

Witness Name: Donna Tully-Brown

Statement No: WITN0548001

Exhibits: **WITN0548002**

Dated: 3 April 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF DONNA MARGARITA TULLY- BROWN

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 February 2019.

I, Donna Margarita Tully-Brown, will say as follows: -

#### Section 1. Introduction

1. My name is name is Donna Margarita Tully-Brown. My date of birth is GRO-C  
GRO-C 1965 and my address is, GRO-C Bristol, GRO-C  
GRO-C
2. I am married to my husband Josh and we do not have any children. I have made this statement with my husband's assistance. For reasons, which will become apparent later I took redundancy from my job at Bristol City Council in 2013 and have been unable to work since.
3. I intend to speak about my infection of Hepatitis C from a blood transfusion I received in 1984. In particular, the nature of my illness, how

the illness affected me, the treatment I received and the devastating impact it has had on me and my husband and our lives together.

4. I am not legally represented and am content for the investigators to take my statement.
5. I was born in GRO-C Merseyside and moved to Bristol in 1988 because my then boyfriend Paul started studying at Bristol Polytechnic in 1985. I went to Sheffield Polytechnic but would visit him in the holidays and get temporary work. When I finished college in 1988 I moved to Bristol because I knew I could find a job there. I lived with Paul and we loved the area.
6. We broke up in 1991 and I considered moving back to the North but ultimately ended up staying in Bristol. I met my now husband Josh in 1994 through my job as the project coordinator for the Cold Weather Project ("CWP"), set up in partnership with voluntary and statutory sector services. The CWP was founded with the intention of providing accommodation and support to homeless people in Bristol throughout the winter months.
7. Josh and I became a couple in 1995 and we married on 25 February 2013.
8. When I first moved to Bristol I got a job as an administrative assistant with Bristol City Council, I quickly moved on to become a housing benefit officer. Through this I worked my way into to the welfare system.
9. I was a housing benefits officer from 1991, during the evenings I would do the soup runs every Thursday. I enjoyed this and had a passion for helping people.

10. In June 1995, when I was nearly 30 years old I became involved with another project called 'The Hub' which worked with a number of organisations to allow a homeless person to walk in off the street and have all the amenities they would need, such as access to a doctor. Throughout my career I helped to establish coordination between the voluntary sector and the council to help homeless people. I regularly worked with drug addicts or alcoholics but I considered them my clients and I would do my best to ensure they got the help they needed. I worked with Bristol City Council for 23 years.
11. In my time as a Housing Benefits Officer I worked with various organisations including Townsend House, (mother and baby unit) and the Salvation Army and helped re-organise our system so that claims could be processed more efficiently and properly.
12. I was working as a Tenant Support Officer for Bristol City Council when I was diagnosed with Hepatitis C in 2008. I worked there until I took a redundancy in 2013.

## **Section 2. How Infected**

13. In 1984 I was due to sit my A Levels in the summer months. I was 18 years old and still at school in Merseyside. I had previously failed my Maths O level and had to retake this in the May. During the exam I vomited, I thought this was due to nerves as I am often sick when I get nervous. I then had to sit my A levels.
14. I remember the day before my A Levels were due to start I had the most horrendous pain from cramps in my stomach. I went to the doctors to find out what was wrong and told him I had my exams the next day. He gave me a pregnancy test and I found out I was pregnant. I had absolutely no idea before that.

15. I think I vomited my contraceptive pill when I was being sick due to my exams nerves and I was still having my period so there was nothing to indicate I was pregnant. I was only 18 at the time and really knew no better.
16. I went into school and sat all my A Levels. I did the best I could but due to what I was going through I didn't do my well. I was 18 and pregnant and very worried about telling my parents that I was pregnant, it was awful.
17. I got my results in August and found out I had failed all of them; I was also starting to show.
18. At the end of GRO-C beginning of GRO-C 1984 my then boyfriend (Paul) and I went to our friends Norah and Mickey's for dinner. I remember Norah made baked Alaska. I didn't feel well and told Paul I wanted to go home so we left. We could have walked but we decided to get the bus instead.
19. We went to the bus stop which is in front of a row of shops, which had a lay-by for cars to park in front. A fight broke out between some young lads who were about our age, it was absolutely horrible, they were having this fight and it was only about 9pm in the evening.
20. Paul and I were waiting at the bus stop; we couldn't get past as all these boys who were fighting. Suddenly these men turned up and looked as though they were in their 30s. There was obviously something going on and we were in the middle of it unable to get away.
21. One of these men went to the boot of his car and pulled out a crow bar. He threw it at one of the lads but it twisted in the air, changed direction and hit me full pelt across the stomach.

22. I went down. Paul was screaming at the man and as I stood back up the man who threw the crow bar realised I was pregnant. He grabbed my hand and wanted to take me to the hospital. I could smell alcohol on his breath and I refused. The man who had thrown the crow bar appeared to panic, he jumped into his car and drove off.
23. I can't remember how Paul and I got home but we did. I told my mum what had happened and I was bruised all down my front. It was never reported to the police. The boys who had been fighting had run away and the men drove off straight after.
24. I went to the doctors the following day. I don't know why we didn't go to the hospital that evening but we didn't. The next morning I went to my GP on [GRO-C] which was just down from my house and saw Dr [GRO-D] (He has since passed away)
25. I definitely think he should have referred me to hospital, I was pregnant and had been hit in the stomach with a crow bar and had already experienced some severe abdominal cramps in May when I first realised I was pregnant. I had been in pain from the onset but apart from the Dr informing me I was pregnant they did not check me out for the pain I was in. He just told me I was pregnant.
26. Dr [GRO-D] examined me and checked me out but did not refer me to have an ultrasound. He told me the baby was protected in the sack and everything was fine. The only scan I ever had in my pregnancy was the one I had at the end of my first trimester. At that point everything appeared to be fine.
27. Norah, Micky, Paul and I decided to rent a little caravan in St Asaph in North Wales for a week; We thought it would be nice after such a horrible incident. Micky drove us down there as we were still on our summer holidays and still at school as Paul and I needed to re-sit exams.

28. On the second day I was in the most excruciating pain, I was screaming in the Caravan, on reflection these were contractions. We were young and didn't really understand what was happening. I started to spot and an ambulance was called. I was taken to the hospital in St Asaph at about 11 o'clock in the evening. The crow bar incident had only taken place about 10 days prior to this.
29. At the time I was 18, but I have always looked younger than I am so I probably looked about 14 or 15. I was taken into a ward, apparently it was the labour ward, and a nurse wanted to know where my scan book was. I hadn't brought it with me and she told me off, scolded me for not having done so. I was in so much pain.
30. I remember feeling like I had been put to one side and was being treated like a silly kid who didn't know what was going on. They kept telling me I wasn't having contractions. They were dismissive of my concerns and condition.
31. We had been left in this side room and I don't recall anyone coming in and checking on me regularly, it was just Paul and I. As far as the hospital was concerned there was only a bit of spotting. I don't think they understood the gravity of my situation. I was in terrible pain and knew something wasn't right.
32. In the early hours of the morning, at about 2 or 3 o'clock I was lying in bed and Paul was in the room with me. I suddenly felt wet and said to Paul that I thought I'd wet myself but it was my water breaking, suddenly I saw the blood rising up through the sheets, there was blood absolutely everywhere.
33. Paul called the nurses in and suddenly all hell broke loose. Three people came into the room one after the other, a nurse and maybe a doctor. The last person was a man with a tweed suit on. I will never forget that tweed

suit I can picture it now. They asked Paul to leave and they took my nightdress that I had been wearing off. I was naked on the bed and everyone was examining me. The man in the suit had my blood all over him. They had been telling me I was fine.

34. The nurse or doctor was going over my stomach with a stethoscope to hear the baby's heart beat and it was loud. I felt like I could hear it myself. They kept checking the heartbeat but it became harder and harder to find and much fainter.
35. I was haemorrhaging so hard that they started getting me ready for a caesarean, they shaved me but it was too late, they couldn't stop the contractions, my baby was coming naturally.
36. I can't remember at what point they put a drip in my jugular vein and a drip that went over my shoulder and down my back with a very thin wire but I remember it feeling go through all the fibres in me. It was really painful.
37. I was given blood transfusion because I had lost so much blood. It was so bad they put it straight into my jugular vein. I remember being told they needed to get me to Liverpool but I wouldn't make it in the ambulance.
38. I had obviously been given some type of drug, at some point I must have had an epidural but I don't remember any other needles and I just wanted to go to sleep but the nurses wouldn't let me. All I kept saying was that I wanted to go to sleep. Apparently they told Paul I was a fighter but I don't remember this.
39. Apparently I delivered the placenta first. My understanding is that the placenta is the baby's oxygen, life supply and comes after the birth of the baby, my placenta arrived first. I have a feeling that the impact of the crow bar damaged my womb. My body thought it was time for the baby to be born and things moved on very quickly.

40. The hospital letter states I was around 25 weeks pregnant, I was already quite big. Exhibit **WITN0548002** is a letter from the hospital to my GP dated [GRO-C] 1984. Detailing in stark medical terms what had happened. I remember seeing this letter on my doctor's desk, it was then that it really sank in that my baby was a boy.
41. I prematurely gave birth to my baby on [GRO-C] 1984. This letter also details the fact that I had received 7 units of blood. The letter also states that 'She had a tense bag of membranes bulging at the vulva. These ruptured shortly after admission' This is not correct, It was at least 5 hours after being admitted that my waters broke. I question why this comment is made. As I said earlier, the hospital staff did not recognise the gravity of my situation.
42. I remember sitting up a little bit and he was wrapped in a green coloured cloth and they took him straight away.
43. The nurse whispered in my ear, 'he's stillborn lovey' that was it; I was then allowed to go to sleep. I was high as a kite and couldn't understand what they were telling me. I remember holding the nurses hand because Paul wasn't in the room. I thought it was Paul's hand but it felt so tiny.
44. I never saw my baby, we had no funeral arrangements and no counselling was offered to me. I gave birth and he was taken away from me straight away. The hospital probably incinerated my baby, that's what they thought of him. I don't recall anyone talking to me or telling me what had happened. I never even had the opportunity to hold him or say goodbye. I still feel absolutely devastated.
45. When I woke up Norah was sitting by my side and tears were rolling down her cheeks. She was never an emotional person normally. I asked her where my baby was and she just looked at me.



46. I had drips in me left right and centre and I remember I woke up because the doorframe was being bashed. They couldn't move me because I was haemorrhaging so they were trying to bring a piece of equipment to me but it was too big for the door. The banging woke me up.
47. My mum and dad arrived because Paul had been phoning them. They arrived first thing in the morning as this had all been going on throughout the night.
48. At some point the hospital had identified that there was a risk of both me and my baby dying. They were updating Paul on my chances of survival, which he had been relaying to my parents. The hospital had realised that they couldn't save both of us so they made me sign a form which basically gave them my consent to save my life over my baby's, relieving them of any liability. I remember the form; I was high as a kite so my writing looks like a child's.
49. I was moved to a ward and during the doctors rounds I remember hearing a doctor say to the nurses and other Doctors "No we won't discuss this one in front of her, it's too upsetting, you'll have to read the notes"
50. I was in bed and remember needing the toilet and asking a nurse for the commode. She said I could walk to the toilet but I knew I couldn't. She wouldn't let me have the commode and insisted that I had to walk. I started walking to the toilet and haemorrhaged as I was walking. I went into the full details, suffice to say it is the most horrible feeling. I was put in a wheelchair and taken back to my bed. They had to re-pack me.
51. I was in the hospital for 2 or 3 nights, the week was coming to an end and Paul, Norah and Micky had to leave the caravan. My mum, dad, sister and dog came to get me and took me home to Merseyside.

52. When I got home I had to go to the doctor's because I had some kind of infection in my lower body and I needed antibiotics.
53. On GRO-C 1984 I turned 19 years old. I enrolled to go back to college to re-sit my A Levels and started two weeks later. I got very poor grades.
54. The next year I took the first place at Polytechnic that I could. I wanted to get away and I left home. I spent an academic term in Manchester so I could get out of Merseyside then I got offered a place at Sheffield Polytechnic. I went there in 1986, left in 1988 and moved to Bristol.
55. I don't recall feeling any effects from the transfusions I had received, but when I had them in 1984, HIV was starting to hit the news. I remember feeling really stressed that I might be HIV positive but also not brave enough to do something about it because I was so scared.
56. My friend Casso was diagnosed with HIV in 1991 and he passed away in 1994, I saw the deterioration of his health, he lasted about 3 years. As time went by I remember thinking I can't be HIV positive because I could see what was happening to Casso. It was always a worry and a stress in the back of my mind but as long as I didn't see symptoms I thought I was ok. I would have moments of panic when I got ill though. An infection such as Hepatitis C never even crossed my mind.
57. I started to give blood within a year after my transfusions because I thought I was doing the right thing. My blue blood donor card shows that I gave blood on the following nine dates. 12-04-86, 22-10-86, 14-04-87, 13-01-88, 16-01-91, 30-01-92, 18-06-92, 17-06-93, 18-07-97.

58. I never heard anything back from the National Transfusion Service about my donations. I never received any form of communication to say they had found something in my blood.
59. I never experienced any warning signs, I don't remember ever really feeling very tired or unwell.
60. Josh and I wanted a family and were trying for a baby; I miscarried in December 1997 at 11 weeks. We had been away with some friends for New Years. Josh took me to hospital when we got back. They did a pregnancy test. The nurse said to me "Donna you're pregnant and miscarrying at the same time"
61. The next day I went to St Michael's Hospital and had a follow up scan. I was told there was no baby there. I am sure the hospital would have known my history and about my previous pregnancy.
62. Josh and I kept trying for a baby throughout the early 2000s but I was not getting pregnant. GRO-C
63. In 2007, I went to a fertility clinic in Bristol called the 'Bristol Centre for Reproductive Medicine' I had an examination and blood tests done and they told me everything was fine. There was nothing to indicate why I couldn't get pregnant.
64. GRO-C
65. GRO-C I had to go to the fertility clinic to do repeat blood tests and provide more samples in preparation for starting GRO-C treatment and it was

after these tests that I was told I had Hepatitis C. I had no idea I was being tested for Hepatitis.

66. In December 2008 a nurse from the fertility clinic called me at work and told me I was Hepatitis C positive. When she told me I shouted across the office "Oh My God am I going to die". I was given no preparation or warning and I was in the middle of the office at work. I regularly worked with people who had Hepatitis C and I was freaking out. There was no, are you free to talk? The nurse just simply told me with no warning.
67. The fertility clinic nurse told me I would have to have a second blood test to make absolutely sure. She also told me that [GRO-C] treatment wouldn't continue until I had my Hepatitis sorted. I spoke to my GP about it and she said maybe this test had only recently been introduced for [GRO-C] as I clearly wasn't tested for Hepatitis C in 2007.
68. The day I was told I had arranged to meet my friend [GRO-D] for lunch and I was panicking. Josh was working somewhere else and was too tied up and he didn't know what to do. I remember feeling like I was going to be sick.
69. The same day I was being sent to a meeting with Occupational Health ("OH") at work by my supervisor. I used to get really heavy periods and I was taking days off at short notice, [GRO-D] and a meeting had been called. She said it was my leave at short notice painting the wrong impression re my sickness days. I was being sent by my supervisor to find out if my problem was DDA compliant.
70. [GRO-D] phoned OH and told them I had just received some really bad news but they wouldn't speak to him. So I had to go to the meeting and I told them I had just found out that I had Hepatitis C. I was told we were not there to talk about that, however I did find out that my periods were DDA compliant.

71. I went to my GP to give a blood sample and I phoned the surgery for my results. The receptionist said to me "it is as you expected", which was a nice way of them letting me know. I think I must have arranged this with the surgery in advance.

72. Then my GP started the referral process for me to go see the Hepatologist at Bristol Royal Infirmary ("BRI").

73. 

GRO-C
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### Section 3. Other Infections

74. As far as I am aware, I've never suffered from any other infections stemming from the contaminated blood.

### Section 4. Consent

75. I signed the form allowing the hospital in St Asaph in North Wales to save my life over my baby's but I don't remember giving them any permission for the blood transfusions. The situation dictated that they just gave them to me.

76. I remember the doctors at one point say that they needed more blood.

77. I consented to my Hepatitis treatment.

78. I was tested for HIV as part of the fertility treatment I underwent, fortunately this came back negative.

## Section 5. Impact

79. After I successfully finished my Hepatitis treatment in September 2009, I went back to the [GRO-C] clinic to restart the fertility process.
80. Josh and I saw [GRO-C] consultant, Mr [GRO-D] in December 2009 as I was scheduled to have a laparoscopy. They wanted to take a proper look inside to see if there were any reasons within my womb as to why I was not able to carry a child full term.
81. Prior to this procedure I had to have an MRSA swab and it transpired that I was a carrier of MRSA. I followed all the instructions exactly as I was told before I went in to have the laparoscopy
82. They didn't test me again for MRSA. I was taken from the first on the list of people to have the procedure that day to the last on the list because I was a "risk factor". They also took me off the ward and put me in a side room and forgot about me due to the handover of the nurses. They also knew I had had Hepatitis C. I often wonder if they did this because of the Hepatitis?
83. I had been in the hospital since 7.30am and by this point it was about 2pm. I was feeling sick and stressed because I hadn't eaten. Josh had to remind the nurses that I was there. Eventually I had the procedure and we were waiting for Mr [GRO-D] to come and speak to us and tell me my results.
84. He came in and said, "We have a problem Donna, we have a problem" Josh wasn't in the room at the time because he'd gone to top up the parking meter. I asked Mr [GRO-D] to wait for Josh to come back before he spoke to us but he continued to talk to me. Josh walked in and I asked Mr [GRO-D] to start again.

85. He was telling me how I had fibroids and they were right in the place where the egg would normally go in my body. He made a comment about the chances of me being able to have a full term pregnancy were very limited and said I should not have left it so long before I started trying to have children.
86. His bedside manner was awful; he was very rude and unsympathetic. Josh told him about my previous pregnancy and miscarriages and we explained about all the Hepatitis treatment I'd had and the delays but he was very abrupt and unpleasant.
87. Mr [GRO-D] said that if we wanted to go ahead I would have to have 3 months worth of hormone injections to shrink the fibroids with a view to removing them. The side effects of the hormones would bring on symptoms of early menopause. It was only after this had been done and my womb had fully recovered that any possible implementation of the egg could take place. The surgery also ran the risk of a full hysterectomy.
88. We were left to try and get the process sorted to start the hormone injections, it had to be coordinated around the first day of my period which was coming up in about 2 weeks time. This all took place over the Christmas period in 2009 and when we tried to arrange it for me to start the hormone injections with the hospital it was an absolute farce. No one knew what was going on.
89. We later found out that Mr [GRO-D] had been so abrupt and in a rush with us in that appointment because he was on his way to the Christmas party.
90. Delays after delays would have now meant my starting the hormone injections in at least February. The whole point of the [GRO-C] treatment was for me to at least try and give myself a chance of having a baby. I collapsed with the stress and pain of it all and had to take six weeks off work in 2010.

91. I told Josh I couldn't do it any more. It was too much to put my body through these hormone injections. By this point I was in my mid 40s and so it was with a very heavy heart that we closed the door on that particular avenue. I did not have the mental capacity to even consider becoming a mum. I had nothing left after the Hepatitis treatment and this [GRO-C] experience.
92. We went back to my GP after our experience with Mr [GRO-D] she was surprised that we were 'not impressed' as apparently he is quite highly regarded. We asked for a private referral to the Nuffield Hospital.
93. This consultant basically confirmed what Mr [GRO-D] had said about the low chances of success but she did suggest that we give the [GRO-C] treatment a go despite of the fibroids. As I have said, I just couldn't carry on; I was exhausted with the whole process. Some days I regret it but I didn't have the strength to do anything else.
94. Nobody ever mentioned the fact that my Hepatitis might have affected my fertility or the ability to carry to full term. Josh researched this himself and found out that the Hepatitis can increase the chances of miscarriage. If this had been picked up earlier with my previous miscarriages or someone had put two and two together with the timing of my transfusions I could have gone through the treatment earlier and this could have possibly allowed me to have children. It could have been different had my Hepatitis been caught earlier than 2008.
95. I got pregnant before I had Hepatitis and pregnant thereafter and had lost the baby at 11 weeks. Neither Mr [GRO-D] nor the other consultant we saw ever mentioned any connection between Hepatitis C and pregnancy.
96. My stillborn baby was taken away from me before I could even hold him; the Hepatitis and [GRO-C] treatment took me back to that awful time. My GP



thinks I have PTSD and I have developed into a hypochondriac; a headache is a brain tumour as far as I'm concerned.

97. When I had an endoscopy recently, I had to fill out a form with some questions, on the form I stated that I'd had and been successfully treated for Hepatitis C. Before I had the endoscopy the nurses in the room were whispering in the corner and I knew it was about my Hepatitis. I had to say to them "I am still here you know, you should feel safer that I answered the questions honestly"
98. I remember coming back to the office after my six-week period off in 2010 and another member of staff announced to the whole room "whose being using my cup? I don't want to be catching any Hepatitis C"
99. Another support worker I had worked with was bad mouthing people with Hepatitis C and being really derogatory. My friend [GRO-D] was sitting beside me as this woman was doing this and I asked my colleague how she felt about people who had contracted Hepatitis C by mistake. This woman said she wouldn't go into someone's house if she knew they had Hepatitis. She was supposed to be a support worker helping people, some of whom had Hepatitis.
100. My dentist has been absolutely brilliant. I think I've had to declare my Hepatitis on forms but I've never had anything untoward from them.
101. Mr [GRO-D] and his team who put me in a different room before my laparoscopy in 2009 and the two nurses who were carrying out my recent endoscopy stigmatised me. These are supposed to be medical professionals.
102. I told my brother because I had to take needles with me when I went to stay with him when I was having the treatment. My older sister sussed

because she kept asking my brother what was wrong with me, as I looked so awful. My brother told her I had a cold and then later told me that she'd been asking questions so I told her. I never told my mother or other members of my family.

103. Around the same time I was diagnosed with Hepatitis C, my family found out that my stepdad Ritchie's cancer had come back and he only had about 3 – 6 months to live, when he passed away everyone was grieving so I didn't want to take away from that and make it all about me.

104. I took my redundancy in 2013 because I had no capacity left to help other people. I used to bring home about £1750 a month and if I was still working now I'd be bringing home more than that and I'd still be contributing to my pension. The virus has affected us financially.

105. I couldn't be the support worker I wanted to be, I couldn't engage with my clients like I had before.

106. I went on employment support allowance for a year after my redundancy but I still had to go to the office where my ex-colleagues and ex clients could potentially be. I was now on the other side of the counter. I would phone and ask the DWP if I could enter through the back door. This was refused.

107. I don't work at all now, Josh is convinced this is because of the Hepatitis C and that I would not be able to sell myself at interview. I am so utterly exhausted and shocked from the whole experience and even now my energy levels aren't as good as they were. Sometimes I don't even have the energy to get through the day.

108. I love the winter because the weather normally gives me an excuse not to go out. It's usually dark and raining so I can use this as my excuse.

Sometimes Josh will want to go for a bike ride but I will try and find an excuse so I don't have to.

109. I used to be so positive before all this and now my mind set has shifted, now I am more negative.
110. Financially, Josh and I have just about been able to manage with my not working. It has been tight at times because I'm not at retirement age and we've had to cut our cloth accordingly. We have not been on holiday for years. Josh has practically spent [GRO-C] since I stopped working.
111. We have been fortunate because Josh is a self-employed builder and this has allowed him some flexibility, without this he would not have been able to look after me the way he has done.
112. On occasions I do get 'brain fog' I can be very forgetful. I found it particularly difficult when I went back to work after my six weeks off in 2010.
113. My taste has been permanently affected by the Hepatitis treatment, there are some foods that I can no longer taste and there are others I can't stand to have in my mouth, broccoli for example.
114. I have been on anti-depressants ever since I finished my treatment in 2009 and as I mentioned earlier, I have become a hypochondriac, I have been to my doctors more times in the last few years that I have ever been in my life.
115. I have had so many tests because I was so asymptomatic with the Hepatitis that it has become the legacy. I always believe there might be something wrong with me. I have PTSD and my worrying and anxiety is extreme.

## Section 6. Treatment/Care/Support

116. After I was diagnosed in December 2008, I remember freaking out and stressing all the time, I had a feeling of desperately needing to get this sorted. I was so anxious about it all that I was physically sick.
117. There was a waiting list to see the hepatologist at the Bristol Royal Infirmary (BRI) and I wanted to try and get a cancellation so I could be seen quicker.
118. Josh spoke to the hospital on my behalf and expressed I would ideally like to be seen as soon as possible, he explained that due to the nature of our jobs we were very flexible and could come to the hospital at very short notice.
119. On 6 February 2009, Bristol experienced extremely heavy snow. Josh phoned me at work and said that BRI had said to him that if we could get to the hospital and had the time to sit and wait we would probably be seen that day. I asked my boss if I could go and he said yes.
120. Josh and I went to BRI and met Eric, the Hepatitis nurse, he was absolutely lovely.
121. Eric gave us some booklets on Hepatitis C; we had similar ones that I'd seen at work because some of my clients had Hepatitis. Josh and I already had some awareness about risks and precautions because we both worked in the social sector with homeless people. I don't think any further information was ever given to us bar these booklets Eric showed us.

122. Eric did all the tests and the other things that he needed to do and then I was referred to see the consultant to find out what the next steps were. I had to have an ultrasound of my torso, Eric took blood from me to find out what genotype I was and he explained to me what was happening. Eric was able to spend more time with me that day because of the weather; no one else had really showed up.
123. When I went to the hospital for treatment I regularly saw Eric, he was always ready to answer any questions I had. I kept a little notebook detailing everything that was happening to me, which I still have. Margaret was another nurse I regularly saw and she was also brilliant.
124. I saw the consultant and she told me about Interferon and Ribavarin, she told me all about the treatments and what it entailed and how sick I was going to feel after the injections. She told me I was to have the injections on a Friday evening so I could be at my worst sick over the weekend so I shouldn't have to take any time off work. I told her I worked for Bristol City Council and they were a very good employer. She told me that she'd had other patients who worked for them and had undergone treatment and they'd been sacked.
125. I didn't want to do the injections on a Friday evening as Richie my stepfather was dying and I wanted to be able to go up to Merseyside to see him or be able to go camping if I wanted to. I basically wanted my weekends to be my own. She was really pushing me to have the injections on a Friday but I threatened to walk out and not have the treatment at all so in the end she relented and I did them on a Sunday instead.
126. Eric taught me how to do the injections in my stomach. I injected myself every week for 26 weeks.

127. I felt awful but I had the motivation of knowing that if the treatment made me better I could go back to the GRO-C clinic. I so desperately wanted to have a baby so I just carried on despite everything.

128. After the first month of treatment I asked Eric if he would give me a Hepatitis test, he did. After six weeks of treatment I got the result back from the test and it came back negative, but I still had to continue with the remainder of the treatment, as I needed two consecutive negative results to start GRO-C

129. My mouth was covered in ulcers and I felt so tired and exhausted. I was passing heavy clots in my periods; this really scared me because I didn't know what was happening. I ached all over my body and I felt so sick that I had to take anti-sickness tablets. I also suffered from heat rashes and really bad upset stomach.

130. I used to say to Josh that I was so exhausted with so little energy that I couldn't even do a single star jump. I would say that even if someone was to pay me a million pounds I still wouldn't be able to do the star jump. Josh and I used to count down the days until I could do a star jump again. That was our own benchmark as to how I was feeling.

131. I still kept going to work throughout the six months of treatment because I needed a sense of normality. I told my manager at work because I knew he'd been sympathetic to me. GRO-D

GRO-D

132. I offered to come in and answer the phones, I knew I would be able to do this and it was better than sitting at home and feeling depressed.

133. I did have to have some time off a few times throughout those six months but it was only ever for a few days. Work kept me busy, occupied and distracted.
134. I felt very stressed about the situation and very upset but I would say at least I don't have HIV and I would try and turn it into a positive.
135. My genotype was one of the weaker ones, it was something with an 'a' at the end of it. Maybe 3a? Eric said to me because I was a vegetarian, young, healthy, white and female, these all worked in my favour.
136. I would come home from work, Josh would run me a bath and I would have that and then put my pyjamas on. I would have tea on the sofa and then I would go to bed so early. Josh did everything, all the cooking and I didn't have to do anything. Sometimes I couldn't even open the washing machine door. Everything was such hard work; sometimes I couldn't even be bothered to put food in my mouth. Josh would tell me that I had to eat but I was so exhausted that it was such hard work. I had no appetite at all; just lifting a fork was too much.
137. I pushed myself to go to work, to help me psychologically but I would be physically tired at the end of the day. Sometimes I would have something like a migraine and have to have a few days off work to recover from it. My physical strength depleted very quickly. Josh and I used to go for long walks and mountain biking and I couldn't do that once I started the treatment.
138. My hair fell out a little bit and my sense of taste has still not recovered. When I was eating I would say to Josh that food tasted and felt like toilet rolls in my mouth. My mouth was so dry and I always felt like I had bad breath.

139. I have fibroids and since the treatment every period I've had has been excruciating.
140. My treatment ended in September 2009, I had to wait six months and in March 2010 was given the all clear. I had another test after 12 months and remained in the clear.
141. As far as I am aware, according to Eric, my liver has suffered mild to moderate damage. I'm not a heavy drinker but I do drink. I went to Glastonbury when I was having the treatment and told the nurse I was going, I asked her if I was allowed a glass of wine. She said I was doing really well so why not. We took a bunch of non-alcoholic beers and some really decent wine.
142. When I was going through the treatment I had to go to the hospital where there was every possibility that I would bump into my ex clients or my ex colleagues as I was still working as a support worker at the time. This caused me a lot of angst and stress, Josh and I used to pretend that I was there to support him in case we saw anyone.
143. I remember one time I was at an appointment with the Hepatitis nurse who made a comment to me about my red blood cell count being a bit low, she said to me if it went any lower they would "whip me in and have a blood transfusion". I was shocked at her comment and wondered whether she'd even looked at my notes. She wouldn't really let me speak and I remember all I had wanted to know was whether what I was experiencing was normal.
144. At one point I was on 26 tablets a day, Josh had to make a spreadsheet to keep track of them all.

## **Section 7. Financial Assistance**



145. Eric told me about the Skipton Fund. He explained to me what it was and my manager at work also told me about it. I got given the form in February 2009 and completed it in about July. I received a lump sum of £20,000 later in July. I sent them a copy of the letter Exhibited at **WITN0548002** which they accepted.
146. I started to get quarterly payments from the Skipton Fund in 2015, since 2016 I've had regular annual payments of £3,500 and this has now gone up to £4,500. I received the payments in quarterly instalments.
147. At some point I was transferred to WIBSS and I suddenly received £3000 when this happened. I had absolutely no idea what this was for? I started to try and find out what was going on and I phoned WIBSS for several days before I finally spoke to GRO-D She was laughing as she told me they'd had some teething problems with the phones. I told her it was no laughing matter. I finally found out that they hadn't got round to sending the letters out before they made the payments.
148. Another time WIBSS made a double payment by mistake. I got £2,000 paid into my bank account instead of £1,000. I got told I could send it back but this would cause an administrative hassle or I could keep it as an advance payment of my next instalment, which I did. I was receiving an annual payment of £4672, which I had in quarterly instalments.
149. I have recently applied for the enhanced payment, which has been agreed. As a result, I will now receive £18,500 a year. I also received a little lump sum as a backdated payment.
150. I was successful in my application because of the effect Hepatitis C and the treatment it has had on my life, I was taking anti-depressants on my wedding day and as I mentioned I have some form of PTSD. I have

had my liver tested god knows how many times as well as my thyroid and several blood tests for other potential ailments.

151. I would definitely rather have children and my full health over the money. My GP said to me no money in the world could compensate for what I've been through. When she heard that I wasn't able to hold my stillborn son she had tears in her eyes.

### **Section 8. Other Issues**

152. I've come so far now in where I'm at mentally and physically that I don't see the point of finding out whether or not the National Transfusion Service knew whether I was infected or if someone could have told me earlier than 2008. I think it will just open up a whole new round of regret, anger and upset.
153. When I told one of my very good friends about all this she said to me that she was so surprised that I was not bitter about it all. I told her being bitter would kill me and I will not let this defeat me.
154. I get very nervous around the medical profession. I have to go in for an operation soon and I am very nervous. I will never trust them 100%. Some medical professionals can be absolutely lovely but others can make you feel like you are just another patient on a conveyer belt.
155. Mistakes have been made throughout my medical history and I have to live with the consequences.
156. If requested, I would be willing to provide verbal evidence at the public hearings.

### Statement of Truth

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

Signed

GRO-C

Dated 3rd April 2019.