for most people.
- 97. Furthermore, I have never been able to get life insurance cover because of the HCV. When we were arranging our mortgage, Halifax said they don't turn anyone down but then their underwriters refused it.
- 98. NatWest offered me life insurance for £900 per month, and at the time I earnt about £700 per month, so the cost was obviously prohibitive.
- 99. Fortunately I was able to get the mortgage, but only because of my wife, as it was a dual mortgage.

- 100. I was brought up to enjoy simple things in life, I have never been a flash person. Furthermore, my mentality has always been to bank money, so that if I drop dead there will be money for my family.
- 101. I wouldn't want my wife to have to sell the house, especially as we live next to my mum and dad, so I wouldn't want her to lose that lifestyle. I always feel like I need to have a large financial cushion in case I lose my job, which I have always felt like I could at any moment.
- 102. The HCV has had a very significant impact on my wife, GRO-B She was very upset when she found out about it. She was tested at the suggestion of the medical staff at my centre and I wanted to know the results direct from them not my wife for fear that she would protect me from the result. Luckily, she was negative.
- 103. She had a level of naivety as she has never experienced anything like this in her own life or within her own family, and I have kept her away from certain things.
- 104. I am very concerned about passing it on to others, for example, I become very distressed if my toothbrush gets mixed up with the others. I place huge importance on the precautions like this. When it comes to myself, I am very matter of fact about things, I tend to take the view 'it is what it is'.
- 105. However, my mum and dad have had to put up with a lot, and that makes me sad. They were amazing. They would do anything for me. They would drive 100 miles to get me an injection when I needed it.
- 106. They could have had more kids, or done more things with their lives, if it wasn't for my illnesses.
- 107. I also feel that my wife GRO-B could have had it a lot easier with someone else.

- 108. I know I'm the one having to deal with things, but I always feel they are all having to deal with them with me and it shouldn't be that way.
- 109. It really made me question my worthiness in respect of having a wife and kids. It made me very worried about having kids in the first place.
- 110. I am angry with having both HCV and haemophilia, but in some ways, I use them to push me to keep going.
- 111. I know I can't dwell on things as it will consume me, so I just get on with it as much as possible.

# Section 6. Treatment/Care/Support

- 112. When I was first told about the HCV, they didn't go into massive detail as they didn't know exactly what it was at the time. There were subsequently issues of doctors keeping things from me, due to age, which I would say was probably mostly done in my interest.
- 113. Once I moved to the Hallamshire Hospital, I was classed as a 'mini adult'. This was when I was around 15 years old. After this, I was regularly monitored. I had liver function tests every 3 months for a long time.
- 114. Dr GRO-B I think he is a professor now or possibly retired, was the main doctor at the GRO-B hospital. He was unbelievable.
- 115. Joy Farmsworth and Carol who were nurses at the Hallamshire, were both wonderful. I have known them for the last 30 years and have great relationships with them.
- 116. When I was an older teenager, I was told about not sharing towels, toothbrushes and those kinds of precautions. I always keep my toothbrush separate, even now.

- 117. When I was first diagnosed, they may have told mum and dad about precautions, I don't remember that though.
- 118. I started attending the hospital more frequently when I was aged 19-20. The appointments would wind me up as would take me 1.5 hours to get there and the appointment itself would only be about 10 minutes long.
- 119. When I was in my mid 20s, I was told I was genotype 1A. I remember asking if that was good or bad, and they said it was just 1A, it was neither a good thing or a bad thing.
- 120. I started to have conversations with doctors about possible treatment options. This was initially talked about for in the future. They would say 'let's leave it for now and keep an eye on it', those kinds of things.
- 121. I was aware of other haemophiliacs in the waiting room being on Interferon. I observed them having treatment and chatted with them. I was told Interferon was awful. I was glad to not have been put on it myself at that point.
- 122. In my monitoring, the doctors regularly mentioned the possibility of a liver biopsy but I didn't have to have one in the end.
- 123. On several occasions, I turned up for appointments, and a doctor I wouldn't have seen before would go into the full spiel about HIV, then Joy or Carol would come in and correct them, saying I haven't got HIV.
- 124. These incidents were not with the normal staff who knew me, but with new or locum doctors. However, they filled me with angst. They would start talking about HIV and I would get a tight feeling in my chest. I always felt at least I didn't have HIV. This was a way of making myself feel better. So, when this happened, it was very stressful.

- 125. They kept the HCV treatment away from me for as long as possible. I think they put me off, in a nice way, due to the side effects. I seemed to be doing okay so they avoided starting me on it.
- 126. I had a level of naivety in that I never thought too much about what the HCV was doing to me. It was only when I met my wife when I was 21, that I got more serious about it due to me not wanting to pass it on to her.
- 127. The HCV treatment was a dichotomy for me. The Factor VIII had been a chance to have more normal life, so I would take it every time. But the fact the Factor VIII gave me HCV led me to not want other treatment, i.e. for the HCV. It made me concerned about it. But at the same time, I didn't want to infect anyone else.
- 128. My mum became really good at injections, and even once I was an adult, she would sometimes have to help me. I was always anxious that she could catch the HCV when helping me with injections.
- 129. I developed like an OCD about putting needles into a plastic bag. My mum was not very worried about it but I was.
- 130. When the doctors were talking to me about the treatments, it was like they were selling me a dodgy car. When they spoke about Interferon, they would say I can have it, but its rubbish. This obviously put me off.
- 131. I knew of lots of lads that were starting to have HCV treatment at around 40, so I was kind of expecting it around that age.

132.	I ended up commencing treatment when I was 39, in around July 2015.
	GRO-D

GRO-D	
GRO-D	
GRO-D	

- 137. The Infectious Diseases specialist said we can't leave it any longer. He showed me a green and red scale, and pointed out where I was on the scale compared to normal. I was way up in the red area.
- 138. It was all a bit of a panic. He thought I was going to kick off but I'm used to things going wrong, so I didn't.
- 139. He tried to put a positive spin on it by saying there were worse people than me on the scale. I asked 'are they alive?' He said no. I said 'how is that going to make me feel better?'
- 140. GRO-B is a teacher, so she doesn't usually come with me to appointments as its hard for her to get the time off work. However she came with me to this appointment. She was very upset.
- 141. I had to have a psychiatric test before treatment could start. I had a pink sheet I had to fill out. There were questions on it like 'are you angry at work?'

- 142. Initially I was being truthful with my answers, but was told I had to put no to everything otherwise I couldn't have treatment. So the sheet was a bit of a farce really.
- 143. I was aware I could have flu-like symptoms, and I was warned about other side effects such as shakes, thinning hair, getting out of breath. I knew in my head, as long as I could hide it, I was okay.
- 144. It had got to a point where there was no choice, so I would have to go ahead with the treatment. I was essentially told my liver was knackered and that I needed treatment imminently.
- 145. I went to work and told them about it. They were brilliant about it but it still felt like an Achilles heel. With regard to work, I knew I could be poorly during school 6-week holiday. The doctors wanted me to start treatment in around the April, but I said I needed to delay treatment until the school summer holiday, which would have meant delaying it until the July.
- 146. In the meantime, fate dealt me a good hand. I was due to have Interferon, but there was an acceleration in the development of another, better drug. This treatment had around a 60% success rate.
- 147. This treatment also had fewer side effects than Interferon and the success rate was higher. Moreover, Sheffield was a trial area. I knew this would be a one-off as you could not have it a second time.
- 148. I was told some people can work during treatment, others can't. The timescale of how long I would need to be on the treatment was unclear, though was likely to be shorter than with Interferon. It could have been a month, 3 months, or more. I was worried about having time off work, as I didn't want to get sacked.

- 149. They phoned me in June and said if I didn't sign up for it, they would give it to someone else. I felt they were right for doing this as I had been stretching it out.
- 150. I recall being told it was 'mega-bucks'. I don't know what it cost but it was a very expensive treatment.
- 151. The treatment was tablet form, and I had to take around 8 tablets a day.
- 152. I don't like taking tablets, I have a fear of swallowing them, so this was very difficult. I asked for chewable ones but they didn't exist.
- 153. So I had to put the tablet in fruit or other food. It took me ages to take each one, sometimes by the time I took one, I was ready for the next one.
- 154. The treatment made me very fatigued. I would became out of breath just going upstairs. On one occasion, I collapsed in the shower, and my wife couldn't wake me up.
- 155. I was working and still doing long hours at the same time as treatment, so I became extra fatigued. GRO-B would have to drag me out of bed in the morning. At first, she thought I was messing about, but I was almost in a coma at times.
- 156. I was red hot, even more so than normal. I was shaking all the time. I got exhausted walking very short distances, there were times when I fainted. I couldn't sleep well at night.
- 157. On one occasion, I crashed my car, I probably shouldn't have even been driving. Luckily no one else was involved.
- 158. Work kept sending me home as I was unwell. I also felt angry and frustrated a lot at work with my condition. I remember at some point during

treatment having to do a presentation to 90 people, and I was dripping sweat and shaking. I don't know how I got through it

- 159. All I wanted to do was go home and lay on the floor. But then when I did, I couldn't sleep. I would be wide awake when I laid down.
- 160. I lost weight, though I didn't struggle with eating. I had started to put weight on at 33, but the weight dropped off me during the treatment.
- 161. I had to go into hospital every week during treatment, and I would report I was feeling unwell but I was told to persevere. I responded really well to treatment and my viral load reduced very quickly. After 4 months on the medication, I was clear from HCV.
- 162. Towards the latter end of having the treatment to get rid of Hep C I'd developed quite a lot of deep chest pains and flutters throughout the day. I'd never had any problems in and around my heart before so I was worried something was going to go seriously wrong. After about 5-6 hours of scans and waiting for scans at the Northern General Hospital (Sheffield) it was determined that it might be micro bleeds around my heart, but the extent of the bleeding couldn't be established due to my diaphragm so I was advised to just take it steady.
- 163. I wasn't running marathons at the time (going up and down stairs at home was about the extent of my exercise) so I was worried how I could take it any easier. I relayed this information to the infectious diseases department who were treating me for the HCV and it was decided that as I'd got about 2 weeks left, we'd carry on with the current level of treatment but monitor it more regularly and closely (ECGs, etc) to see if the treatment needed to be reduced or even stopped if I got any worse. We got to the end of treatment without changing it, but I spent the next month on the sofa and the pains didn't subside until about 12-18 months after. It wasn't the best of times.

- 164. I didn't tell anyone about treatment, not even my mum and dad. I was elated that the infection was gone, not only for myself but for my wife and family. However, the joy was slightly tinged with by the problem with my heart and the pain it caused as mentioned above.
- 165. After clearing the HCV, I went a whole a year without bleed. This was unheard of for me before. I used to have several bleeds a week. Even a draught or wearing the wrong clothes would cause a bleed.
- 166. Since finishing treatment for HCV, my joints have been a lot better, so I have a lot less pain and discomfort. My spontaneous bleeds have reduced a huge amount.
- 167. I would still have a bleed if I punched a wall, for example, I know that.
  But internal spontaneous bleeding has reduced massively. There is no doubt that HCV compounds the effects of haemophilia on your joints.
- 168. Furthermore, at the age of 21, I started to experience kidney issues.

  For example I had internal bleeding in my kidneys a number of times, and I had stints of peeing blood and being in agony with my kidneys.
- 169. After the treatment for HCV, I have had no kidney issues. I still cover my back and avoid draughts, but haven't had any issues.
- 170. Now I tend to have only a couple of bleeds a year, it's a vast difference. I strongly feel the HCV must have been exacerbating my bleeds.
- 171. Nothing else has changed. For example I have not moved house, I have not changed diet or anything like that.
- 172. These issues are now not having to be at the forefront of my mind, which makes a big difference, particularly when I go on holiday for example.

- 173. I have never been isolated in hospital or noticed extra gowning or PPE, or treated differently as a result. I have never had an issue with dental treatment.
- 174. There might have been counselling offered to me or my family when I was diagnosed with HCV, but I can't really remember it.
- 175. Even if there was, when I was younger, I would probably have taken the view that I had this thing, no one can help me, and to just get on with it.
- 176. Nowadays, I talk a lot with my wife, but I don't really know how much talking really achieves anyway.
- 177. As mentioned, my wife has been tested and was negative. The kids weren't tested for HCV. No one has ever suggested they were tested.

# Section 7. Financial Assistance

- 178. I was given some money when I was about 20, I believe there was an inquiry or something and, as a result, I received a payout.
- 179. I got about £2000. I remember I used it to get the windows done on the house.
- 180. I applied to the Skipton Fund in May 2014.
- 181. I found out about Skipton from the hospital nurses and the form came through to me at home to fill out.
- 182. I used to feel embarrassed about getting money. I feel like I should earn any money I am given, so I had a hard time accepting it.

- 183. I didn't fill out the form straight away, and at some point, the hospital got in touch with me asking why I hadn't applied.
- 184. I said I wasn't doing it. The staff at the hospital said I should do it, as I was entitled to financial support. So I somewhat reluctantly filled out the form.
- 185. The first time around, Skipton rejected my application. They said there wasn't enough evidence to show liver damage.
- 186. The hospital contacted Skipton and asked what they were playing at. The hospital told me to come in and see someone there about it. The chances are I hadn't filled the form in properly as I wasn't bothered.
- 187. The hospital then supported me to fill it out properly. Nurse Carol did the form with me. The consultants also supported us to fill out forms by signing them. This was after my HCV treatment.
- 188. I received £20,000 as a lump sum, which is the first stage payment.
- 189. I now also receive monthly payments of around £2,000 per month. My case is now with EIBSS.
- 190. I found it was a massive relief when the monthly payments started. I always had a fear of being off work and not earning, and this monthly payment has alleviated that. It lifts the pressure, and gives me breathing space.
- 191. I did not have any issues with the process, and I don't recall having to sign anything in order to receive the money.
- 192. I got an unrelated letter from the NHS, which was all-encompassing rider that I was asked to sign with regard to future NHS treatment.

193. It looked like a management letter that had been drafted by a 12-year old. The only thing I can attach it to is the vCJD issue, as it was around the same time.

#### Section 8. Other Issues

- 194. I have never met anyone who would swap their life for mine, in any walk of life. It has been tough.
- 195. My way of dealing with it when I was younger was to distance myself from the community as much as possible.
- 196. To that end, I have only met about 6 haemophiliacs in my life.
- 197. As I have got older, I have learnt to appreciate interacting with others similar to myself. I feel like I have finally found my type of people. It makes me feel comfortable due to us having common issues.
- 198. Some people might feel differently, but even if I was told of the risk, I would have probably taken the Factor VIII anyway.
- 199. In my opinion, if the infected blood was given to us all in good faith, then I don't think there is anything to more to be said on the matter than that.
- 200. However, if someone along the chain knew there was risk of infection, then I would have a problem.
- 201. If they did know and went ahead anyway, I can only assume it's about money. Even now, medicines are often changed for cheaper versions. But if it's going into my body to treat me for an illness, I want it to be the best possible.

202. Of course, if people knew there were significant risks and knowingly proceeded, then they should be held accountable.

# Statement of Truth

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

Signed Si